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Optimising care for **P**eople with palliative care needs, and their families, in the **A**ustralian hospita**L** setting: the **OPAL** Project

by Claudia Virdun

Thesis submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy 92984 Nursing

under the supervision of:
- Professor Jane Phillips
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Certificate of original authorship

I, Claudia Virdun, declare that this thesis, is submitted in fulfilment of the requirements for the award of Doctor of Philosophy 92984 Nursing, in the Faculty of Health at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

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Statement of format of thesis

This thesis presents a thesis by compilation. It includes a single manuscript comprised of seven Chapters, with some of these presenting an edited version of published manuscripts. Where this is the case, this is clearly noted and details of the reference provided. In order to increase the accessibility of information, linking information is provided within each Chapter to enable flow between each and connection across the full Project.

Publications arising from this research

Virdun, C., Luckett, L., Davidson, P., and Phillips, J (2020). Strengthening palliative care in the hospital setting: a codesign study. BMJ supportive & palliative care, *(In Press).*

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Conference presentations

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1. **Virdun, C.,** Phillips, J., Luckett, T., Lorenz, K., and Davidson, P. (2020) What is most important for Australians with palliative care needs requiring care within the hospital setting, and their families/carers? A qualitative study. *2020 Palliative Care Nurses Australia Conference, November 22-25, virtual platform*
2. **Virdun, C.,** Phillips, J., Luckett, T., Lorenz, K., and Davidson, P. (2020) Strengthening the delivery of palliative care in the Australian hospital setting: A co-design study using patient and family identified areas of importance to design recommendations for practice, policy, education and research. *2020 Palliative Care Nurses Australia Conference, November 22-25, virtual platform*
3. **Virdun, C.,** Phillips, J., Luckett, T., Lorenz, K., and Davidson, P. (2019) Co-designing improvement measures for people with palliative care needs requiring care within the hospital setting, and their families: a mixed methods project. *PCOC Outcomes & Benchmarking Conference 2019: Using evidence on patient outcomes to improve the future of palliative care, International Convention Centre, Sydney 20 - 21 November 2019*
4. **Virdun, C.,** Phillips, J., Luckett, T., Lorenz, K., and Davidson, P. (2019) Harnessing well-designed policy to drive meaningful and sustainable improvements in hospital based palliative care: preliminary results from a sequential mixed method study. *National Nursing Forum, 'Nursing Now – Power of Policy', 21-23 August, Hobart*
5. **Virdun, C.,** Phillips, J., Luckett, T., and Lorenz, K. (2019) Measuring the quality of palliative care in the hospital setting – co-designing improvement measures with patients and families/carers. *22nd CNSA Annual Congress, 20-22 June, Melbourne*
6. **Virdun, C.,** Phillips, J., Luckett, T., and Lorenz, K. (2018) Fostering excellence through measuring the quality of palliative care in the hospital setting – a foundation to inform improvement efforts. *2018 Palliative Care NSW State Conference, Riding the Waves of Change, 8-10 November, Kiama*
7. **Virdun, C.,** Phillips, J., Luckett, T., and Lorenz, K. (2018) End-of-life care measurement approaches used by 15 countries leading in this care provision. *Emerging Health Policy Research Conference 2018, July 26, Menzies Centre for Health Policy, University of Sydney*

8. **Virdun, C.,** Phillips, J., Luckett, T., and Lorenz, K. (2018) Current end-of-life care measurement approaches used by 15 countries leading in this care provision: A foundation from which to move forward. *7th Biennial Conference for Palliative Care Nurses Australia Inc, 20-21 May, Brisbane*
9. **Virdun, C.,** Phillips, J., Luckett, T., and Lorenz, K. (2018) Fostering excellence through measuring the quality of palliative care in the hospital setting – a foundation to inform improvement efforts. *7th Biennial Conference for Palliative Care Nurses Australia Inc, 20-21 May, Brisbane*
10. **Virdun, C.,** Luckett, T., & Phillips, J. (2017) End-of-life care in hospitals: Utilising patient and family identified areas of importance as the foundation to drive change and improvements – awarded best oral presentation. *2017 UTS Research Student Forum, 5-8 December, Sydney*
11. **Virdun, C.,** Luckett, T., & Phillips, J. (2017) Quality measurement of end-of-life care: a review of international approaches. *2017 Australian Palliative Care Conference – Connection with Community, 6-8 September, Adelaide*
12. **Virdun, C.,** Luckett, T., & Phillips, J. (2017) End-of-life care in hospitals: Utilising patient and family identified areas of importance as the foundation to make change happen. *Australian College of Nursing 2017 National Nursing Forum, 21-23 August, Sydney*
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14. **Virdun, C.,** Luckett, T., & Phillips, J. (2016) End-of-life care in hospitals: Utilising patient and family identified areas of importance as the foundation for future improvement efforts. *Palliative Care Nurses Australia Conference, 11-12 September, Canberra*
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16. **Virdun, C.,** Luckett, T., & Phillips, J. (2014) Dying in the hospital setting: A systematic review identifying the domains of end-of-life care that patients and their families rank as being most important. *Palliative Care NSW Conference, 22-24 October, Sydney*
17. **Virdun, C.,** Luckett, T., & Phillips, J. (2014) Dying in the acute care setting: What do patients and caregivers consider important for optimal end-of-life care? *Palliative Care Nurses Australia National Conference, 6-7 April Sydney*

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1. **Virdun, C.,** Phillips, J., Luckett, T., and Lorenz, K. (2021) Co-designing palliative care research with consumers – developing relevant and appropriate research through collaboration and design. *International Conference on Cancer Nursing, Feb 2-5, virtual platform*
2. **Virdun, C.,** Phillips, J., Luckett, T., and Lorenz, K. (2021) Improving care for people with palliative care needs, and their families, within the hospital setting: a mixed methods project. *International Conference on Cancer Nursing, Feb 2-5, virtual platform*
3. **Virdun, C.,** Phillips, J., Luckett, T., Lorenz, K., and Davidson, P. (2020) Co-designing improvement measures for people with serious chronic illness requiring palliative care within the hospital setting, and their families/carers: a qualitative study. *11th World Research Congress of the EAPC, 7-9 October 2020, virtual platform*
4. **Virdun, C.,** Phillips, J., Luckett, T., Lorenz, K., and Davidson, P. (2020) Improving palliative care within the hospital setting – designing feasible solutions through co-design. *The BMJ and IHI International Forum on Quality and Safety in Healthcare*, delayed to 2021, Sydney
5. **Virdun, C.,** Phillips, J., Luckett, T., Lorenz, K., and Davidson, P. (2020) Co-designing palliative care research with consumers – developing relevant and appropriate research through collaboration and design. *2020 Palliative Care Nurses Australia Conference, November 22-25, virtual platform*
6. **Virdun, C.,** Phillips, J., Luckett, T., Lorenz, K., and Davidson, P. (2019) Enabling optimal palliative care within Australian hospitals – opportunity for improvement: preliminary results from a sequential mixed method study. *Palliative Care in Queensland annual summit – Dec 2, Brisbane*
7. **Virdun, C.,** Phillips, J., Luckett, T., Lorenz, K., and Davidson, P. (2019) Enabling optimal palliative care within Australian hospitals – opportunity for improvement: preliminary results from a sequential mixed method study. *Online International Palliative Care Network Poster Exhibition November – December, 2019 (1st place prize winner)*
8. **Virdun, C.,** Phillips, J., Luckett, T., Lorenz, K., and Davidson, P. (2019) Co-designing palliative care research with patients and families – an opportunity to enable our research to answer questions that truly matter to those we are providing care for. *Online International Palliative Care Network Poster Exhibition November – December, 2019 (honourable mention prize winner)*
9. **Virdun, C.,** Luckett, T., and Phillips, J. (2019) Co-designing palliative care research with patients and families – an opportunity to enable our research to answer questions that truly matter to those we are providing care for. *Oceanic Palliative Care Conference, 10-13 September, Perth*

10. **Virdun, C.,** Phillips, J., Luckett, T., Lorenz, K., and Davidson, P. (2019) Enabling optimal palliative care within Australian hospitals – opportunity for improvement: preliminary results from a sequential mixed method study. *Oceanic Palliative Care Conference, 10-13 September, Perth*
11. **Virdun, C.,** Phillips, J., Luckett, T., and Lorenz, K. (2019) Hospital palliative care: Using consumer identified areas of importance to improve practice. *22nd CNSA Annual Congress, 20-22 June, Melbourne*
12. **Virdun, C.,** Phillips, J., Luckett, T., and Lorenz, K. (2019) Current palliative care measurement approaches used by 15 countries leading in this care provision: A foundation from which to move forward. *22nd CNSA Annual Congress, 20-22 June, Melbourne*
13. **Virdun, C.,** Luckett, T., Lorenz, K., & Phillips, J. (2019) Measuring the quality of palliative care in the hospital setting – co-designing improvement measures with patients and families/carers. *2019 Patient Experience Symposium, April 29-30, Sydney NSW*
14. **Virdun, C.,** Luckett, T., Lorenz, K., & Phillips, J. (2018) Current end-of-life care measurement approaches used by 15 countries leading in this care provision: A foundation from which to move forward. *Online International Palliative Care Network Poster Exhibition November – December, 2018*
15. **Virdun, C.,** Phillips, J., Luckett, T., and Lorenz, K. (2018) Current end-of-life care measurement approaches used by 15 countries leading in this care provision: A foundation from which to inform change. *2018 Palliative Care NSW State Conference, Riding the Waves of Change, 8-10 November, Kiama*
16. **Virdun, C.,** Luckett, T., Lorenz, K., & Phillips, J. (2018) Current end-of-life care measurement approaches used by 15 countries leading in this care provision: A foundation from which to move forward. *10th World Research Congress of the EAPC. 24-26, May, Bern, Switzerland*
17. **Virdun, C.,** Luckett, T., & Phillips, J. (2017) Hospital end-of-life care: Strengthening improvements through connecting with consumers. *2017 Australian Palliative Care Conference – Connection with Community, 6-8 September, Adelaide*
18. **Virdun, C.,** Phillips, J., & Luckett, T. (2016) Transforming the future of end-of-life care in hospitals: Utilising patient and family identified areas of importance as the foundation for change. *Palliative Care NSW Conference, Broken Hill*

Invited oral presentations

1. Measuring the quality of inpatient palliative care informed by what is most important to inpatients with palliative care needs, and their families. *Palliative Care End of Life Working Group meeting, Mental Health and Palliative Care Unit, Australian Institute of Health and Welfare. August 7, 2020, via Webinar*
2. Involving consumers with palliative care needs and their families in research. *Cancer Institute NSW, Translational Cancer Research Network, Consumer Advisory Panel meeting, June 9, 2020, via Webinar*
3. Optimising care for People with palliative care needs, and their families, in the Australian hospitaL setting: the OPAL Project. *Sacred Heart Health Service Palliative Care Forum, March 2, 2020, via Webinar*
4. Palliative care in hospitals: Utilising patient and family identified areas of importance to drive change. *Safer Care Victoria, Palliative Care Clinical Network via Webinar, 17 October 2018*
5. Interviewed by Jean Kittson for a podcast developed by Carbon Creative, on behalf of the Australian Government Department of Health, for a national palliative care awareness campaign, focused on the importance of having a conversation about care at the end of life. This focused both on my clinical career and also the key domains of importance for optimal palliative care found through the OPAL Project, *26 June 2018.*
6. End-of-life care in hospitals: Utilising patient and family identified areas of importance as the foundation to make change happen. *IMPACCT NSW education day: Improving Palliative Care in Acute Care Hospitals. 31 May, 2018 Concord Hospital, Sydney*
7. Interviewed by 2SER’s Think: Health radio program about my research to inform media used by the University of Technology Sydney in line with National Palliative Care Week, *May 2017*

Table of contents

List of appendices

List of figures

List of tables

Abstract

Background

Demand for palliative care provision within hospitals is significant and projected to increase in line with the population ageing and an increase in non-communicable disease. However, not all Australian inpatients with palliative care needs have access to best evidence-based quality care. Understanding how to optimise care for this population is a global priority.

Aim

To identify how to optimise care for people with palliative care needs and their families in the Australian hospital setting.

Methods

A three phase fully mixed sequential dominant design. The OPAL Project is informed by pragmatic assumptions and the *Innovative Care for Chronic Conditions* and *Person-centred Practice Frameworks*. Phase 1 focused on scoping the problem and involved a systematic review and meta-synthesis of the needs of inpatients with palliative care needs and their families (Studies 1a and b). Phase 2 involved a qualitative interview study with patients and families to better understand domains of importance, their implications for practice and relevance for the Australian population (Study 2). A mid-point meta-inference of data obtained across Studies 1a, 1b and 2 followed, to inform Phase 3 and project conclusions. Phase 3 included a global environmental scan (Study 3) and a co-design workshop (Study 4) focused on understanding how to drive reform in relation to Australian inpatient palliative care. The end-point meta-inference drew together all of the OPAL Project's data to generate a series of recommendations.

Results

The OPAL Project identified that Person-centered care, Expert care and Optimal environment of care are the three overarching categories of importance to inpatients with palliative care needs and their families. Within each of these three categories are specific care-related domains (n=14) and a series of practice points (n=68), that provide guidance at the macro, meso and micro levels. The end-point meta-inference identified five key drivers for embedding the categories and domains identified in the OPAL Project, including: recognising and valuing palliative care as core business and a priority for inpatient care; leadership; measurement; innovation; and targeted skill development to support clinicians and ancillary staff in their delivery of palliative care.

Conclusion

Improving inpatient palliative care requires a concerted effort to enable the implementation of strategies aligned with the care that matters most to inpatients with palliative care needs and their families. The OPAL Project provides a robust platform for clinicians, health administrators and policy experts to re-

orient their inpatient palliative care policy focus, improvement indicators and skill development on what matters most to inpatients and families with palliative care needs. System-level improvement will only occur with discrete but interrelated work undertaken in partnership with all stakeholders, including palliative care consumers, at the macro (national), meso (hospital) and micro (ward) levels.

Abbreviations

Australian Commission on Safety and Quality in Health Care	The Commission
Gold Standards Framework	GSF
Integrated Palliative Outcome Scale	IPOS
National Health and Medical Research Council	NHMRC
National Safety and Quality Health Service Standards	Standards
Nursing Unit Manager	NUM
Optimising care for People with palliative care needs, and their families, in the Australian hospitaL setting: the OPAL Project	OPAL Project
Palliative Care Outcomes Collaboration	PCOC
Preferred Reporting Items for Systematic Reviews and Meta-Analyses	PRISMA
The Supportive and Palliative Care Indicators Tool	SPICT
States and Territories	Jurisdictions
United Kingdom	UK
United States of America	US
World Health Organization	WHO

Glossary of Terms

Ancillary staff	Hospital employees who provide support to the primary purpose of the organisation,[1] for example: cleaners, laundry staff, kitchen staff and caterers.
Category	A grouping of importance with shared characteristics[1] with this being of higher classification order than 'domain' (defined below). Examples of a 'category' in this project include: Person-centred care; Expert care.
Clinical Quality Register	System that contains *"data about patients with a particular kind of condition, often including outcomes"*[2] *(page 8)*
Clinician	*"A healthcare provider, trained as a health professional, including registered and nonregistered practitioners. Clinicians may provide care within a health service organisation as an employee, a contractor or a credentialed healthcare provider, or under other working arrangements. They include nurses, midwives, medical practitioners, allied health practitioners, technicians, scientists and other clinicians who provide health care, and students who provide health care under supervision."* [3] *(page 69)*
Co-design	The OPAL Project used the following definition for co-design: *"It involves patients and staff exploring the care pathway and the emotional journey patients experience along it, capturing experiences, then working together to understand these experiences and improve them."* [4] *(p.4)* Importantly, the OPAL Project added to this definition by also including carers alongside patients and staff within the co-design process.
Consumer	The OPAL Project used the term 'consumer' to describe a person with palliative care experience (patient or family) supporting organisations in their work related to palliative care. This project worked with consumers from either the: • University of Technology's Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT) Centre's Consumer Advisory Group: https://www.uts.edu.au/impacct/consumers; or • NSW Translational Cancer Research Network's Consumer Advisory Panel: http://www.tcrn.unsw.edu.au/groups/tcrn-consumer-advisory-panel.
Domain	A distinct subset[1] of the aspects noted to be important for optimal care, sharing common aspects and framed by a project 'category' (defined above). That is, a 'category' in this project is Person-centred care with 'domains' of respectful and compassionate care or enabling family involvement being subsets with greater levels of detail in relation to inpatients with palliative care needs.
End-of-life care	The period of time when a person is living with, and impaired by, a progressive and eventually fatal condition.[3] The OPAL Project used palliative care in this context as defined below.
Experience	An outline or description of an event or occurrence with which the person has had direct contact.[1]

Family and carers	*"The term family includes people identified by the person as family and may include people who are biologically related and people who joined the family through marriage or other relationships, as well as the family of choice and friends (including pets). Carers may include family members and other members of their community (such as close friends and neighbours) who the person agrees to being involved in their care."* [5]*(p6)* The OPAL Project used the term 'family' to encompass all of the above.
Generalist palliative care	Care provided to those with palliative care needs by any clinician, where their substantive work is not within specialist palliative care.[5]
Hospital	All acute inpatient care excluding psychiatric, hospice or inpatient specialist palliative care, and alcohol and drug treatment centres.
Importance	Being of great significance or value.[1]
Indicator	*'A measurable component of the standard, with explicit criteria for inclusion, exclusion, time frame and setting'* [6] (p79). Many publications refer to an indicator as a measure and vice versa. The OPAL Project used indicator in line with the above definition and 'measure' as a verb.
Inpatient	The OPAL Project used this term to refer to any patient with palliative care needs within the 'hospital' setting as defined above. That is, not within specialist palliative care settings but more generic hospital environments.
Integrated model of palliative care	The OPAL project used this term to refer to "the coordination of disparate services centred on the needs of each individual patient and family with the aim of ensuring continuity of care"[7]
Measure	To ascertain the size, amount, or degree of (something) by using an instrument (tool). That is, the OPAL Project uses 'measure' as a verb, to measure.[1]
Palliative care	*'Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'*[8] The OPAL Project acknowledged the complexity in terminology use between end-of-life care and palliative care and opted to use palliative care (as defined here) throughout this thesis for clarity.
Palliative care provision	The OPAL Project accords with the direction provided by Palliative Care Australia (PCA)[5] whereby palliative care is core business for all health care providers. *PCA refers to this type of care that is provided by other health professionals, including general practitioners, as 'palliative care' (although it is also sometimes known as 'generalist palliative care').*[5] *(p.7)*

Person-centred care	*"a standard of care that ensures the patient/client is at the centre of care delivery."*[9] *(p.1)*
Practice points	The OPAL Project used the term 'practice points' to describe details within each domain that inform actual care provision. That is the highest order grouping was 'category' with this informed by 'domains' and each domain was made up of practice points to inform care provision.
Qualitative studies	Studies aimed at providing an in-depth understanding and exploration[10] of the experience of inpatients with palliative care needs and/or their families.
Quality	The standard of something as measured against other things of a similar kind; the degree of excellence of something.[1]
Quality indicator	*"Quality indicators are explicitly defined and measurable items referring to the outcomes, processes, or structure of care."*[11]*(p.146)* Quality indicators are based on established aspects of care that reflect good or poor quality to assist evaluation.
Quantitative studies	Studies aimed at examining relationships amongst variables, often measured through survey data.[10]
Satisfaction	A measure of fulfilment in relation to expectations or needs.[1]
Specialist palliative care	Care provided by clinicians whose substantive role is within palliative care.[5]
Standard	An evidence-based process that should be undertaken or outcome to be achieved for a defined circumstance.[6] This might also be called a benchmark.
Systematic review	*"A systematic review is a review of a clearly formulated question that uses systematic and explicit methods to identify, select, and critically appraise relevant research, and to collect and analyze data from the studies that are included in the review."*[12] *(p. 334)*
Tool	A method and/or instrument used to gather data to inform a quality indicator and standard. Tools in isolation cannot be used to monitor quality, rather they must contribute to aggregated evidence to inform the defined quality indicator.[6, 13]

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Chapter 1: Introduction to the OPAL Project

1.1 Introduction

Historically, palliative care commenced when curative treatments had finished.[1] However, there is now good evidence that palliative care provided alongside disease-modifying therapies contributes to better outcomes for patients and their families.[2, 3] New integrated models of palliative care are increasingly relevant as more people live longer with chronic and complex illness and are therefore likely to benefit from earlier referral to palliative care.

Good palliative care is a basic human right and a fundamental component of any health care system.[4] While palliative care is variously defined, the World Health Organization (WHO) definition is one of the most widely adopted and will be used in this thesis. The WHO defines palliative care as:

> *an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*[5]

It is important to note that this definition makes no reference to diagnosis or stage of disease as requisites for palliative care, nor is the provision of this care assigned to one particular specialty, service or setting of care. The WHO definition highlights the importance of palliative care being an *approach* to care that all clinicians ought to be able to provide to patients with prescribed needs, regardless of the location of that care.

The national peak body representing palliative care in Australia, Palliative Care Australia, builds upon the WHO definition to advocate for all clinicians developing the minimum core competencies required to ensure optimal palliative care.[1] These competencies include: effective symptom assessment and management; provision of or referral for psychosocial care; and communication skills enabling the discussion of goals of treatment and a person's prognosis.[1] Where a person's needs exceed the capabilities of the clinician or team caring for them, referral to a specialist palliative care service is recommended.[1] Otherwise it is expected that the person's usual health care team, often referred to as the 'generalist' provider(s),[6, 7] ought to have the capabilities to provide best evidence-based palliative care, regardless of care setting. There is an increasing need for generalist clinicians to be involved in the provision of palliative care, driven by changes in the way that people are dying, as discussed in the next section.

Population-based surveys consistently show that the majority of people would prefer to die at home rather than in hospital.[8, 9] However, preference for place of care often changes over time as people approach death and become more worried about whether their symptoms will be successfully managed at home, as well as the burden their family may face in caring for them.[10] Thus, rather than conclude that most people would prefer to die at home, it may be more accurate to say that most people would prefer to stay at home for as long as possible. The next section explains that the changing epidemiology of dying is placing increasing demands on the 'possible' component, emphasising the need for continuing investment in the quality of hospital-based palliative care.

1.2 Epidemiology of dying in the 21st Century

Globally, there are considerable differences in cause of death and life expectancy, due to country of residence, socio-economic circumstances, lifestyle risks, ethnicity, gender and genetics.[11] Low income countries report an overall life expectancy of 58.4 years, largely due to significant maternal and newborn deaths and deaths from communicable diseases.[11] In contrast, high income countries have an overall life expectancy of 76.9 years, with the leading causes of death due to non-communicable diseases.[11, 12] It is projected that by 2030 the leading causes of death in high income countries will be: ischaemic heart disease, stroke, Alzheimer's disease and other dementias, lung cancer, lower respiratory infections, chronic obstructive pulmonary disease, colorectal cancers, diabetes, hypertensive heart disease and kidney disease.[11]

The global epidemiological shift is evident within the Australian population, where life expectancy is now 80.4 years for men and 84.6 years for women, and non-communicable diseases are the leading causes of death for both genders.[9, 13] The proportion of the Australian population aged 65 years and older is increasing rapidly and is expected to reach 19% of the population by the year 2031.[14]

As a result of these epidemiological changes, the patterns of dying in high income countries, and in Australia more specifically, have moved away from sudden deaths to the bulk of deaths being expected. Seminal work by Lynn and Adamson (2003)[15] has suggested that expected deaths can generally be classified as following one of three illness trajectories, namely: 1) *a short period of evident decline* (mostly cancer) where a person lives with illness, maintaining good function, followed by a reduction in this functioning, predominantly in the last few months of life; 2) *long-term limitations with intermittent serious episodes* (mostly organ failure) where a person lives with an overall decline in function, often over several years, with irregular acute episodes that contribute to ongoing functional decline; and 3) *prolonged dwindling* (mostly frailty and dementia) where people live with long-term functional decline and progressive disability and are at ongoing risk of dying from events such as infections, falls or fractures. Individuals following any one of these three trajectories can incur a significant symptom burden and have a commensurate need for palliative care.

In addition to advancing age and an increase in non-communicable diseases, there have also been ongoing changes to the way that people in Australia live, with one in four people now living alone.[16] These factors combine to confer complex health care needs and mean that an increasing proportion of

Australians require care in the hospital setting, even if most would prefer to be cared for at home for as long as possible. In 2014-2015, half (50%, n=76,856) of the Australian population's deaths (n=153,580) occurred in hospital, with most terminal admissions having an average length of stay of 10.6 days.[17] Decedents were most commonly aged more than 85 years and almost exclusively (94%) aged 50 years or over.

Over the decade preceding the 2014-2015 report analysing deaths in Australia,[17] the number of deaths in hospital for people aged 85 years and over had increased by 5%.[17] Two-thirds of hospital deaths (67%, n=51,124) were related to either cancer (31%, n=23,769), cardiovascular disease (20%, n=15,308) or respiratory disease (16%, n=12,047).[17] Of these inpatient deaths, the majority were cared for by generalist clinicians, with only a third (33%, n=25,570) receiving specialist palliative care input.[17] In addition to the proportion of people who are dying in hospital at a given time, there are also an estimated 27-33%[18, 19] of inpatients living with serious and life-limiting illness who will not die on the current admission, and these numbers are expected to rise.[13, 18-20] These patients living with serious and life-limiting illness require care that acknowledges their advanced disease and attends to their symptom management needs, as well as their psycho-social and spiritual needs and addresses their family's needs.[21] These groups combined - hospital inpatients with palliative care needs – form the population of interest for this thesis and will be referred to using the shorthand of 'inpatients' unless otherwise specified.

1.3 Palliative care in the hospital setting

Internationally, there is evidence that inpatient palliative care is sometimes suboptimal.[7, 18, 22-25] The reasons for this are varied and complex,[7] but largely relate to ineffective communication, too little input into decision making and poor symptom management.[22, 26-29] It has been suggested that the dominance of the biomedical model, with its focus on cure,[25, 29, 30] has led to dying being viewed by hospital clinicians as a 'failure' of care rather than as an opportunity to excel in care of a different kind.[31] A focus on cure[29, 30] serves the needs of people who require active treatment, but may make it harder for clinicians to move from a problem-solution orientated approach to a palliative approach to care that is person-centred and grounded in comfort and dignity.[22, 31, 32] Viewing death as a failure may inadvertently inhibit honest communication between clinicians, inpatients and/or families. Systemic issues relating to a lack of skilled clinicians, uncertainty in clinician roles, the complexity of multi-level organisations, and a lack of safety and quality indicators to measure performance and inform change are also noted barriers to the provision of quality inpatient palliative care.[7, 22, 32-35]

A 2014 integrative review focusing on the inpatient and family palliative care experience found that there was a need for better symptom management, greater opportunities for communication and supported decision making and fostering interpersonal relationships with clinicians, as well as improvements to the hospital environment.[36] Studies of bereaved family member experience after a hospital death highlight the need for care coordination and communication improvements, including more timely information and knowing what to expect, as well as greater opportunities to prepare for a loved one's death.[25, 26, 37] Improving inpatient palliative care experiences by providing person-centred care focused on responding to individual need has also been called for.[26] Therefore, there is a need to strengthen inpatient palliative care internationally, made all the more urgent because of the projected rise in expected inpatient deaths.

1.3.1 Palliative care in Australian hospitals

Australia has just over 1300 public and private hospitals.[13, 38] These hospitals vary with regard to the number of beds and types of service provision they offer, and are dispersed across a wide array of geographical settings, including metropolitan and inner and outer regional and remote areas.[38] Australian hospitals also vary widely with regard to their fiscal and human resources.[38] In addition to this, the communities served by Australian hospitals vary considerably with regard to sociodemography. Variance of data infrastructure, collection and reporting for inpatients with palliative care needs and their families has also been noted as a key area for improvement within the Australian National Palliative Care Strategy.[2] This results in difficulty identifying, monitoring and evaluating the quality of care provision for a large proportion of inpatients within Australian hospital settings.

Several Australian studies have been undertaken using retrospective audit data[18, 19, 23, 39] or observations of nursing care[40] to understand the prevalence of inpatients with palliative care needs and the quality of the care they receive. These studies have found that: identification of inpatients with palliative care needs is a challenge;[18, 23, 40] comprehensive communication and shared decision making are poor;[18, 23, 39] skill development for the acute care workforce is needed in relation to recognising dying and completing needs-based assessments;[19, 23, 40] there is variability in quality of palliative care;[23, 39] low numbers of patients are referred to specialist palliative care clinicians;[19, 23] there is a lack of symptom monitoring;[39] and many patients receive potentially inappropriate interventional care (for example observations and blood tests) close to the time of their deaths.[39] The research to date therefore suggests that Australia may be no exception to the need to improve palliative care within the hospital setting identified by studies internationally. However, the voice of Australian inpatients and families is almost entirely absent in informing this area of study, with only one study of carers available at this time.[41]

1.4 The Australian palliative care context

Internationally, the development of palliative care can be viewed across three distinct phases: care of the dying led principally by religious organisations (prior to 1967),[42] the modern palliative care movement (1967 through to current day)[42, 43] and population based models of palliative care (from the turn of the 21st Century).[44-47] The modern palliative care movement, led initially by Dame Cicely Saunders from England, focused principally on the care of those with advanced cancer through inpatient specialist care within hospices. As this movement gained momentum, different models of palliative care emerged globally over the next two decades. While throughout the 1980s, hospice units rapidly emerged across the United Kingdom (UK), with approximately 10 per year opening.[42] Australia took a somewhat different approach.[43] Rather than investing predominantly in inpatient hospice units, Australia focused its investment on developing and integrating inpatient and community palliative care teams within existing public health services.[43] As a result, different palliative care services evolved to support people dying in a variety of inpatient and community care settings developed across Australia.

A global ranking of palliative care availability and quality was completed in 2015 and positioned Australia second out of 80 countries.[48] This ranking focused on five categories, each with a range of indicators used to contribute to overall ranking scores inclusive of: the palliative and healthcare environment (20% weighting, 4 indicators); human resources (20% weighting, 5 indicators); affordability of care (20% weighting, 3 indicators); quality of care (30% weighting, 6 indicators); and community engagement (10% weighting, 2 indicators).[48] Australia performed especially well with regard to palliative care policy, public spending on healthcare, well developed workforce, and access to opioids.

Although Australia is a world leader in palliative care quality, there remains a need to improve equity of access both geographically and for minority populations, and to better integrate generalist and specialist palliative care.[2, 49-52] Finding ways to enable optimal palliative care, irrespective of setting or provider, remains a challenge.

1.4.1 National Palliative Care Policy

Australian palliative care is guided by a National Palliative Care Strategy developed by the Department of Health and endorsed by all state and territory health ministers.[2] First developed in 2000 and recently updated in 2018, this Strategy articulates six guiding principles and seven goals to guide improvement that are inclusive across all settings.[2] The six guiding principles state that:

1. *palliative care is person-centred care;*
2. *death is a part of life;*
3. *carers are valued and receive the care they need;*
4. *care is accessible;*
5. *everyone has a role to play in palliative care; and*
6. *care is high quality and evidence-based*.[2] (p5)

The Strategy's first goal is focused on seeking to enable greater understanding about palliative care within the community, including the benefits it provides and how to access services. The second goal focuses on workforce capability and identifies the need for skill development in: identifying and assessing palliative care need to inform optimal and evidence-based care provision; and effective communication and shared decision making. The third goal focuses on access and choice for both patients and carers and, although stating the need to support care across all settings, explicitly notes the need for investment in community-based palliative care provision. Goal four describes collaborative practice across all care settings and emphasises the need to work with consumers to assist in ongoing service development and innovation. The need for this development work to be informed by collaborative networks and collected data across all jurisdictions is highlighted. The fifth goal describes the need for investment in workforce and systems to enable quality palliative care provision. Although noting the need for palliative care across all care settings, goal five again notes the community setting as a priority, informed by consumer preference and funding constraints. Goal six articulates the need for improved data and evidence to inform ongoing research and improvement efforts. Finally, goal seven focuses on a national governance system to enable collaboration and accountability across all Australian jurisdictions and a strengthened voice for palliative care across the health system.[2] While the National Palliative Care Strategy focuses disproportionately on the community setting in recognition of the evidence that most people prefer to be cared for at home for as long as possible, it also emphasises the need to support optimal palliative care in the hospital environment.

In addition to the National Palliative Care Strategy,[2] Australia has developed a number of other national supports for service providers and administrators including: a set of National Palliative Care Standards;[53] a National Palliative Care Service Development Framework;[1] National Palliative Care Projects;[54] and a National Consensus Statement for Safe and High Quality End-of-life Care.[55] All such work is inclusive of and informs palliative care provision within the hospital setting. However, the policy environment with the greatest degree of influence within the Australian hospital environment is the national accreditation system led by The Australian Commission on Safety and Quality in Health Care ('the Commission').[56]

National hospital accreditation

The Commission was established in 2006 to lead and coordinate national improvements in the safety and quality of health care across Australia.[57] Following this, in 2011, the Commission developed into an independent and permanent statutory authority, funded jointly by the federal, state and territory governments.

The development and implementation of the National Safety and Quality Health Service Standards ('Standards') has been one of the Commission's key new initiatives.[56, 58] Since 2013, all public and private hospitals across Australia have been assessed against the Standards in order to gain accreditation. A primary aim of these Standards is ensuring the public's protection from harm and improving quality of health service provision. Achieving these Standards requires hospitals to implement a quality assurance approach to testing systems and processes to ensure that the care provided is in alignment with outlined expectations.[56] While, the first edition of the Standards did not have an explicit focus on palliative care, there was an emphasis on advance care planning, along with a clear focus on person-centred health systems and care provision.[58] Since these Standards were introduced, the Commission has generated a background paper on the safety and quality of palliative care in hospitals[59] and a National Consensus

Statement for Safe and High Quality End-of-life Care.[55] The second edition of the Standards,[56] released in late 2017 and implemented from 2019, includes quality items specifically referring to optimal inpatient palliative care. These new quality items refer to the need for: comprehensive screening and assessment leading to goal-oriented care plans developed in collaboration with inpatients and their families; processes to identify inpatients with palliative care needs; designated pathways of access to specialist palliative care advice; processes to ensure advance care plans are available within the health record; clinicians to support shared decisions in relation to palliative care; processes for routinely assessing and reviewing the quality of inpatient palliative care provision; and identified supervision and support for clinicians and ancillary staff providing palliative care.[56]

In addition to the work with Standards and accreditation, the Commission commenced a program of work in 2013 focused on the development of Clinical Care Standards, co-designed by clinical experts and consumer representatives, on health conditions that would benefit from a nationally coordinated approach to care.[60] While there are currently 9 clinical care standards in use and three due for implementation throughout 2020, none specifically cover palliative care provision.[60]

1.4.2 Jurisdictional Palliative Care Policy

Australia has strong policy support for quality palliative care provision at the jurisdictional level, regardless of setting of care.[49, 50, 52, 61-64] Australia has eight states and/or territories including: New South Wales, Victoria, Queensland, Australian Capital Territory, South Australia, Northern Territory, Western Australia and Tasmania. The Northern Territory does not currently have policy support available. However, all other jurisdictions have specific guidance available, noting that South Australian and Australian Capital Territory Plans were due for a review and update at time of writing.[61, 63]

Available and current jurisdictional policies and/or frameworks collectively note the following areas for prioritisation: person-centred palliative care provision;[49, 50, 52, 62, 64] explicit support for families and carers of people with palliative care needs;[49, 52, 64] a skilled workforce, noting that all clinicians and care providers (i.e. generalist as well as specialist) deliver palliative care;[49, 50, 52, 62, 64] coordinated care across care settings; [49, 50, 52, 62, 64] equitable access to high-quality care;[49, 52, 62] community engagement and enablement;[50, 52, 64] strengthening of specialist palliative care service provision;[49, 50, 62] and early identification of people with palliative care needs, followed by needs-based care planning.[62]

Whilst acknowledging hospitals are an important provider of palliative care, all policies/ frameworks describe efforts to decrease unwanted or unnecessary hospitalisation in order to meet the majority patient preference and optimise the cost-effectiveness of care. To achieve this, jurisdictions note the need for better collaboration and integration of care provision across settings, including hospitals. Victoria is alone in explicitly stating the need for hospitals and hospital executives to acknowledge palliative care as part of their care delivery and match this with a skilled workforce to enable high-quality care.[50]

Recommendations within jurisdictional palliative care policies are not mandated for either specialist or generalist service providers, nor enforced in relation to provision of hospital care, the implementation of which is devolved to local health districts.

1.5 Impetus for the OPAL Project

This Chapter has outlined the global and national drivers to improve equitable access to high-quality palliative care across settings, with a focus on hospital-based care.[2, 4, 45, 48 3, 45, 65, 66] The majority of expected deaths in high income countries occur in hospitals,[20, 26, 67-69] and a significant proportion of inpatients on any given day is likely to have palliative care needs.[18, 19] Australian hospitals can and do provide excellent palliative care,[26, 70-72] but high-quality care in this setting cannot currently be assured.[18, 19, 23, 39, 40] Understanding how to enable optimal inpatient palliative care, based on what patients and families identify to be most important, is a priority in moving forward.

The **O**ptimising care for **P**eople with palliative care needs, and their families, in the **A**ustralian hospita**L** setting: the **OPAL** Project, was designed to address this priority.

1.6 Project aim

The OPAL Project aimed to identify how to optimise care for people with palliative care needs, and their families, in the Australian hospital setting.

1.7 Key definition and concepts

Before presenting the research questions, it is important to understand the definitions and concepts informing the OPAL Project. These key concepts and operational definitions are introduced here and elaborated on in subsequent Chapters.

Hospitals

In this Project, hospitals were assumed to include any metropolitan, rural or remote inpatient ward or unit (‘ward’) in Australia, including small multi-purpose services where Australians living in rural communities might be admitted for palliative care. All types of acute inpatient care were considered to be of interest, excluding psychiatric, hospice or inpatient specialist palliative care, and alcohol and drug treatment centres. The exclusion of inpatient specialist palliative care is important to note given the Project’s aim to inform optimal palliative care provision within hospitals across Australia, not solely within specialist palliative care units or hospices. Psychiatric and alcohol and drug treatment centres were assumed to have quite different work practices, populations and staffing and considered outside the scope of this

Project. Intensive Care Units, Emergency Departments, sub-acute inpatient units (e.g. rehabilitation services) and Haemodialysis Units were all included.

Inpatients with palliative care needs and their families

The population referred to and included within this Project included adult patients (age 18 years or over) predicted to be in their last 12 months of life with recent experience in the hospital setting ('inpatients'). Adopting this definition identifies that the care provision this research relates to is for inpatients living with advanced disease, inclusive of but not limited to those who are imminently dying.

Prognosis was defined by having one or multiple life-limiting conditions in accordance with the Supportive and Palliative Care Indicators Tool (SPICT™).[73] The SPICT tool lists clinical indicators of deteriorating health as a result of one or more of the following: cancer; dementia; frailty; neurological, heart and/or vascular, respiratory, kidney or liver disease; and deterioration and risk of dying with other irreversible conditions.

In addition to inpatients as defined above, a current family member or a recently (in the past two years) bereaved family member informed by the following definition of family provided by Palliative Care Australia has been adopted:

> *the term family includes people identified by the person as family and may include people who are biologically related and people who joined the family through marriage or other relationships, as well as the family of choice and friends (including pets). Carers may include family members and other members of their community (such as close friends and neighbours) who the person agrees to being involved in their care* [1]*(p6)*

To prevent repetition throughout this thesis, this population of interest ('inpatients with palliative care needs and their families) will be termed 'inpatients and families'. Where patients without palliative care needs are described, these people are termed 'non-palliative inpatients' for clarity.

Person-centred care

Australian national and jurisdictional policy[2, 49, 50, 52, 61-64] and palliative care standards[53] outline that person-centred care is required in order to achieve quality palliative care, irrespective of care setting. Defined as "*a standard of care that ensures the patient/client is at the centre of care delivery*"[74] (p.1), person-centred care was central to the OPAL Project's design and analysis strategy. The ultimate aim of this Project was to understand how to optimise care within all Australian hospitals, for people with palliative care needs, recognising such care experience is influenced by the way they are treated as a person as well as how their condition is treated and/or managed.[75] The design centering upon inpatient and family viewpoints throughout and informed by *the Person-centred Practice Framework*[76] was considered critical to honouring and harnessing their voices to drive any identified reforms.

Palliative care consumer representation

The OPAL Project was designed to prioritise the voices of: 1) inpatients with palliative care needs and their families; and 2) people who have personal experience with caring for someone close to them who has died and have taken on the role of consumer representative. When referring to current inpatients with palliative care needs and their families (including bereaved family members), the thesis uses the terms 'inpatients', 'family members', 'bereaved family members' or (in the context of Studies) 'participants'. When referring to the second group, this thesis used the term 'palliative care consumer' as noted within the glossary of terms.

The voice of inpatients and families was considered central to the OPAL Project in order to ensure that recommendations for change at policy, organisational and practice levels were based upon that which matters most to people requiring palliative care. This design accords with the Project's conceptual frameworks, the *Innovative Care for Chronic Conditions*[77] and *Person-centred Practice*[76] Frameworks, wherein the design of systems of care to enable better care outcomes is founded upon patient and family requirements and incorporates considerations at macro, meso and micro levels.

Palliative care quality

Understanding quality of palliative care provision is critical to informing sustained improvements.[78] From a health care and ethical perspective, sub-optimal palliative care has serious implications in relation to patient and family outcomes.[78] Of the 16,000 hospital care complaints received by the UK Healthcare Commission between 2004-06, over half (54%) concerned palliative care, which is double the number (22%) of complaints related to patient safety in the hospital setting.[24] A seminal UK review, the Neuberger review, found there is a need for more than just guidelines and standards to effect real change and improvement in the care for the dying in UK hospitals.[79] This review calls for a strategic and system-wide approach that is both measurable and monitored, founded upon person-centred approaches to assessment and care.

Within Australian hospitals, no initiatives currently provide a set of quality indicators that describe what structures, processes and outcomes ought to be measured to enable better outcomes for inpatients with palliative care needs, and their families. Developing valid indicators of care processes linked to scientific evidence of health outcome improvements for patients and families is vital for improving palliative care in Australian acute care settings.[65, 80]

1.8 Research questions

To address the research aim, the OPAL Project answered the following research questions:

Research Question 1: What are the domains of care that are most important to inpatients with palliative care needs and their families?

Research Question 2: Is there a suite of indicators to assist measurement of inpatient palliative care quality?

> 2a: What national quality indicators are available to support measurement of quality palliative care and do these align with the domains of care that matter most to inpatients with palliative care needs and their families?
>
> 2b: Where a country has national palliative care indicators available, have they been successfully implemented?

Research Question 3: What are the key drivers for enabling improvement in palliative care provision within Australian hospitals?

1.9 Thesis outline

The OPAL Project answered the stated research questions through a three-phase, pragmatic, fully mixed sequential dominant design (Quan → QUAL)[81] involving four discrete and sequential studies.

The *Innovative Care for Chronic Conditions*[77] and *the Person-centred Practice*[76] Frameworks underpinned the OPAL Project design and analysis, ensuring that the research was focused on identifying strategies to enhance patient and family outcomes through organisational change.

- Phase 1 focused on *scoping the problem* and incorporated Studies 1a and 1b. This phase is presented in Chapter 2 and includes the results of a systematic review of quantitative data (Study 1a)[82] and a metasynthesis of qualitative data (Study 1b).[83]

  Chapter 3 reports the design and methodology adopted for Phases 2 and 3 of the Project.

- Phase 2 focused on *understanding importance* and is reported across two Chapters: Study 2 is presented in Chapter 4, detailing the results of a semi-structured interview study;[84] a mid-point meta-inference is then reported in Chapter 5 detailing the mixing of data from studies 1 and 2 to answer Research Question 1.

- Phase 3 focused on *driving reform*, and incorporated Study 3, Study 4 and an end-point meta-inference. Study 3 details the results from an environmental scan focused on identifying and describing national quality indicators and supporting policies used by countries leading in their provision of quality palliative care.[85] Study 4 reports outcomes from a workshop that co-designed actions for practice, policy, education and research to strengthen the delivery of palliative care in the Australian hospital setting.[86] Both Studies 3 and 4 are reported within Chapter 6 before Chapter 7 reports the Project's end-point meta-inference, conclusions and recommendations.

Where Studies have been published, the Chapters closely follow the articles but are edited to enhance congruence and provide a logical flow across the thesis. Table 1.1 provides an overview of the presentation of this thesis.

Table 1.1: Overview of Project phase, Study and alignment with Chapters within thesis

Project phase	Key content	Chapter
Preparatory	Introduction to the OPAL Project	**One**
1 – Scoping the problem	Study 1: Identifying the domains of palliative care that inpatients and their families perceive as being most important, including: Study 1a: A systematic review of published quantitative data; and Study 1b: A systematic review and meta-synthesis of published qualitative data	**Two**
	Research design and conceptual framework	**Three**
2 – Understanding importance	Study 2: Confirming key domains of importance for optimal palliative care in the Australian hospital setting: a qualitative study	**Four**
	Mid-point meta-inference of data from Studies 1a, 1b and 2	**Five**
3 – Driving reform	Study 3: National quality indicators and policies from 15 countries leading in adult palliative care: a systematic environmental scan; and Study 4: Strengthening the delivery of palliative care in the Australian hospital setting: A co-design study to design actions for practice, policy, education and research	**Six** **Six**
	End-point meta-inference of data from all four Studies informing Project conclusions and recommendations	**Seven**

1.10 Summary

A large number of inpatients in Australian hospitals have palliative care needs. These patients and their families cannot always access optimal care. The OPAL Project undertook a series of studies to understand, firstly, what is most important for care from the perspectives of inpatients and families and, secondly, what key drivers will enable this care within all Australian hospitals. The first Study within the OPAL Project is reported in the next Chapter. This systematic review (Study 1a) and meta-synthesis (Study 1b) investigated the most important domains of hospital-based care for people with palliative care needs, from published and peer-reviewed literature. Reporting Study 1 outcomes prior to the methods Chapter seeks to ensure a comprehensive understanding to inform study design for subsequent studies.

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Chapter 2 Phase 1: Scoping the problem

2.1 Chapter preface

Chapter 1 demonstrated the need for inpatient palliative care and the fact that, at present, such care is not always provided in line with the best available evidence. In order to optimise inpatient palliative care, an understanding of which domains of care are important to inpatients and their families is required. This Chapter reports the first part of Phase 1, a systematic review and meta-synthesis of published studies on this topic. Given the heterogeneity of the study designs available, the data were analysed and reported separately before integrating to inform final Study outcomes. Providing the outcomes of Phase 1 work prior to the description of the full Project methods, provided in Chapter 3, sought to provide a comprehensive understanding of the evidence without repetition between the introductory chapter and Phase 1 outcomes.

2.2 Publication references

An edited version of two published reviews reporting the Studies undertaken in Phase 1 of the OPAL Project is provided: a systematic review of quantitative data (Study 1a) and a meta-synthesis of qualitative data (Study 1b). The systematic review of quantitative data was published in 2015 in *Palliative Medicine,* a peer reviewed journal with an impact factor of 4.956, focused on improving knowledge and practice in palliative care. The publication was noted as the 'editor's choice of the month' and was accompanied by a podcast to increase accessibility of the findings. As of 31/12/2020 this article had been cited 160 times.

> **Virdun C**, Luckett T, Davidson PM, & Phillips J. (2015) Dying in the hospital setting: A systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. *Palliative Medicine*. 29: 774-796.

The meta-synthesis focused on qualitative data and was also published in *Palliative Medicine,* to clearly articulate their relationship as 'companion' manuscripts with complementary findings. As of 31/12/2020 this article had been cited 53 times.

> **Virdun C,** Luckett T, Lorenz K, Davidson P.M, & Phillips J. (2016) Dying in the hospital setting: A meta-synthesis identifying the elements of end-of-life care that patients and their families describe as being important. *Palliative Medicine.* 31: 587-601.

2.3 Overview

As explained in Chapter 1, most people state their preferred place of death is at home,[2] but the majority of deaths in high income countries occur in hospitals.[3, 4] In addition to hospital deaths, it is estimated that, at any given time, between 23% and 36% of all hospitalised inpatients have palliative care needs.[5-8] Despite policy initiatives emphasising options to better support people to die at home,[9, 10] the number of people requiring inpatient palliative care is expected to increase.[4, 11] This is primarily due to the population ageing, increased burden and complexity of chronic illness and more people living in single person households with no carers and care needs that exceed community resources. Despite the expansion of specialist palliative care services, promotion of a palliative approach and other reforms, inpatients cannot be guaranteed optimal palliative care[12-14] and continue to have unmet needs.[5, 6, 15] Basing reforms on what inpatients and their families consider most important for optimal inpatient palliative care values the uniqueness of living with a terminal illness,[16] upholds a person-centred approach to care[1] and is central to improving care outcomes.[17] Given substantial published work was available to inform this area of research, a systematic review was determined the best method to inform policy and/or practice change. Presented in two parts (Study 1a and Study 1b) to account for heterogeneity of study design and data types, data are then synthesised to inform overall Study outcomes.

2.4 Objective

To identify the domains of care that are most important to hospitalised patients with palliative care needs and their families.

2.5 Methods

A systematic review was undertaken in the first quarter of 2014. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) method[18] guided the sourcing, inclusion and quality review of all manuscripts.[19] The reporting of qualitative results adheres to the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) criteria.[20]

2.5.1 Eligibility criteria

Manuscripts were included if they reported: quantitative, qualitative or mixed methods studies generating primary data and were published in an English peer-reviewed journal between 1990 – 2014; and empirical patient and/or family data articulating importance, experience and/or satisfaction in relation to palliative care in hospital. For the purposes of this review, ‘experience’ was defined as an outline or description of an event or occurrence; ‘satisfaction’ as a measure of fulfilment in relation to expectations or needs and ‘importance’ as being of great significance or value.[21] Manuscripts were excluded if they reported on a primary data set already included without relevant new perspectives provided, or due to quality review outcomes. The quality review used a tool for appraising evidence for palliative care guidelines in Australia[22] focused on a manuscript’s level of evidence, quality of methods, strength of evidence and relevance to question. Where a maunscript received a quality rating of 2 or less for ‘relevance to question’ it was excluded.

2.5.2 *Search Strategy*

Medical Subject Headings (MeSH) and key words (Table 2.1) were developed (CV and supervisors) with support from a health service librarian and informed by key terms from known publications in this area of research. A search of relevant electronic databases was performed in March 2014 and updated in April 2015, with slight variances made to these terms to account for different database requirements.

Table 2.1: Search terms used

dying, death, ‘end of life’, terminal, ‘terminal care’, terminally ill, palliative, ‘final day*’ (combine all with ‘or’)
‘good death’, ‘consumer satisfaction’, ‘patient satisfaction’, perspective*, important, experience (combine all with ‘or’)
Hospital, acute care, intensive care, emergency, inpatient* (combine all with ‘or’)
Patient*, family, families, consumer*, carer* (combine all with ‘or’)
Adult*
Qualitative or quantitative
1 and 2 and 3 and 4 and 5 and 6
Limit ‘7’ with 1990 – current and English language
NB: Slight variations with truncations were used to account for database requirements

2.5.3 *Information sources*

Databases included: Academic Search Complete (EBSCO); Amed (OVID); Cinahl (EBSCO); Medline (EBSCO); Medline (OVID); Embase (OVID); Psychinfo (OVID); Pubmed and Cochrane. Desktop searching of the internet via Google and Google Scholar search engines, CareSearch and handsearching was also completed. The reference lists of all included studies and other relevant reviews were searched manually to identify other potentially relevant manuscripts.

2.5.4 *Study selection*

Manuscripts returned from the electronic database searches were imported into Endnote (version X5). Titles and abstracts were examined (CV) according to inclusion criteria. Uncertainty regarding inclusion was resolved through consensus discussion (CV and supervisors).

2.5.5 Data collection and items

Data were extracted into an electronic proforma in Microsoft Word. Both Study 1a and 1b focused extraction on: source / country; aim; design and method; participants and setting. Study 1a (quantitative data) also extracted outcome measures; and results / top five elements of importance whereas Study 1b (qualitative data) also extracted: participant details; and results / findings. The raw qualitative data (patient and family quotes) reported in each study included in the meta-synthesis were also extracted for synthesis.

2.5.6 Bias rating – quantitative studies (Study 1a)

Quality appraisal of potential quantitative studies was completed independently by two researchers (CV and supervisor) using the Australian Palliative Residential Aged Care (APRAC) Guidelines for a Palliative Approach in Residential Aged Care: Evidence evaluation tool for quantitative studies,[22] and this guided decisions about the final studies for inclusion. The quality indicator of 'relevance to the research question' was used to limit inclusion. The level of evidence generated by each study was classified according to the (Australian) National Health and Medical Research Council (NHMRC)[23] (Appendix 2).

2.5.7 Quality appraisal – qualitative studies (Study 1b)

Quality appraisal of potential qualitative studies was completed independently by two researchers (CV and supervisor) using predefined criteria noted to enhance transfer of qualitative findings to practice[24] (Appendix 2). These criteria specifically sought to focus on clarification of research aims, justification for qualitative method use, procedural rigour, representativeness, interpretative strength, reflexivity and evaluative rigour as well as transferability of findings.

2.5.8 Synthesis

Quantitative studies (Study 1a)

A narrative approach to synthesis allowed for the integration of the broad range of designs and methods within the quantitative studies. The synthesis followed the methods recommended by Popay and colleagues,[19] notably tabulation and content analysis. Content analysis occurred through the organisation of data into care 'domains'- distinct subsets of the aspects noted to be important for optimal care. Elements of care ranked as the top five most important in each article were tabulated, analysed and grouped into domains. The initial domains were compiled inductively by a single researcher (CV) before being reviewed by the team. Where there was a difference in opinion, discussion was held to reach consensus. The frequency of each domain was summarised as an index of overall priority from a patient and family perspective. Where data were shared across manuscripts,[25, 26] the frequency count was only calculated once.[26]

Qualitative studies (Study 1b)

The three stage thematic analysis approach developed by Thomas and Harden[27] proceeded by means of: 1) line by line coding (CV); 2) descriptive theme development (CV and supervisors); and 3) analytical theme generation (CV and supervisors).[19, 27] Critical analysis of data allowed key areas to emerge inductively within each theme. However, the analytical framework was informed by the domains identified in the systematic review (Study 1a) and, for congruence, the resultant analytical themes from the meta-synthesis are also titled 'domains'. Data included for theming was led by the research question[19] and limited to patient and family quotes (raw data). Privileging the raw data ensured the patient and family voice were central to generating domains and limited bias due to secondary interpretation of themes generated by others.

Quotes were extracted and imported into EPPI-Reviewer 4.[28] Initial coding (CV) was audited for accuracy and consistency (supervisors), with disagreements resolved through discussion. Original coding was transferred into a Word document for development of descriptive themes (CV and supervisors). CV commenced theming and met with supervisors to ensure agreement. Finally, descriptive themes were examined for fit with the domains generated by Study 1a (CV and supervisors). Where qualitative data did not fit a domain, new domains were developed using an inductive approach. All data contributed to domain development irrespective of number of studies or times reported.

2.6 Findings

2.6.1 Study selection

Of 1922 manuscripts returned by searches, 24 were assessed as meeting inclusion criteria (see Figure 2.1). Two manuscripts [25, 26] within Study 1a reporting on different aspects of the same data set were included because one[26] reported on the whole data set, while the other reported on importance from the perspectives of inpatients with cancer and COPD.[25] An outline of the quality review of all manuscripts is provided in Appendix 2. Findings are presented by data type, quantitative (Study 1a) and then qualitative (Study 1b). Study 1a included 8 manuscripts and Study 1b, 16 manuscripts.

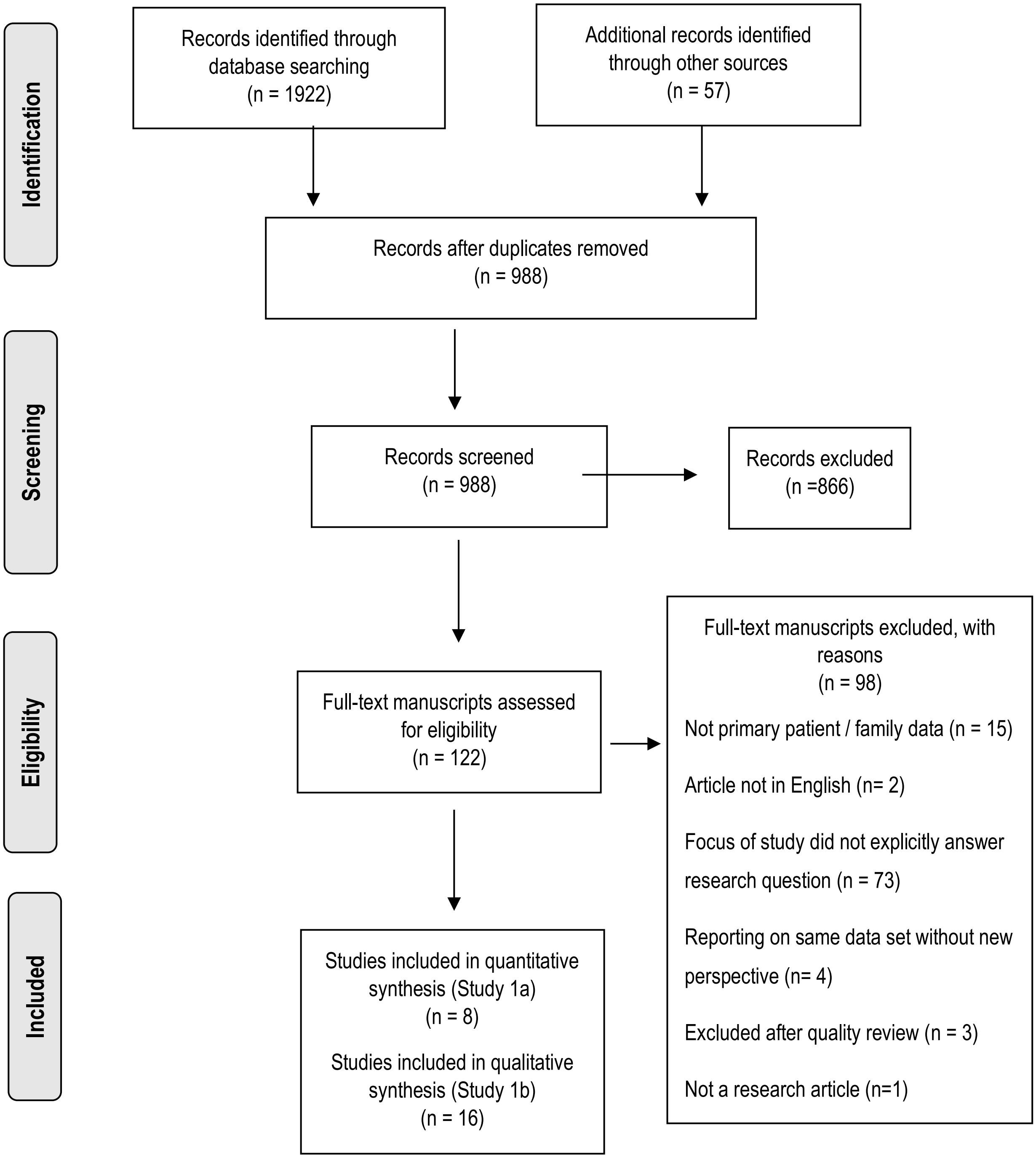

Figure 2.1: PRISMA[18] diagram of included and excluded studies informing Study 1a and Study 1b

Study 1a - Quantitative data

2.6.2 Study characteristics

Study location

The included studies came from three high income countries in the northern hemisphere: Canada (n = 4),[25, 26, 29, 30] United States of America (US) (n = 3)[31-33] and the United Kingdom (UK) (n= 1) (Table 2.2).[34]

Study design

The majority of studies (n=6) employed descriptive designs, using mostly postal or face-to-face surveys.[25, 26, 29, 31, 33, 34] One study used a prospective cohort study design comparing usual care with an intervention where additional support was provided by a Clinical Nurse Specialist.[32] However, the data relevant to this review was retrospective and cross sectional survey data. The other study used a Q-Sort methodology where participants ranked elements of importance identified by a previous qualitative study.[30] All were classified as Level IV studies according to the NHMRC classification system, indicating a lower level of evidence in line with descriptive design use only.[23]

Sample characteristics

Seven studies included family[26, 29-34] with three of these also including patients.[26, 29, 33] One study included patients only,[25] with the sample drawn from a larger previously reported study.[26] The views from 1,141 patients and 3,117 families are captured in Study 1a. Studies reporting patient data come from two research centres[26, 29, 33] in two countries, Canada and the US. Four of the manuscripts [26, 29, 31, 33] which reported a mean age, report the mean age of patients was 71.5 years (SD ± 3.88). The studies that provided age ranges had patient cohorts >70 years (86%)[34] and >50 years (87%).[30] All studies had equal representation of males and females. The majority of patients (≥ 70%) had no post school qualifications, with the proportion of white participants ranging from 69% in one study[33] to ≥87% across all other studies.[25, 26, 29, 33] Family members tended to be younger than patients and included ≥ 65% of females except in one study where there was gender equity (52%).[34] Families had mixed education levels but higher levels of education compared to the patient sample; were predominantly a spouse or adult child and white on ≥76% of occasions.[26, 29-34] Four studies surveyed bereaved relatives.[31-34]

Table 2.2: Summary of extracted data from included quantitative studies (Study 1a)

Source / Country	Aim	Design and method	Participants and setting	Outcome measures	Results / top five elements of importance
Osborn et al., 2012 [31] USA	To identify areas requiring improvement in end-of-life care in the ICU.	Descriptive design. Surveys posted to caregivers 4-6 weeks post bereavement. Data analysis was performed to describe associations between 2 tools so a performance-importance grid evolved providing data about the areas of high importance and low satisfaction.	15 hospitals with an ICU. All caregivers who had a loved one die within an ICU (or within 30 hours of transfer out of an ICU) between Aug 2003 and Feb 2008. Response rate 45%, n=1290. 79 incomplete data sets therefore total for analysis: n = 1211.	Family Satisfaction in the ICU (FS-ICU) and the Single-Item Quality of Dying (QOD – 1) questionnaires.	The 5 areas ranked as of highest importance were: 1. Level of control over the care of the family member (1/24) 2. How well the nurses cared for the family member (2/24) 3. How well the ICU staff treated the family member's pain (3/24) 4. Feeling supported in the decision-making process (4/24) 4. The courtesy, respect, and compassion the family member was given (4/24) (Both items ranked equally as 4/24) 5. How well the ICU staff treated the family member's agitation (5/24) High QOD-1 scores significantly ($p<.05$) associated with: perceived nursing skill and competence; support for family as decision makers; family control over the patient's care; ICU atmosphere. Three areas noted as highly important but with low satisfaction scores: 1. atmosphere of the ICU ($p=0.03$); 2. level of support given for decision-making ($p=0.03$); 3. amount of control over care ($p=<0.01$)

Source / Country	Aim	Design and method	Participants and setting	Outcome measures	Results / top five elements of importance
Heyland et al., 2010 [29] Canada	To identify key areas of end-of-life care requiring improvement from the perspectives of patients and families.	Descriptive design. Face to face survey using a validated tool. This tool is the result of several studies including those reported below. Statistical analysis to derive relative importance of elements conducted through association with the global rating of satisfaction.	Inpatient, outpatient and home care clients from a large region of Canada, (inpatient data only provided here). Older patients with advanced disease with an estimated prognosis of 6 months or less, and their caregivers. Response rate for hospital patients: 54%, n= 256 (77% RR for all care settings). Response rate for hospital family caregivers: 45%, n= 114 (76% RR for all care settings).	CANHELP questionnaire (www.thecarenet.ca).	The top five elements noted as important for inpatients include: 1 Doctors and nurses preserve patient dignity (1/37); 2 Good care when family / friend not present (2/37); 3 Appropriate tests and treatments used for medical treatment (3/37); 3 Health care workers work as a team (3/37); 3 Doctors and nurses compassionate and supportive (3/37); 4 Well informed doctors and nurses about the patient's health problems to give you the best possible care (4/37); 5 Adequate environment for care (5/37); 5 Physical symptoms adequately assessed and controlled (5/37); The top five elements noted as important for family caregivers: 1 Trust and confidence in doctors (1/38); 2 Availability of doctors (2/38); 3 Doctors and nurses compassionate and supportive to family caregiver (3/38); 4 Doctors and nurses compassionate and supportive to patient (4/38); 5 Doctors take a personal interest in patient (5/38).

Source / Country	Aim	Design and method	Participants and setting	Outcome measures	Results / top five elements of importance
Young et al., 2009 [34] UK	To explore the determinants of satisfaction with care at the end-of-life for people dying following a stroke in hospital.	Descriptive design. Postal survey of bereaved relatives followed by exploratory analyses to identify determinants of satisfaction.	Random sample of informants who had registered a stroke death across 4 Primary Care Trusts in London (2003). N= 183 (RR= 37%) with n=126 (76%) died in a hospital setting. Data related to this setting and related to satisfaction determinants only is reported here.	Survey tool adapted from the VOICES questionnaire. The stroke specific version was adapted following a literature review, interviews with 21 professionals and 6 bereaved family members. This study focuses on data from the domains: last hospital admission and care in the last 3 days of life.	High satisfaction with hospital doctors and nurses predicted by: • able to discuss worries and fears with hospital staff about deceased condition, treatment or tests (p = 0.004); • doctors and nurses knew enough about deceased's condition (p<.001) and role of carer (spouse / partner V other) (p=0.049) High satisfaction with health and social services in the last 3 days of life predicted by: • Enough help available to help with personal care needs (<0.001); • Involved in decisions about the deceased treatment and care (p=0.006); • Felt the deceased died in the right place (p=0.041) Rankings for the top five areas of importance: 1. Doctors and nurses knew enough about the deceased's condition (focus on doctor) (1/7) * 2. Enough help available to help with personal care needs (2/7) * 3. Doctors and nurses knew enough about the deceased's condition (focus on nurse) (3/7) 4. Able to discuss worries and fears with hospital staff about deceased condition, treatment or tests (focus on doctor) (4/7) 5. Felt that the deceased died in the right place (5/7)

Source / Country	**Aim**	**Design and method**	**Participants and setting**	**Outcome measures**	**Results / top five elements of importance**
Rocker et al., 2008 [25] Canada ***NB: This study reports on data used within the Heyland 2006 study (reported below)***	Describe key elements of end-of-life care and the relative importance of these from the perspective of people with advanced COPD as compared to people with cancer.	Descriptive design. Face to face questionnaire starting with an open-ended question and followed by the provision of 28 elements for rating. Comparative statistics used to determine differences / similarities between patients with COPD and cancer in relation to rated elements of importance.	5 teaching hospitals. Older patients with advanced COPD with an estimated prognosis of 6 months or less. Patients = 118 (COPD) and 166 (cancer).	Survey tool developed following literature review, expert opinion and focus groups with patients, enabling a tool with 28 elements of care organised into 5 domains.	Top five elements rated 'extremely important': 1. Not to be kept alive on life support when there is little hope for a meaningful recovery (COPD: 55%; Ca: 58%); 2. Symptom relief (COPD: 47%; Ca: 37%) 3. Adequate plan of care and availability of homecare resources (COPD: 40%; Ca: 44%) 4. Trust and confidence in doctors (COPD: 40%; Ca: 65%) $p<0.01$ 5. Not to be a physical or emotional burden on family (COPD: 40%; Ca: 47%)
Heyland et al., 2006 [26] Canada ****NB: This study uses the same data set as reported above by***	Describe key elements of end-of-life care and the relative importance of these from a patient and caregiver perspective.	Descriptive design. Face to face questionnaire starting with an open-ended question and followed by the provision of 28 elements for rating. Caregiver and family questionnaires identical in content.	5 teaching hospitals. Older patients with advanced disease with an estimated prognosis of 6 months or less, and their caregivers. Response rate = 77%.	Survey tool developed following literature review, expert opinion and focus groups with patients, enabling a tool with 28 elements of care organised into 5 domains.	The top five elements noted as important for patients include: 1. To have trust and confidence in the doctors looking after you (1/28); 2. Not to be kept alive on life support when there is little hope for a meaningful recovery (2/28); 3. That information about your disease be communicated to you by your doctor in an honest manner (3/28); 4. To complete things and prepare for life's end (life review, resolving conflicts, saying goodbye) (4/28); 5. To not be a physical or emotional burden on your family (5/28); 5. Upon discharge from hospital, to have an adequate plan of care and health services available to look after you at home (5/28)

Rocker et al. 2008			Patients n=440; Caregivers n=160.		The top five elements noted as important for family caregivers include: 1. To have trust and confidence in the doctor looking after the patient (1/25); 2. To not have your family member be kept alive on life support when there is little hope for a meaningful recovery (2/25); 3. That information about your family member's disease be communicated to you by the doctor in an honest manner (3/25); 4. To have an adequate plan of care and health services available to look after him or her at home, after discharge from hospital (4/25); 5. That your family member has relief of physical symptoms such as pain, shortness of breath, nausea (5/25)
Source / Country	**Aim**	**Design and method**	**Participants and setting**	**Outcome measures**	**Results / top five elements of importance**
Baker et al., 2000 [32] USA	To examine factors affecting family satisfaction with end-of-life care in the Study to Understand Prognoses and Preferences for Outcomes and Risks of	Descriptive design. Initial prospective cohort study with patients randomized to usual care or intervention. Intervention included access to palliative care clinical nurse specialists. This study reports on after death interviews conducted by telephone 4-10 weeks after patient death. Descriptive and statistical analysis used to convey data and look for	5 teaching hospitals. Caregivers for seriously ill, hospitalized adults who died from an expected death at least 48 hours after admission between February 1993 and January 1994. Response rate 78% (n = 767).	After-death interview consisting of 8 items adapted from previous studies of satisfaction with terminal care. Satisfaction measures focused on two areas: patient comfort and communication / decision making.	• Satisfaction with patient comfort decreased as financial impacts increased ($p<0.5$) • Satisfaction with patient comfort greater when family preferences for care were followed ($p<0.0001$) • Satisfaction with communication and decision making was significantly higher when patient died on that admission ($p=0.05$)

	Treatments (SUPPORT).	relationships between scores.			

Source / Country	Aim	Design and method	Participants and setting	Outcome measures	Results / top five elements of importance
Steinhauser et al., 2000 [33] USA	To determine the factors considered important at the end-of-life by patients, their families, physicians, and other care providers. *Only patient and family data summarised here.	Descriptive design. Cross-sectional, stratified random national survey (March – August 1999).	Seriously ill patients randomly selected from the national Veteran Affairs database (using disease classification codes to account for advanced chronic illness) and recently bereaved family selected from the same database in relation to patients who had died 6 months – 1 year earlier. Response rate: patients 77% (n= 340); family members 71% (n= 332).	Survey tool of 44 attributes generated from 12 previously conducted focus groups and in-depth interviews with patients, family members and health care professionals who were asked to define attributes of a good death.	The top five attributes (out of 44) rated as important by patients and/or families include: Patient rankings of importance: 1. Be kept clean (1/44) 2. Name a decision maker (2/44) 3. Have a nurse with whom one feels comfortable (3/44) 4. Know what to expect about one's physical condition (4/44) 5. Have someone who will listen (5/44) 5. Maintain one's dignity (5/44) (elements noted as 5 received same ranking) Family rankings of importance: 1. Be kept clean (1/44) 2. Name a decision maker (2/44) 2. Maintain one's dignity (2/44) 2. Have a nurse with whom one feels comfortable (2/44) 2. Have someone who will listen (2/44) 3. Trust one's physician (3/44) 4. Be free of pain (4/44) 4. Presence of family (4/44)

					5. Have physical touch (5/44) 5. Have financial affairs in order (5/44)
Source / Country	**Aim**	**Design and method**	**Participants and setting**	**Outcome measures**	**Results / top five elements of importance**
Kristjanson, 1989 [30] Canada NB: Article retrieved via handsearching as original date range searched = 1990 - 2014	To identify health care professional behaviours that are important to patients and their caregivers and identify whether care settings influence these perceptions.	Descriptive design. Q-sort methodology used to identify most important elements of care that were informed from a previous qualitative study. These elements were separated into patient care and family care with caregivers sorting one group only. Cards ranked from most important to least important. This study looked at Hospice, home care and acute care settings. Acute care data only is reported here.	Convenience sample of 210 caregivers of patients with advanced cancer, from 3 wards within a tertiary hospital. 108 caregivers sorted cards for patient care and 102 sorted for family care.	Importance of key elements of care developed via a phase 1 qualitative study.	Patient care items, acute care – 5 most important: 1. Physician assesses symptoms thoroughly 2. Symptoms treated quickly 3. MD pays attention to patient's description of symptoms 4. Pain relieved quickly 5. Tests and treatments followed up Family care items, acute care- 5 most important: 1. Information about patient's prognosis 2. Caregivers straightforward when answering questions 3. Information on side effects 4. Information on future stages of treatment and care 5. Family conference arranged by MD to discuss patient's illness

2.6.3 *Study 1a - Synthesis*

Inpatient data on elements of importance were synthesised into six domains and family data into five domains (Figure 2.2). Four domains were in common across inpatient and family reports: i) effective communication and shared decision making; ii) expert care; iii) respectful and compassionate care; and iv) trust and confidence in clinicians. There were two additional domains that inpatients ranked as being equally important: i) adequate environment for care and ii) minimising burden. Families noted one additional domain: i) financial affairs. The frequency of ranked elements of care within the four common domains was very similar across the patient and family sample (Figure 2.2).

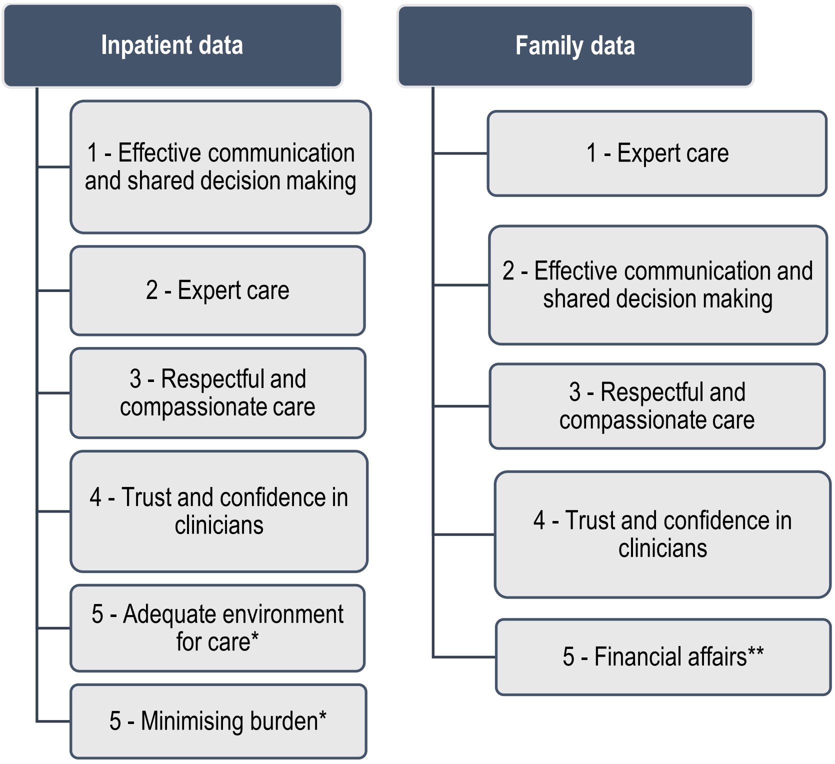

Figure 2.2: Rankings determined by frequency of representation of domains in top 5 categories of rated importance for inpatients and families.

**The domains of adequate environment for care and minimising burden were unique to inpatient data and both achieved equal rankings (5*th*).*

***The domain of financial affairs was unique to the family data.*

Effective communication and shared decision making and expert care were noted ≥50% more often than other domains by all samples, suggesting these two domains may be of highest importance for both patients and families (Tables 2.3 and 2.4). The key care strategies that inpatients and families identified as part of the most important elements of palliative care are summarised below.

Effective communication and shared decision making

Across all included studies, effective communication and shared decision making was noted as highly important - the only domain for which this was the case. For inpatients, honest communication, the ability to prepare for life's end,[26] ensuring availability of someone to listen and being aware of what to expect about their physical condition[33] were considered to be especially important elements of palliative care. In relation to shared decision making, inpatients specifically noted the importance of appropriate tests and treatments,[29] not being placed on life support when there was little hope for recovery [25, 26] and having an opportunity to nominate their preferred decision maker.[33]

In addition to the elements of care noted by inpatients above, families also identified the availability of doctors to talk to as required[29] and the opportunity to participate in a family conference to review the patient's illness as being highly important.[30] Similarly to inpatients, families also ranked the need for honest communication as one of the most important elements of inpatient palliative care, and being sheltered from the reality of the situation as one of the least important aspects of care.[30] Furthermore, families noted the importance of feeling supported in decision making and having a sense of control over their loved one's care,[31] with one study showing a statistically significant linkage between satisfaction and family's reporting that patient preferences were followed.[32] In addition, the value of being able to speak with medical clinicians about a loved one's condition, treatment and tests[34] and to receive straightforward information about prognosis, tests, treatments and future options for care[30] were all ranked as highly important by families.

Expert care

Expert care was noted across all studies providing inpatient data (Table 2.3) and six out of the seven studies reporting family data (Table 2.4). This domain includes three main concepts for care including: i) good physical care; ii) symptom management; and iii) integrated care.

Good physical care was noted by inpatients and families as the most important element of care in one study[33] specifically noting this as 'being kept clean'. Families also stated this in relation to personal care needs[34] and the importance of how well nurses cared for their loved one.[31] Lastly, inpatients noted the importance of receiving good care when family members were not present.[29]

Inpatients ranked the importance of symptom relief in the top five ranked elements of care in a recent Canadian study,[29] having not ranked this in the top five elements prior to this time. Families specifically noted management of pain and agitation to be highly important[30-33] as well as noting the importance of rapid and thorough assessment and treatment with a focus on the patient's description of their symptoms.[30]

The importance of integrated care was noted by both inpatients and families specifically in relation to effective discharge planning[25, 26] and by families in ensuring the deceased died in the right place. [34] The importance of clinicians being knowledgable about the specific condition of the inpatient was noted by both inpatients and families.[29, 34] Finally, inpatients noted the importance of clinicians working together as a team in relation to their care.[29]

Respectful and compassionate care

Respectful and compassionate care was noted as highly important for both inpatients and families and has been since 2000.[33] As respectful care ought to ensure the preservation of dignity, these elements of care were considered to fall into the ‘respectful and compassionate care’ domain identified in our synthesis (Tables 2.3 and 2.4). The preservation of dignity was noted by inpatients as highly important in two separate studies conducted over a decade apart.[29, 33] Indeed, the more recent study noted the preservation of dignity as the most important element of care.[29] In addition to this, inpatients noted the importance of clinicans being compassionate and supportive[29] and this was echoed by families in relation to the care of the inpatient and also themselves.[29, 31] Families also noted the importance of doctors taking a personal interest in their loved one[29] as well as the presence of family, the ability to have physical touch and again, the maintenance of dignity.[33]

Trust and confidence in clinicians

Similar to the domain of respectful and compassionate care, trust and confidence in clinicians was noted as important to both inpatients and families and has been across several studies since 2000.[25, 26, 29, 33] When analysed by diagnosis, this element of care was found to be more important for patients with cancer (65%, n= 166) than for patients with COPD (40%, n=118) with this difference found to be statistically significant ($p<0.01$).[25]

Adequate environment for care – domain ranked by inpatients only

Canadian inpatients noted the importance of an adequate environment of care (Table 2.3).[29] However, this is in contrast to earlier data outlining that only 16% of inpatients rated this as extremely important (ranked 25 out of 28) and 37% of families (ranked 18 out of 28).[26] This concurs with earlier work by Kristjanson [30] which outlined that two of the five least important aspects of care for inpatients were having a large hospital room with personal effects allowed from home. Nevertheless, an adequate environment of care was evident for one set of inpatients within this review (Table 2.3).

Families did note the importance of the ‘atmosphere of an ICU’ with this correlating with a low satisfaction score ($p=0.03$).[31] However, as noted by the authors,[31] the exact nature of what was meant by this statement is unclear and therefore this element of care was not included within any specific domain for families (Table 2.4, noted in the key).

Minimising burden– domain ranked by inpatients only

Ensuring one is not a physical or emotional burden was ranked as highly important by inpatients in Heyland's study[26] with these results remaining consistent when analysed by patient diagnosis (COPD / Cancer).[25] This aspect of care was not specifically questioned in the family dataset for the Heyland study.[26]

Financial affairs - domain ranked by families only

Two large US studies[32, 33] noted the importance of financial affairs in relation to palliative care. One study focused on the impact of an inpatient's illness on finances, with this significantly affecting family's satisfaction with patient comfort ($p<0.05$).[32] Another US study showed that families ranked having financial affairs in order as being in their top five categories of importance in relation to inpatient palliative care (Table 2.4).[33] While the Canadian studies[26, 29] included financial affairs on the ranking instrument, this element of care did not rank within the top five elements considered most important by family.

Table 2.3: Representation of the top 5 ranked elements of palliative care in the hospital setting from the perspectives of inpatients

Domains **Study**	**Effective communication and shared decision making**	**Expert care**	**Respectful and compassionate care**	**Trust and confidence in clinicians**	***Adequate environment***	***Minimising burden***
Heyland et al., 2010 [29]	With the tests that were done and the treatments that were given during the past month for your medical problems? (3/37)*	That during the past month, you received good care when a family member or friend was not able to be with you? (2/37) * That health care workers worked together as a team to look after you during the past month? (3/37) * That the doctors and nurses who looked after you during the past month knew enough about your health problems to give you the best possible care? (4/37) * That physical symptoms you had during the past month (for example: pain, shortness of breath, nausea) were adequately assessed and controlled? (5/37) *	That you were treated by the doctors and nurses in a manner that preserved your sense of dignity during the past month? (1/37) * That the doctors and nurses looking after you during the past month were compassionate and supportive? (3/37) *	*Domain not rated in top 5 elements of care in this study*	With the environment or the surroundings in which you were cared for during the past month? (5/37) *	*Domain not rated in top 5 elements of care in this study*
Rocker et al., 2008 [25] **	Not to be kept alive on life support when there is little hope for a meaningful recovery (COPD: 1/28; Cancer: 2/28) *	To have relief of symptoms i.e., pain, shortness of breath, nausea, etc. (COPD: 2/28; Cancer: 12/28) * To have an adequate plan of care and health services available to look after you at home upon discharge from hospital (COPD: 3/28; Cancer: 6/28) *	*Domain not rated in top 5 elements of care in this study*	To have trust and confidence in the doctors looking after you (COPD: 4/28; Cancer: 1/28) *	*Domain not rated in top 5 elements of care in this study*	That you not be a physical or emotional burden on your family (COPD: 5/28; Cancer: 5/28) *

Domains / Study	Effective communication and shared decision making	Expert care	Respectful and compassionate care	Trust and confidence in clinicians	*Adequate environment*	*Minimising burden*
Heyland et al., 2006 [26]	Not to be kept alive on life support when there is little hope for a meaningful recovery (2/28) * That information about your disease be communicated to you by your doctor in an honest manner (3/28) * To complete things and prepare for life's end (life review, resolving conflicts, saying goodbye) (4/28) *	Upon discharge from hospital, to have an adequate plan of care and health services available to look after you at home (5/28) *	*Domain not rated in top 5 elements of care in this study*	To have trust and confidence in the doctors looking after you (1/28) *	*Domain not rated in top 5 elements of care in this study*	To not be a physical or emotional burden on your family (5/28) *
Steinhauser et al., 2000 [33]	Name a decision maker (2/44) * Know what to expect about one's physical condition (4/44) * Have someone who will listen (5/44) *	Be kept clean (1/44) *	Maintain one's dignity (5/44) *	Have a nurse with whom one feels comfortable (3/44) *	*Domain not rated in top 5 elements of care in this study*	*Domain not rated in top 5 elements of care in this study*
Frequency:	**7**	**6**	**3**	**2**	**1**	**1**

Key: Domains = overarching categories developed by this review through data synthesis; Domain name in italics = domain that is specific to inpatient data (not found in top rankings of family data);Data in each cell = primary data from each article ranked in their top 5 elements of care; Frequency = overall frequency count for data within each domain collated by this review; *numerical data in brackets is the ranking of all elements of care measured in each article; * *Same primary data used and therefore frequency count uses major data set only (Heyland 2006); Shaded cells = domain not ranked in the top 5 rankings for this particular study

Table 2.4: Representation of the top 5 ranked elements of palliative care in the hospital setting from the perspectives of families

Domain / **Study**	**Expert care**	**Effective communication and shared decision making**	**Respectful and compassionate care**	**Trust and confidence in clinicians**	***Financial affairs***
Osborn et al., 2012 [31] **	How well the nurses cared for your family member (2/24) * How well the ICU staff treated your family member's pain (3/24) * How well the ICU staff treated your family member's agitation (5/24) *	Did you feel you had control over the care of your family member? (1/24) * Did you feel supported in the decision-making process? (4/24) *	The courtesy, respect, and compassion your family member was given (4/24) *	*Domain not rated in top 5 elements of care in this study*	*Domain not rated in top 5 elements of care in this study*
Heyland et al., 2010 [29]	*Domain not rated in top 5 elements of care in this study*	That the doctor(s) were available when you or your relative needed them (by phone or in person) during the past month? (2/38) *	That the doctors and nurses looking after your relative during the past month were compassionate and supportive of you? (3/38) * That the doctors and nurses looking after your relative during the past month were compassionate and supportive of him or her? (4/38) * That the doctor(s) took a personal interest in your relative during the past month? (5/38) *	With the level of trust and confidence you had in the doctor(s) who looked after your relative during the past month? (1/38) *	*Domain not rated in top 5 elements of care in this study*
Young et al., 2009 [34]	Doctors and nurses knew enough about the deceased's condition *(focus on doctor)* (1/7) * Enough help available to help with personal care needs (2/7) *	Able to discuss worries and fears with hospital staff about deceased condition,	*Domain not rated in top 5 elements of care in this study*	*Domain not rated in top 5 elements of*	*Domain not rated in top 5 elements of*

	Doctors and nurses knew enough about the deceased's condition *(focus on nurse)* (3/7) * Felt that the deceased died in the right place (5/7) *	treatment or tests *(focus on doctor)* (4/7) *		*care in this study*	*care in this study*

Domain Study	**Expert care**	**Effective communication and shared decision making**	**Respectful and compassionate care**	**Trust and confidence in clinicians**	***Financial affairs***
Heyland et al., 2006 [26]	To have an adequate plan of care and health services available to look after him or her at home, after discharge from hospital (4/25) * That your family member has relief of physical symptoms such as pain, shortness of breath, nausea (5/25) *	To not have your family member be kept alive on life support when there is little hope for a meaningful recovery (2/25) * That information about your family member's disease be communicated to you by the doctor in an honest manner (3/25) *	*Domain not rated in top 5 elements of care in this study*	To have trust and confidence in the doctor looking after the patient (1/25) *	*Domain not rated in top 5 elements of care in this study*
Baker et al., 2000 [32] ****	Comfort score was inversely associated with the degree of patient pain during the last 3 days of life	Surrogates who reported patient's preferences were followed moderately or not at all had less satisfaction	*Domain not rated in top 5 elements of care in this study*	*Domain not rated in top 5 elements of care in this study*	Surrogates who reported that the patient's illness had greater effect on family finances had less satisfaction

Steinhauser et al., 2000 [33]	Be kept clean (1/44) * Be free of pain (4/44) *	Name a decision maker (2/44) * Have someone who will listen (2/44) *	Maintain one's dignity (2/44) * Presence of family (4/44) * Have physical touch (5/44) *	Have a nurse with whom one feels comfortable (2/44) * Trust one's physician (3/44) *	Have financial affairs in order (5/44) *
Domain **Study**	**Expert care**	**Effective communication and shared decision making**	**Respectful and compassionate care**	**Trust and confidence in clinicians**	***Financial affairs***
Kristjanson, 1989 [30] ***	*Important for patients:* Physician assesses symptoms thoroughly (1/74) * Symptoms treated quickly (2/74) * MD pays attention to patient's description of symptoms (3/74) * Pain relieved quickly (4/74) *	*Important for patients:* Tests and treatments are followed up (5/74) * *Important for families:* Information provided about patient's prognosis (1/77) * Caregivers are straightforward when answering questions (2/77) * Information provided about side effects of treatments and drugs (3/77) * Information on future stages of treatment and care (4/77) * Family conference arranged by MD to discuss patient's illness (5/77) *	*Domain not rated in top 5 elements of care in this study*	*Domain not rated in top 5 elements of care in this study*	*Domain not rated in top 5 elements of care in this study*

Frequency	**16**	**15**	**7**	**4**	**2**

Key: Domains = overarching categories developed by this review through data synthesis; Domain name in italics = domain that is specific to family data (not found in top rankings of patient data); Data in each cell = primary data from each article ranked in their top 5 elements of care; Frequency = overall frequency count for data within each domain collated by this review; *numerical data in brackets is the ranking of all elements of care measured in each article; **this study had one element of care that was not categorised due to insufficient information as disclosed by the authors. This element was 'the atmosphere of ICU (3/24) *' with it being unclear whether this referred to the physical environment, policies regarding visitation or clinician efforts to enable family comfort. *** Study asks participants to rank important elements for patient care and family care. Both sets of ranked data are provided (noted as patient or family focus) and both counted in overall frequency; **** Data not formally ranked – statistically significant scores included here; Shaded cells = domain not ranked in the top 5 rankings for each particular study.

Study 1b - Qualitative data (Study 1b)

2.6.4 Study characteristics

Study location

Countries represented include: US (n=5),[35-39] England (n=3),[40-42] Northern Ireland (n=1),[43] Japan (n=2),[44, 45] Norway (n=1),[46] Switzerland (n=1),[47] Germany (n=1),[48] Australia (n=1)[49] and Thailand (n=1).[50]

Study design

Data collection occurred through one to one interviewing (n = 7);[37, 38, 41-44, 47, 49, 50] focus groups (n = 3);[35, 36, 39] survey with open ended questions (n=3).[40, 45, 48] Approaches to data analysis included content analysis (n = 11);[35-41, 44, 45, 48, 49] Husserlian (n=1) [43] and Interpretive Phenomenology (n = 2); [47, 50] and Grounded Theory (n = 2).[42, 46]

Sample characteristics

Eleven studies[36, 37, 39-41, 43, 45, 46, 48-50] focused on family participants, three[35, 42, 47] included both patients and families and two[38, 44] included patients only.

Fifty-seven percent of patient participants[35, 38, 42, 44, 47] were male, with a mean age across manuscripts reporting age ranging between 54.5 – 63.3 years.[35, 38, 44, 47] Only the US manuscripts[35, 38] reported ethnicity with one study recruiting predominately white patients (73.3%)[35] and the other [38] recruiting a broader patient sample (Table 2.5).

Fourteen manuscripts included family participants,[35-37, 39-43, 45-50] with a larger proportion of females represented (75.6%). Eight manuscripts[35-37, 39, 41, 46, 47, 50] reported family participants' mean ages ranging from 47 – 80.2 years. Two US manuscripts[35, 39] described ethnicity showing a majority Caucasian family sample (>60%). Six manuscripts[36, 41, 42, 45, 47, 49] described family participants' relationship to the patient, with the most common relationship being spousal (60%) or offspring (20%).

Quality appraisal

Included manuscripts (n = 16) all provided a clear aim and data collection techniques, 15 outlined their data analysis approach, and 13 were informed by theory relevant to practice and/or policy. However, more than three-quarters (n=12) failed to provide a rationale for their research design and/or detail researcher reflexivity (Appendix 2).

Table 2.5: Summary of extracted data from included qualitative studies in meta-synthesis (Study 1b)

Source / Country	Aim	Design and method	Participants and hospital setting	Participant details	Results / findings
Bussman et al. 2015 Germany	To analyse family members' suggestions for improvement in end-of-life care in general hospitals	Cross-sectional survey with one open-ended question. Free text analysis of responses made	Randomly chosen family members (N=633) of inpatients hospitalized during last 4 weeks of life	Participants (n=270) 52% female	Seven main categories concerning improvement suggestions and reported deficiencies generated from the 270 responses, namely: 1. Medical care and nursing; 2. Care before and during dying; 3. Interpersonal humane interaction; 4. Support for families; 5. Psychological and spiritual welfare; 6. Consultation, information and communication; and 7. Structural aspects in hospital management.
Steinhauser et al. 2014 USA	To define the relevant aspects of quality of experience for families of hospitalized patients	Focus groups (n=2) using semi-structured interviews. In-depth interviews with 2 members of each group to provide additional detail. Content analysis used open and axial coding	Family members (n=14) of patients who had died 6-12 months prior in one of 2 large hospitals	Age range: 46-83, mean 62 yrs. 100% female. 64% Caucasian; 21% African American; 14% did not report ethnicity	Participants were asked what was important, most needed and what constituted quality of experience. Content analysis yielded 64 attributes within 8 domains: 1. Completion; 2. Symptom impact; 3. Decision making; 4. Preparation; 5. Relationship with healthcare providers; 6. Affirmation of the whole person; 7. Post-death care; 8. Supportive services
Kongsuwan et al. 2012 Thailand	To describe a peaceful death from perspectives of Thai Buddhist family members of	Descriptive qualitative study informed by a phenomenological approach using interviews, and transcript analysis	Family members (n=9) of Buddhist people who died peacefully in an ICU in one hospital from southern Thailand	Age range:30-62, mean 47 yrs. 78% female. Daughters 5;	5 core qualities of a peaceful death: 1. Knowing death was impending; 2. Preparing for a peaceful state of mind; 3. Not suffering; 4. Being with family members and not alone; and 5. Family members were not mourning

	people dying in ICU			sons 2; wives 2	
Source / Country	**Aim**	**Design and method**	**Participants and hospital setting**	**Participant details**	**Results / findings**
Mossin and Landmark 2011 Norway	To gain an in-depth understanding of family experience of a loved one dying in hospital	Grounded theory using in-depth semi-structured interviews. Data analysis via coding and use of memos	Family members (n=15) of patients who died of cancer in a nine-bed oncology / palliative care ward in 2006. Interviewed 10-15 weeks after death	Age range: 55-82, mean 66 yrs; Female: 100% All long-term relationships	Participants n = 8 (RR = 53%) with 7 people declining participation. After 5 interviews only a few nuances were seen. After the 8th interview – theoretical saturation was considered to have been achieved. Core category = Maintaining presence for the other and for one's own sake. Including 4 categories: 1. to find one's place; 2. to know; 3. to support each other; and 4. to terminate.
Dzul-Church et al. 2010 USA	To describe experiences of serious illness including concerns, preferences, and perspectives on improving end-of-life care in underserved inpatients	Qualitative analysis of 1-hour semi-structured interviews, with thematic analysis to enable development of themes	Patients (n=20) with a terminal illness in an American hospital with an estimated prognosis of <1 year	Age range: 38-78, mean= 54.5 yrs. Female 30% Black 30%; White 25%; Hispanic 35%; American Indian 5%; Other 5%	Data themed into three categories: 1. a description of the participants' lives; 2. how their past histories influenced end-of-life; 3. suggestions about how to improve end-of-life care (centre around improved relationships with providers [health care professionals], accessible chaplaincy and community support, feeling welcome in the hospital and the need for a humanist approach).
Nelson et al. 2010 USA	To understand how patients and families, who have experienced care in the ICU for at least 5 days, define high-quality palliative care	Focus groups (n= 9) with open-ended questions and scripted probes. Content coding and domain development	Randomly selected patients who survived the ICU (length of stay >5 days), families of survivors and families of patients who died in one of 3 hospitals, in 2007 – 2008	Age range: patients 34-87, mean= 58.5yrs yrs; family 24-86, mean = 60.4 yrs; Female: patients 46.7%; family 78.8%	Participants n = 48 (patients 15; family members 33) A shared definition emerged from the data in relation to important domains of high-quality ICU palliative care: 1. Communication by clinicians about the patient's condition, treatment and prognosis; 2. Patient-focused medical decision making; 3. Clinical care of the patient to maintain comfort, dignity, personhood, and privacy; 4. Care of the family: Providing access, proximity, and support. Furthermore, participants endorsed important care processes and structural aspects of high-quality ICU Palliative Care:

				Race: patients- White 73.3%, Black 6.7%, Hispanic 6.7%; Family- White 60.6%, Black 21.9%, Hispanic 12.5% Family relationship to patient: Spouse 43.8%; adult child 21.9%; other 34.4%	1. Regular family meetings with attending physician and nurse; 2. Flexible, liberal policy on visiting; 3. Early identification of surrogate decision-maker/advance directive/resuscitation status; 4. Frequent assessment of pain and titration of analgesia to maximize comfort and achieve desired level of consciousness; 5. Offer of pastoral care with sensitivity and without mandate; 6. Offer of practical and emotional (social work) support; 7. Printed information about ICU for families; 8. Offer of bereavement support to families of patients dying in the ICU; 9. Waiting room affording comfort and privacy to families.
Source / Country	**Aim**	**Design and method**	**Participants and hospital setting**	**Participant details**	**Results / findings**
Spichiger 2008 Switzerland	To explore terminally ill patients' and their families' experiences of hospital end-of-life care	Interpretive phenomenology including participant observations, conversations with patients and interviews with family members	Terminally ill patients from a general medical ward within a Swiss public tertiary care hospital (1000 beds) and their designated family member	Patients: Age range 38 – 85; mean = 62.7 yrs. Female 30% Family: Age range 41 – 82; mean = 64.6yrs. Female 70% Relationship to pt: 4; spouses, 3 partners, 1	Participants n = 20 (10 patients and 10 family members) Key findings: 1. Leading a unique life with a terminal illness – people continue to live; 2. Hospital was experienced differently by patients – prison, heaven, necessary sojourn; 3. Providers' commitment and caring is crucial to quality of experience; and 4. Patients' and family members' experiences with care interventions affects quality of life inclusive of the need for valuing the individual

				mother, 1 brother, 1 sister-in-law	
Source / Country	**Aim**	**Design and method**	**Participants and hospital setting**	**Participant details**	**Results / findings**
Payne et al. 2007 England	To explore the experiences of patients and carers of end-of-life care in community hospitals	Qualitative semi-structured interviews analysed using principles of Grounded Theory	Participants were patients and carers admitted for end-of-life care in one of six community hospitals	Patients: Age ranges 65-69 - 3; 70-79 - 10; >80 - 3; unknown -2 Female 55.5%; Family: Female 82%; Relationship to pt: spouse 6; child 5	Participants: Patients n = 18 and Family carers n= 11 The following was valued within a community hospital setting: flexibility, locality (facilitating visiting) and personalised care. Most preferred community hospitals over district general hospitals and considered them to be acceptable places for end-of-life care
Hawker et al. 2006 England	To obtain retrospective carer views about the nature and quality of end-of-life care in community hospitals	Qualitative case study approach using semi-structured interviews followed by line by line coding to inform results	Next of kin for all patients aged over 65 who died in one of 6 hospitals. Hospitals chosen to reflect variance in size, rurality and medical model	Participants: Age range 68 – 99, Mean 80.2 yrs Female 78.4%; Relationship to pt: wife 17; daughter 14; son 7; husband 4; friend 4; sister 3; niece 1; daughter-in-law 1	Participants n =51 (RR = 51%) Overall bereaved carers were positive about care received and specifically noted the following areas as advantages of receiving end-of-life care in a community hospital: Locality; Environment; Familiarity; Nursing staff. Issues of concern noted: Unpredictability of death for older patients; Staffing; Noise

Ogasawara et al. 2003 Japan	To examine how families of patients with cancer, in a large university hospital, perceive and are satisfied with terminal care and to identify barriers to best care for patients and families	Descriptive survey study using a 23-item questionnaire where the last 3 questions were open-ended. This review reports on these last 3 questions only, which asked about expectations of doctors and nurses and noted areas for change in care	Family members who had cared for a patient with cancer treated at the university hospital between April 1996 and October 1998	Age range 26 – 87, Mean 56.1 yrs Female 57%; Relationship: spouse 69%, child 18%, sibling 6%, parent 6%, no response 3%	Participants n =73 (RR = 55%) 5 categories to be involved in terminal care: 1. Pain control and symptom management; 2. Spiritual care; 3. Reduction of medical treatment of the cancer itself; 4. Support for family members; 5. Appropriate information about diagnosis and prognosis 5 categories regarding expectation of nurses: 1. Patient and family-oriented nursing; 2. Improvement of bedside manner and techniques; 3. Concern for psychological care and support; 4. Quick responses; 5. Individualised care 7 categories regarding expectation of doctors: 1. Appropriate informed consent for the family; 2. Psychological support for the patient and family; 3. Desire for satisfactory treatment; 4. Minimal medical tests; 5. Patient-centred treatment; 6. Treatment corresponding to palliative and home care instead of research and treatment-based care; 7. Appropriate timing of treatment
Source / Country	**Aim**	**Design and method**	**Participants and hospital setting**	**Participant details**	**Results / findings**
Kirchhoff et al. 2002 USA	To obtain a detailed overview of the experience of family members whose loved one dies in the ICU	Qualitative semi-structured focus group design followed by content analysis	Patients (>55 years) who had died in the previous 6-18 months, in one of 8 ICUs of 2 large American hospitals	Age range 38-84, Mean 59 yrs Females 75% Relationship: spouse 6; son 1; granddaughter 1	Participants n = 8 (RR = 19.5%) Communication, or lack of it, was a common theme. Families talked about the need for contact and targeted communication with a physician, and those who had this felt the best possible outcome was achieved
McGrath 2001 Australia	To document the experience of the dying trajectory for patients with	Qualitative open-ended interviews focused on the caregiver's description of the	Relatives who were known to the grief support service of the	Females 90% Relationship: Spouse 5;	Participants n =10 (RR = 100%) The following themes were found: • Caregiver Demands

	haematological malignancies and their families	experience of illness for the patient and his or her family. Data analysed via coding and thematic analysis	Leukaemia Foundation of Queensland	Mother 3; Sister 2	- Caregiver–Patient Relationship and the Need to Be There - Patient Advocate - The Need for Information - Doctor Communication - Nurse Communication

Source / Country	**Aim**	**Design and method**	**Participants and hospital setting**	**Participant details**	**Results / findings**
Dunne and Sullivan. 2000 Northern Ireland	To gain understanding and insights into the lived experience of families who journeyed with their loved one during the palliative phase of illness in the acute hospital setting	Husserlian phenomenology using unstructured interviews. Analysis via Colaizzi's (1978) seven-stage process for the analysis of phenomenological data	Family members involved in the end-of-life care of a loved one who was an inpatient in a medical or surgical ward between Sept 1998 and Feb 1999, who lived in a local postcode area and had been bereaved 1-2 yrs	Details not provided	Participants n = 8 (RR = 60%, n= 15). 8 interviewed (not the full 15 who responded) as data saturation met at this time. Four core themes emerged from analysis of the data: 1. The hospital environment as a place to deliver palliative care; 2. Needs and feelings expressed by family members; 3. The family's experience of the patient in pain; 4. Communication as experienced by family members
Rogers et al. 2000 England	To examine causes of dissatisfaction with hospital-based end-of-life care	Analysis of data obtained from 14 open-ended questions within a post bereavement survey (VOICES). Content analysis used where data was organised into categories and themes	Two-thirds of a random sample, from a particular health authority, of deaths of people who had died from cancer between July 1995 and June 1996.	Details not provided	Participants n = 138 who answered free text questions from 229 surveys returned Dissatisfaction arose from: 1. feeling devalued, dehumanized and/or disempowered 2. a breaking of the expectation of the health professional-patient relationship Suggestion that the palliative care approach could reduce dissatisfaction
Pierce 1999 USA	To describe family members' reactions to	Qualitative in-depth interviews. Data analysed via thematic	194 deceased people from 4 counties identified with 75	Age range 30 – 80, Mean 53 yrs.	Participants n =29 (RR 39%) Common, recurrent experiences: Impact of individual caregivers; Persistence of regrets and sadness

	experiencing death of a loved one within a tertiary care setting	analysis using the constant comparative method	randomised into the study. The next-of-kin for these 75 people contacted	Female 72%	Concerns and suggestions: The routinized nature of a complex system; The impact of a routinized system on patients and families; Ameliorate the negative impact of systems on people; Facilitate improved interaction between the dying patient and the family; Improve interactions between caregivers and patients / families; Create a more conducive setting / milieu
Tanaka et al. 1999 Japan	To clarify how terminally ill patients think and feel while hospitalised to inform improvements in the quality of palliative care	Qualitative semi-structured interviews. Analysis included coding to lead to the development of themes	Patients with terminal cancer within a large (502 bed) hospital in Japan	Age range 51 – 93, Mean 63.3 yrs. Female 50%	Participants n = 8 4 major categories: 1. Maintaining pain control 2. Living an ordinary life 3. Hoping for improvement of physical condition 4. Having family nearby

2.6.5 *Study 1b - Synthesis*

One hundred percent of inpatient (n= 71) quotes (n=74) and 99% of family (n=672) quotes (n= 278) were considered relevant to the research question and analysed. The inpatient data generated 32 codes, 10 descriptive themes and 7 domains, while the family data generated 72 codes, 21 descriptive themes and 10 domains. Domains are displayed in Figure 2.3. Key themes of care captured within each domain are summarised below, with exemplar quotes. All quotes and their placement in domains are detailed in Appendix 3 (patient data) and Appendix 4 (family data).

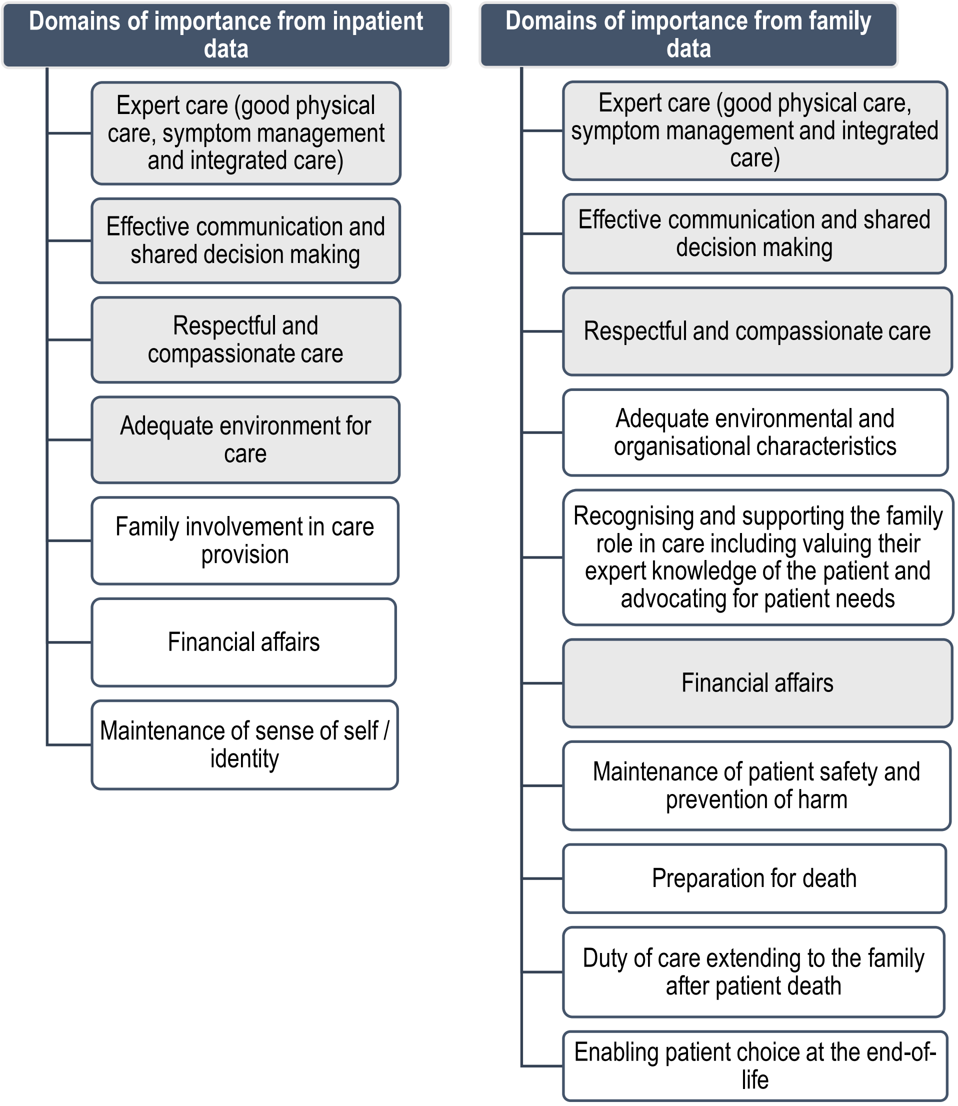

Figure 2.3: Summary of domains revealed from inpatient and family qualitative data

Note: Shaded boxes refer to domains from the analytical framework based on Study 1a's systematic review of quantitative studies.[1] Unshaded boxes are new domains developed through Study 1b's meta-synthesis.

Inpatient data

Synthesis of inpatient data generated seven domains: four also identified in Study 1a's systematic review of quantitative studies (expert care; effective communication and shared decision making; respectful and compassionate care; and an adequate environment for care); and three new domains: family involvement in care provision; financial affairs; and maintenance of sense of self / identity.

Expert Care

Three themes were identified within the broad domain of 'expert care': good physical care, symptom management and integrated care and are used within both the inpatient and family results.

Good physical care: One study[44] noted the importance of good physical care including maintaining hygiene: *I'm thankful for my hair being shampooed[44]* and independence: *I can eat at a table when I wear a corset.[44]*

Symptom management: Inpatients noted the importance of regular, person-centred pain assessment and management and enabling a rapid response when analgesia is required.[35]

> *How can they expect the doctors and the nurses to know what your pain is? They do not know, unless you tell them . . .35*

> *And the one thing I used to hate, when it's coming on and you're pressing the button, and they do not come, and you're in a lot of pain35*

Inpatients described the negative impact of poorly managed pain both in hospital[35, 44] and at home, and how hospital admission enabled profound and rapid relief.[47] Clinicians demonstrating they cared about inpatients' symptoms was also important.[47]

> *They almost suffered themselves. One told me that the whole unit was preoccupied with me. That's good47*

Finally, an inpatient described the importance of sufficient pain assessment and management for a person with a known opioid dependency.[38]

> *They ain't got it under control. They keep thinking because I'm a heroin addict, I'm trying to get more pills38*

Pain was the key symptom discussed with mention also of vomiting and restless legs. Of note is the need for prompt individualised assessment and management delivered through a caring approach.

Integrated care: The importance of clinicians working as a team was highlighted and contributed to inpatients receiving safer care and better outcomes.[35, 38]

> *It’s like a team effort. If you’re a team and they’re all together working with the patient itself, it’s going to work out really good38*

Effective communication and shared decision making

There are three themes within this domain. Firstly, the need for honest and clear information to enable a shared understanding, noting the need for layman’s language and communication delivered with compassion.[35]

> *Using terms that a person that’s not a doctor could understand . . .* [35]

> *Communication, with compassion . . . because, being in the dark is like being in oil* [35]

Secondly, inpatients detail the importance of adequate information throughout a hospitalisation, inclusive of family members, to support decision making, decrease stress and prevent surprises.

> *Knowledge is power, and if my family is informed, then they could have comfort knowing what my status is and how I am progressing or not progressing, day to day, what to expect in the near future*[35]

Thirdly, inpatients described their need to be engaged in care planning, inclusive of advance care planning,[35, 38] to remove the burden for decisions from family members.[35] One patient thought it was crucial for the ICU to *“know what I prefer”* so that her family “*would never feel guilty about having to make a decision.”* [35]

Respectful and compassionate care

This domain encompasses three themes: firstly, patients feeling welcomed and deserving of a hospital admission.[38]

> *I can see where the wheels are turning and people are thinking should he be here? Is he costing us too much?* [38]

Secondly, inpatients being treated with care, respect and with a focus on dignity.[35, 38, 47]

> *What really made it different was she treated me with respect and dignity, and the dignity was what made it above and beyond. . .* [35]

Thirdly, clinicians anticipating patient / family needs, being responsive and demonstrating cheerfulness and care for their work.[42, 47]

> *I can only speak good really, you know, I’ve got no complaints whatsoever. They are so attentive, they’re so cheerful, they don’t mind how many times you ring your buzzer…* [42]

An adequate environment for care

The concept of space was personal, one inpatient described the importance of having their own quiet space whilst another said the opposite was true.[42] Inpatients described the positive impact of community based hospitals in preference to tertiary hospitals, which was attributed to a nicer atmosphere, feeling closer to home, more accessible parking and an increased feeling of safety.[42]

> *It's [community hospital] such a nice atmosphere, you feel so safe* [42]

However, lower levels of nursing availability in smaller hospitals was noted with inpatients having to readjust expectations as a result.[42]

Family involvement in care provision

Company and family connection, including family support, are indispensable in providing comfort and emotional healing.[35, 38, 44]

> *My friends and, more importantly, my family played a very, very big part in my, in my comfort level, and my emotional healing* [35]

Financial affairs

Inpatients in a Japanese study[44] outlined concerns about the financial implications of a hospital admission.

> *I'm concerned about my hospital and living expenses for my family as I have been in hospital for a long time* [44]

Maintenance of sense of self / identity

Two themes emerged within this domain, namely: the profound impact of a terminal illness: *'It is always there, it is never again not there'.*[47] Having a terminal illness was likened to being in prison; and the need to maintain independence, to live well in the context of disease and for some, to maintain a focus on work.[44]

> *I will make an effort to maintain this improved condition… I'm not going to look backwards; I want to live with this disease with all my strength and maintain my quality of life as a human being* [44]

Family data

Synthesis of family data generated ten domains: four also identified in Study 1a's systematic review of quantitative studies (expert care; effective communication and shared decision making; respectful and compassionate care; and financial affairs) and six new domains: adequate environmental and organisational characteristics; recognising and supporting the family role in care including valuing their expert knowledge of the patient and advocating for patient needs; maintenance of patient safety and prevention of harm; preparation for death; duty of care extending to the family after patient death; and enabling patient choice at the end-of-life.

Expert care

Good physical care: Families noted expert provision of core nursing care alongside more specialist nursing competencies.[41]

> *They really were fantastically caring and you know, the process of turning and mouth care, all that was done in an exemplary fashion* [41]

> *I'm not sure how well trained they were for when he needed his bag changing* [41]

Symptom management: Families identified the importance of symptom management generally[45] and specifically effective pain management,[43, 45, 48] timeliness of interventions [39, 49] and management of breathlessness.[50] Sub-optimal pain management was most commonly referred to as a source of distress.[39, 43]

> *Symptom management is the highest priority* [45]

Integrated Care: Families referred to provision of care to the whole person physically, emotionally and/or spiritually[48] and to the importance of one's physician being in charge.[35] Challenges in treating the person as a 'whole',[48] receiving conflicting information and lack of clarity about who is in charge[35] were all attributed to medical sub-specialisation. Multidisciplinary care that included social work and pastoral care input was valued.[35, 37]

> *The specification of professions involves that everyone treats only one aspect. Man, as a whole is falling by the wayside* [48]

Effective communication and shared decision making

There are three themes within this domain. Firstly, effective communication leading to a shared understanding was important and dependent upon the compassionate delivery of understandable and honest information.[35, 39, 43, 48]

> *The doctor did come in and tried to explain to us what it was, but I really wasn't understanding it. It was kind of over my head because we're not doctors* [39]

Secondly, having the necessary information was important as end-of-life decision making is affected by medical complexity, emotional and financial factors.[35, 36]

> *The doctor would tell you, you can do this or this or this …... And, it's a medical decision, but it's also an emotional decision and a financial decision, and . . . I did not know what was best* [35]

Thirdly, sufficient, timely and proactive information provision,[37, 46, 48] involvement in day to day care planning[35, 43] and regular planned discussions with the healthcare team[35] are all important. Given the complexities experienced generally in accessing information,[40, 43] families valued discussions with physicians.[35, 36, 42] However, they noted how hard this was to arrange[40, 43] and that a family meeting assisted them greatly.[39]

> *…that would be the very best thing that I can say all day today. If they would just say, okay, we're real busy, but we can be there at 10:20, then the family member can make it there*[35]

Respectful and compassionate care

Three themes were found within this domain. Firstly, approaches to care that are respectful, compassionate and preserve dignity are important.[35, 37, 39, 40, 48]

> *Everything matters- what people say, how they touch the patient- and you- how they look at you- whether or not you matter* [37]

Secondly, a number of valued attributes were described, in addition to necessary task–oriented care. These included being helpful, empathic, affectionate, appreciative, comforting, gentle, considerate and capable.[40, 41, 45, 48] The need to distinguish between nursing and technical care was outlined.[40] Competence in care was noted in terms of care of the dying (noting a need to increase capability in this area)[48] and managing a specialised need such as a colostomy.[41]

> *First and foremost employment of capable nursing staff characterized by the qualities: helpful, empathic, affectionate, appreciative, comforting* [48]

Finally, individualised care valuing the inpatient and their family is important.

> *[That] they don't become a 'number' but stay a human being and person* [48]

Adequate environmental and organisational characteristics

Three themes are noted within this domain. Hospital rules and processes need to make sense and shouldn't detract from optimal inpatient care.[35, 37, 40, 45, 48] Examples were provided where an inpatient experienced symptomatic distress awaiting formal 'admission',[40] a distressed relative was asked to move her car,[37] poor process management of an Advance Care Directive,[35] and visiting hours restrictions for dying inpatients.[48]

> *… that shouldn't happen to people. Rules need to make sense* [37]

Environmental characteristics contribute to quality palliative care particularly noting the need for privacy,[37, 43, 48]cleanliness [40, 41] and quiet.[41, 42] The need for privacy was noted by numerous family members across several studies, with a lack of privacy leading to a feeling of simply ‘watching’ and not being with their loved one or able to talk openly.

> *I just wanted to be alone with him- that seemed so hard in the ICU. They let us come in and all, but it wasn't like being with him- it was watching* [37]

Space for cultural practices such as congregating family members, chanting or other important rituals is also important.[50]

Recognising and supporting the family role in care including valuing their expert knowledge of the patient and advocating for patient needs

There are three themes within this domain. Family members want their expertise as ‘carer’ to be recognised and respected.[49] They want to be involved both in care provision and care planning[37, 43, 46, 49] and value their role as inpatient advocates.[35, 49]

> *One nurse, one time, asked me to help turn Barbara, while she made the bed ... I got to hold her, and touch her. It was the only time- the only time that I felt like I was able to do something for her. I wanted to do so much to help her- there seemed to be nothing I could do* [37]

Failure to be welcomed as a partner in care leaves family members feeling like observers and out of place.[43, 49]

> *As caregiver, quite often, they didn’t talk to me. So you felt like you were the third person watching the events . . . I found that difficult* [49]

Given family desire to being involved in care, removing them from distressing situations, especially if the inpatient dies, may cause longer term harm.[49]

> *I believe (the patient) would have known that I left the room and that hurts me to this day* [49]

Financial affairs

A UK study[40] noted the importance of proactively supporting inpatients and families with information about financial supports to enhance comfort and decrease stress.

> *I am an 83-year-old pensioner not in the best of health...had we been told of attendance allowance before Graham died his last few months may have been a bit more comfortable* [40]

Maintenance of patient safety and prevention of harm

Three themes were found within this domain. Families noted that hospitalisation did not always provide improved care compared with the care they provided at home.[40, 43] Indeed, one family member explicitly stated they feel the inpatient care received made the patient's condition worse.[40]

> *I think the 'care' he received made him worse not better [40]*

Sub-optimal care impacts adversely on inpatient safety affecting care outcomes and leading to patient harm.[37, 40, 41, 47, 49] Inpatient safety at the end-of-life was perceived to have been compromised by: poor communication;[40, 49] not considering a palliative approach;[37] not considering an inpatient's unique care needs;[37] families not feeling aware of how to best support the inpatient;[37, 47] poor nursing care[40, 41] and lack of timely attention.[49]

> *Henry couldn't hear and the nurse just stood at the bottom of the bed and asked if he wanted anything, when he didn't answer she just left him, if we hadn't asked for drinks he would have died of dehydration [40]*

Families in one study[37] noted a need for support to 'speak up' about care to ensure inpatient safety without repercussions.

> *I'm so glad for this opportunity to say something- and not have it tied to me or my husband in any way. These things need to be said; but you can't when you so desperately need their help [37]*

Preparation for death

Families noted the importance of being prepared for the inpatient's death to ensure they were able to say goodbye and to assist with their bereavement.[35-37, 39]

> *And, I believe I would have benefited greatly, if previous to this, I had been told by the doctor that this is the possibility, you need to start thinking about this. I just wasn't ready for it . . .[35]*

Duty of care extending to the family after patient death

One study[35] noted the need for the family members to be followed up after the inpatient's ICU death to prevent them feeling disconnected and rushed away from the hospital at such a profound time.

> *. . . they just came and closed his eyes, started doing whatever they do when somebody dies, and basically just said to move. And, I just left. I did not know what else to do. . . I would've liked a piece of follow-up, somehow. A call... [35]*

Enabling patient choice at the end-of-life

There are two themes within this domain. Firstly, the importance of following established Advance Care Directives,[35, 36, 48] and secondly a German study noted the need for legalised euthanasia for critically ill patients.[48]

> *Physicians should comply with existing patient advance directive and not prolong the suffering and dying for a few months* [48]

2.7 Discussion

The systematic review (Study 1a) revealed that effective communication, shared decision making and expert care, indicators of quality palliative care, are the domains of inpatient palliative care that inpatients and families consider to be most important. Kristjanson[30] over 30 years ago identified these same palliative care domains as being a priority for dying inpatients and their families. This review emphasised the need for respectful and compassionate care and trust and confidence in clinicians, with these domains ranked among the most important for both inpatients and families. It also identified domains uniquely of importance to inpatients (i.e. an adequate environment of care and ensuring that burden of care is minimised) and to families (i.e. ensuring financial affairs are in order). The financial domain was generated from US data and was not reflected in the data from countries with a universal health system. Whilst a universal health care system may provide an additional safety net and security for families when supporting people with palliative care needs, the reasons for family financial strain are more complex. An Australian report found that family members of those with palliative care needs often experience financial strain as a result of needing to reduce their work hours or to leave paid work alongside increased out of pocket health care expenses.[51] It also identified that financial strain impacted adversely on family members' health and wellbeing.[51] Therefore, this claim requires further analysis prior to final conclusions being drawn, and warrants attention to truly understand the needs of families in relation to financial matters.

The meta-synthesis (Study 1b) validated and deepened insights into identified domains. It also highlighted additional domains of importance not identified in the quantitative data, including the need for care and involvement of family, maintenance of self-identity for inpatients, and factors affecting inpatient safety. Additional insights into environmental needs emerging from the meta-synthesis suggest privacy is of greater importance to families[37, 42, 43, 48] than inpatients.[42] The congruence of domains of importance across inpatients and families and across the systematic review and meta-synthesis is noteworthy. This alignment both validates and emphasises the importance of effective communication and shared decision making, respectful and compassionate care, and expert care (encompassing good physical care, symptom management and integrated care) for people with palliative care needs. Collectively, the systematic review and the meta-synthesis emphasise the need for practice change. The insights generated by this Study largely reflect findings detailed in publications dating back to 1999.[37, 44]

A 2014 integrative review identified that inpatients and familes perceive the above domains of care to be poorly addressed within the hospital setting.[15] This integrative review identified symptom control and burden, communication with clinicians, decision making related to patient care and management, the hospital environment, and interpersonal relationships with clinicians to be areas requiring ongoing focus and improvement.[15] Similarly, a large Canadian study[52] found statistically significant unmet need for inpatients in relation to communication and being treated with respect ($p<0.0001$) and for family members in relation to obtaining information ($p<0.001$), knowing what to expect ($p<0.01$) and coordination of care ($p<0.01$). The considerable body of evidence about both what is important for inpatients and their families and the fact that this is not currently always provided in hospitals reaffirms the importance of palliative care reform within this setting.

The domains highlighted as important by Studies 1a and 1b are strikingly similar to those outlined as the 10 essential elements for safe and high quality end-of-life care in Australian acute hospitals, identified following consultation by the Australian Commission on Safety and Quality in Health Care.[53] This consultation document identifies a need to move from a purely person-centred approach to care to palliative care that is underpinned by trust and confidence in clinicians, respectful and compassionate care, preservation of dignity and clinical expertise. The Commission calls for palliative care to be strengthened across all of these domains, building the capacity of the health workforce to deliver optimal palliative care, as well as for the development of explicit process and outcome measures to support implementation and sustain improvements.[53] A person-centred approach to care complemented by greater development of clinical expertise in symptom management and effective communication, health care systems enabling coordinated care and a supportive policy environment that prioritises palliative care in the hospital system all contribute to important components of a model of care that will enable optimal inpatient palliative care. Developing and validating meaningful indicators of service quality based around the inpatient and family-identified domains of importance is vital to seeing future improvements in hospital palliative care.

Whilst the message is clear in relation to what inpatients and families need for optimal inpatient palliative care, the challenge is to enable this within an environment focused on acute and episodic care. Given the complexity of care, a whole-of-system approach is required to enable real change with consideration of: positive policy reform (macro); appropriate policy, structure and processes at each local hospital (meso); and a focus on adequate processes and measurement of outcomes to inform ongoing quality review alongside locally relevant improvement strategies (micro). Almost two decades ago, the World Health Organization proposed a model for innovative care for chronic conditions that challenges the health system to a new way of thinking and a new way of organising care, with linkages at macro (policy), meso (health care organisation) and micro (community) levels required.[54] Such systems ought to be applied to palliative care with a focus on the inpatient and family unit at the micro level.

2.8 Recommendations for future practice

This systematic review and meta-synthesis provide a comprehensive overview of what inpatients and their families state as important to enable optimal care. This work provides information to guide policy development for the hospital setting and provides useful reading for practitioners working within this setting, to guide everyday practice. It also offers a framework for the development, piloting and refining of a suite of indicators that assess quality inpatient palliative care to assist improvement efforts and future research.

2.9 Strengths and limitations

The strength of these Studies lies in the systematic methodology used to limit bias and assimilate large amounts of information.[55] The exclusive focus on inpatient and family perceived importance provides a firm basis for future policy and health service design in terms of end user priorities. However, there are also several limitations of these reviews. A single author examined the titles and abstracts and undertook data extraction for included studies. However, where uncertainty existed, discussion with the research team was undertaken for a consensus view. The narrative (quantitative) and thematic (qualitative) approach to data synthesis can include some subjectivity in relation to interpretation of data, although again, group consensus was sought to minimise this risk. Available data predominantly reflected White participants from the northern hemisphere and therefore is limited in informing domains of importance for other populations. Inpatient/family perspectives and structural health care differences across studies have been highlighted but did not contribute to the synthesis; caution should be exercised when reviewing and extrapolating these results. Within the meta-synthesis, while focusing analysis on raw data as opposed to full published results increased the likelihood that our findings represent the perspectives of inpatients and families rather than article authors,[56, 57] this approach is limited by the fact the review only had access to raw data reported by original researchers. There may have been selection bias when authors chose quotes to illustrate their codes and themes. Also, the decision to analyse raw quotes only and exclude author narrative resulted in loss of meaning generated through their interpretations. These interpretations were excluded to bring the inpatient/family perspectives into sharper relief. The large number of quotes informing this meta-synthesis, and the congruence of qualitative data with the quantitative data, confer confidence that this Study has captured the voice of a wide range of inpatients and families receiving inpatient palliative care. A further limitation of this Study is that the quality of reporting across included manuscripts was variable (Appendix 2). We excluded studies that focused purely on one aspect of palliative care to generate greater insight into which aspects were perceived by inpatients and families as most important. However, this may have resulted in some lost data for analysis. Finally, results are presented based on data from across all ward settings (generalist wards, intensive care and specialty wards). This could mean some domains are relevant to one setting more than another.

2.10 Summary

This systematic review and meta-synthesis provide a comprehensive understanding of the domains of importance for optimal inpatient palliative care as reported in the research literature. However, data informing this work are predominantly derived from high income countries in the northern hemisphere. In addition to this, only 10 Australian family members contributed in total, with no Australian inpatient data available. Therefore, in order to fully understand the domains of importance for optimal palliative care within Australian hospitals to inform foci for improvement efforts, additional data are required to explore the degree to which the above domains are relevant to the Australian context. A number of domains also require additional understanding informing how to enable such care in practice.

Chapter 3 reports the methodology and conceptual frameworks used in the OPAL Project to understand how to drive reform in palliative care within the Australian hospital setting, based on what is most important to inpatients and their families.

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Chapter 3: Research design and conceptual framework

3.1 Introduction

Phase 1 of the OPAL Project sought to understand what is most important for inpatients and their families in relation to palliative care. The completion of a systematic review and meta-synthesis (Chapter 2) revealed specific domains of importance from the perspectives of high income countries in the Northern hemisphere. Important domains include: expert care (inclusive of physical care, symptom management and integrated care), optimal communication, respectful and compassionate care, valued family involvement in care planning and delivery, maintenance of self-identity for inpatients, environmental privacy for families, ensuring inpatient safety, supporting inpatient choices, preparing families for death and providing contact for families after an inpatient has died. It is unclear if these identified domains of importance reflect Australian inpatient perspectives, or how these insights could be used to inform clinical practice improvement. Better understanding these domains of importance is required to guide improvement efforts within the Australian context.

This Chapter provides an overview of the OPAL Project's research design, including the rationale for using a fully mixed sequential dominant design and the underpinning conceptual frameworks. The specific methods for each of the OPAL Project's four Studies are detailed. The data integration enabling the development of overall conclusions through mid and end-point meta-inference approaches are also described. An outline of the positioning of the researcher and reflexivity used within the qualitative aspects of this doctoral research Project is provided. Finally, this Chapter outlines considerations relating to ethical conduct and data management and storage.

3.2 Objectives

The objectives of this fully mixed sequential dominant design research Project were to:

1. describe the domains of care that are most important to inpatients with palliative care needs and their families;
2. appraise national quality indicators available globally to support measurement of quality palliative care and how these align with the domains of care that matter most to inpatients with palliative care needs and their families;
3. identify the key drivers for enabling improvements in palliative care provision within Australian hospitals; and
4. integrate these data to determine how to optimise palliative care provision within Australian hospitals.

3.3 Research design and conceptual framework

3.3.1 Overview of the OPAL Project

The OPAL Project utilised a fully mixed sequential dominant design[1] conducted over three phases to address the stated objectives. From the outset, Studies were designed to prioritise the perspectives of inpatients and their families. Being sequential, each Phase of the OPAL Project informed the next Phase, as outlined below:

Phase 1 focused on 'Scoping the problem' and included a systematic review of published data describing what inpatients and their families perceive they require for optimal care (Studies 1a and b), reported in Chapter 2.

Phase 2 focused on 'Understanding importance' and involved qualitative interviews with inpatients and their families to better understand domains of importance, implications for practice and relevance for the Australian population (Study 2). The content analysis of this study was followed by a mid-point meta-inference of the integrated data from Studies 1a, 1b and 2. This mid-point meta-inference informed the direction of Phase 3 and shaped the OPAL Project conclusions.

Phase 3 focused on 'Driving reform' and included a global environmental scan (Study 3) and a co-design workshop (Study 4). These Studies were designed to understand how to drive improvement that addressed the inpatient and family perspectives of what constitutes optimal inpatient palliative care (Phase 2). The end-point meta-inference integrated data from the OPAL Project's four Studies to answer the research questions and generate recommendations (Table 3.1).

Table 3.1: Overview of the OPAL Project design

Phase 1 - Scoping the problem

- Study 1a: Identifying the domains of inpatient palliative care that patients and their families rank as being most important: A systematic review of published quantitative data **(QUAN).**[2]
- Study 1b: Identifying the domains of inpatient palliative care that patients and their families describe as being important: A systematic review and meta-synthesis of published qualitative data **(QUAL).**[3]

Phase 2 - Understanding importance

- Study 2: Confirming key domains of importance for optimal palliative care in the Australian hospital setting: a qualitative study **(QUAL).**[4]
- *Mid-point meta-inference: Study 1a, 1b and 2 data*.

Phase 3 - Driving reform

- Study 3: National quality indicators and policies from 15 countries leading in adult palliative care: a systematic environmental scan **(QUAL and Quan).**[5]
- Study 4: Strengthening the delivery of palliative care in the Australian hospital setting: A co-design study to design actions for practice, policy, education and research **(QUAL).**[6]
- *End-point meta-inference: all Studies.*

3.3.2 Philosophical worldview underpinning the OPAL Project

Mixed methods research draws on the tenets of pragmatism, whereby researchers focus on the defined research problem and how best to understand this using practical, outcome-oriented processes and embracing multiple viewpoints.[7-9] Framing the design within a philosophical world view or theoretical lens provides important scaffolding to the interpretation work required when combining the various datasets.[7] A pragmatic worldview was considered important for the OPAL Project because it sought to reveal practical and evidence-based recommendations for use within Australian hospitals.

The OPAL Project used the research paradigm of pragmatism to guide the selection of research methods and overall methodology that best suited the stated research questions and the Project aim.[10] The importance of this was twofold: firstly, pragmatism acknowledges that there are singular and multiple realities within the world open to empirical enquiry with a focus on establishing solutions to real world problems.[7, 10] Secondly, pragmatism acknowledges that different methods and methodologies can contribute to robust research outcomes[7, 11, 12] with a clear focus maintained on the research problem, rather than methods. This allows the researcher to select the methods best suited to understanding and answering specific research question(s).[7]

The philosophical assumption of pragmatism being concerned with what works and how such knowledge can be applied[7] was both important and deeply aligned to the OPAL Project's desired outputs. When considering what is important for optimal inpatient palliative care in Australia, it was clear that multiple realities could contribute to this understanding. The OPAL Project chose to prioritise the inpatient and family perspectives for this aspect of the research and designed methods to amplify this voice through the use of a fully mixed design.[1] This philosophical stance contributed to research design throughout all phases of the OPAL Project and through meta-inference, enabled a strong outcome grounded in inpatient and family experience and real-world solutions.

3.3.3 Defining mixed methods research

Mixed methods research answers a key question through the collection of both quantitative and qualitative data before integrating the two within the context of either philosophical assumptions or theoretical frameworks.[7] A mixed methods design was chosen for the OPAL Project because it provided a practical approach to answering a series of complex questions.[1, 7, 9, 13] Fundamental to mixed methods research design is the assumption that the integration of both types of data enables a richer understanding than could be gained from each data type in isolation[7, 13] and that both quantitative and qualitative data are important and useful in different ways.[1, 8] In Phases 1 and 2 of the OPAL Project, the initial review of quantitative data (Study 1a) provided a hierarchical understanding that informed qualitative coding structures within both Studies 1b and 2. Neither data type was considered more valuable, with both providing important and useful information. When considering what might be required to improve inpatient care (Phase 3), it was decided that identifying the available global quality indicators (Quan) and the barriers and enablers to their use (Qual) would be required to inform the overall Project conclusions, again valuing the contribution of both data types. The alignment of the Project Phases, research questions, research methods and data types are displayed in Table 3.2:

Table 3.2: Overview of OPAL Project Phases, research questions, study methods and data types

Study Phase	Research question	Methods	Data type
Phase 1 – Scoping the problem	What are the domains of care that are most important to inpatients with palliative care needs and their families?	Study 1a: Systematic review[2] Study 1b: Meta-synthesis[3]	QUAN + QUAL
Phase 2 – Understanding importance	What are the domains of care that are most important to inpatients with palliative care needs and their families?	Study 2: Semi-structured interview study[4]	QUAL
	Mid-point meta-inference of data from Study 1a, 1b and 2 to understand the domains of importance in the context of Australian inpatients and their families, to inform Phase 3.	Data verification and joint display tables	QUAN and QUAL
Phase 3 – Driving reform	Is there a suite of indicators to assist measurement of inpatient palliative care quality?	Study 3: Environmental scan[5]	QUAL and Quan
	What are the key drivers for enabling improvement in palliative care provision within Australian hospitals?	Study 4: Co-design study	QUAL
	End-point meta-inference of data across all Studies to inform Project conclusions and recommendations.	End-point meta-inference using joint display tables	QUAL and QUAN

Typologies within mixed methods research

Since mixed methods research was established as a formal research methodology in the 1980s, it has been described as the third major research paradigm.[1, 14, 15] Mixed methods research does not combine data in an ad hoc way. Rather, it is a considered approach designed to leverage each form of data and therefore has multiple design typologies.[1, 7, 8, 14, 16] More recently, it has been argued that some of these typologies assume a linear approach to data collection, analysis and interpretation, which does not always align with multi-faceted research projects designed to answer complex questions.[1, 7, 16] Some have suggested that the mixed methods design typology should centre around the points of inference rather than the sequencing of data collection.[16] Still another view argues for a comprehensive approach that reflects both the collection and interpretation of data that occurs within a complex mixed methods project.

This last view has been described as an ‘integrated typology of mixed methods design’ and was the design adopted by the OPAL Project.[1]

3.3.4 Typology informing the OPAL Project

The OPAL Project’s integrated typology considered the following three discrete dimensions, including the: level of mixing (partially versus fully mixed); time orientation (concurrent versus sequential); and emphasis of approaches (equal versus dominant status).[1] A three-phase, pragmatic, fully mixed sequential dominant design (Quan → QUAL)[1] was considered ideal to answer the OPAL Project’s research questions. Fully mixed methodology refers to the use of both qualitative and quantitative research within any or all of the following: research objectives, type of data, type of analysis, type of inference.[1] The OPAL Project used both data types across all of these stated areas to inform the final Project outcomes.

The timing of a mixed methods project can be either sequential or concurrent whereby concurrent research occurs contemporaneously and sequential occurs at different points in time.[1] The OPAL Project’s four Studies were inter-related sequential studies (Refer Figure 3.1). This sequential mixed-methods design was important given that the Phase 2 mid-point meta-inference provided a base for identifying strategies and co-designing recommendations in Phase 3.

Finally, the emphasis of the approach taken is an important consideration and can be described as either equal (where qualitative and quantitative data have equal emphasis across a project) or dominant.[1] The OPAL Project is described as being a dominant design because overall greater emphasis is placed on the qualitative data (Quan → QUAL). Guided by the Project’s research objectives, qualitative data was dominant but enhanced by understandings provided by quantitative data obtained via Studies 1a and 3 informing both the mid-point and end-point meta-inferences. Figure 3.1 provides an overview of the three-phase design, inclusive of data analysis concepts and their points of interface.[1, 16]

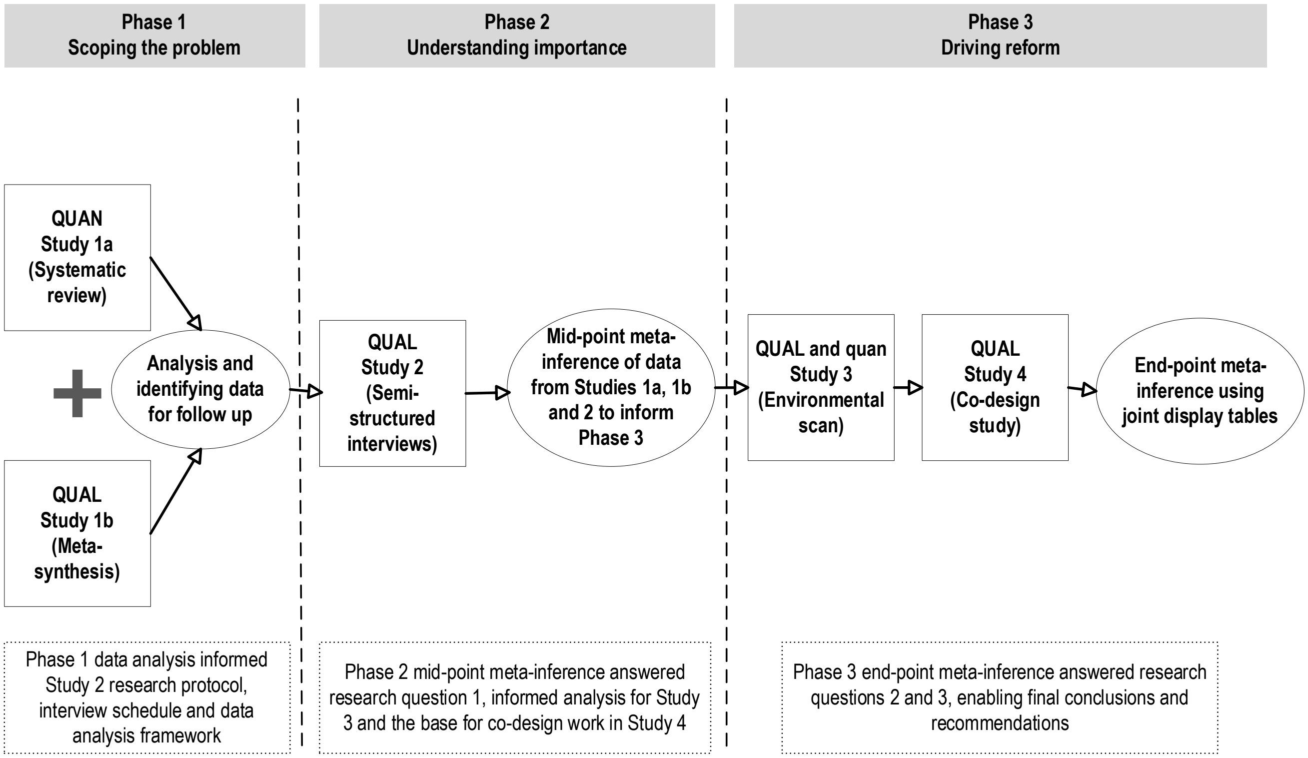

Figure 3.1: A mixed methods Study: fully mixed sequential dominant design (Quan → QUAL)[1]

Although typology descriptions vary,[1, 16] a core set of characteristics for rigorous and robust mixed methods research are well described.[7] How these characteristics are operationalised within the OPAL Project is described in Table 3.3:

Table 3.3: How the core characteristics for quality mixed methods research were addressed within the OPAL Project

Core characteristic[7]	How this was operationalised within the OPAL Project
Data collection and analysis informed by discrete research questions (qual or quan)	Four carefully designed individual Studies, each with discrete research questions.
Data integration - convergent, sequential or embedded means	Each Study informed the next, thereby adopting sequential means.
Prioritisation of data based on the research questions	Quantitative data were prioritised where hierarchical (Study 1a) or classification data were available (Study 3). The Project otherwise focused on deepening understanding prioritising qualitative data.
Interpretation of data within and across Studies	Given the sequential design, the interpretation of data at the mid-point meta-inference was critical to informing Phase 3, with the end-point meta-inference informing Project conclusions and recommendations.
Validation procedures	Considered within each Study, with each designed to optimise validity and reliability (described within each Study's methods below).
Ethical considerations	All Studies were undertaken in accordance with the National Statement on Ethical Conduct in Human Research 2007 (updated 2018)[17] and the Australian Code for the Responsible Conduct of Research (2018).[18]

3.3.5 Rationale for mixed methods in the OPAL Project

The need for mixed methods designs to answer complex health care questions is well understood,[1, 9, 19, 20] and is particularly noted as being of importance within palliative and end-of-life care research.[21] The justification of such a design is in mixing research paradigms to answer complex questions that are not amenable to one paradigm only.[1] Such questions may include research looking to better understand systems and/or models of care, service culture and individual behaviours and perspectives at clinician, patient and family levels. The OPAL Project accords with such thinking.[1, 9] Informing system-wide improvements in care for people with palliative care needs and their families in the Australian hospital setting is a complex undertaking that necessarily requires combining perspectives from different stakeholder groups whether these have been reported quantitatively by means of survey or qualitatively in interview and focus group studies. Within the OPAL Project, quantitative data enabled hierarchical understandings, with the qualitative data adding depth and richness to these understandings and informing how such knowledge can contribute to practice change.

3.3.6 Reporting a mixed methods study

Rigour in both the conduct and reporting of mixed methods studies is critical, with one important criticism being that researchers often fail to integrate the data in an open and transparent way.[20] In order to address this, a set of guidance points for reporting have been provided for mixed methods research, termed the *Good Reporting of A Mixed Methods Study (GAMMS) guidelines.*[20] This Chapter adheres to the *GAMMS guidelines* by reporting on: the justification for choosing mixed methods to answer the noted research questions; the design of the OPAL Project in terms of the purpose, priority and sequence of methods; the design of each Study (n=4) in terms of sampling, data collection and analysis; where and how meta-inference has occurred; and insights gained from integrating methods.

3.3.7 Conceptual frameworks

The OPAL Project was guided by two complementary conceptual Frameworks that supported both the design of each Study as well as the overall methodology and interpretation of findings.[7] The following provides an overview of *The Innovative Care for Chronic Conditions Framework*[22] and *The Person-centred Practice* Framework[23] and how they fit within this doctoral work.

The Innovative Care for Chronic Conditions Framework[22]

The Innovative Care for Chronic Conditions Framework[22] focuses on designing and implementing health services that enable improved outcomes for people with chronic conditions. It describes a health triad incorporating partnerships between patients and families, health care teams and community partners that aims to achieve optimal outcomes for the care of people with chronic illness. This health triad is centred within support from a broader community level (micro), health care system level (meso), and policy environment (macro) (Figure 3.2). This Framework focuses on chronic conditions defined as including non communicable diseases, mental disorders, and certain communicable diseases such as HIV/AIDS.[22] It also examines care models principally within developing nations. Therefore, there are some aspects of this Framework (community care, prevention of illness and political instability) that do not directly align with the foci within the OPAL Project on hospital care for people with palliative care needs in a politically stable country like Australia. However, the Framework's emphasis on improving outcomes, centering on patients and families supported by change at health care organisational (meso) and policy environment (macro) levels was considered to provide an ideal way of framing the OPAL Project.

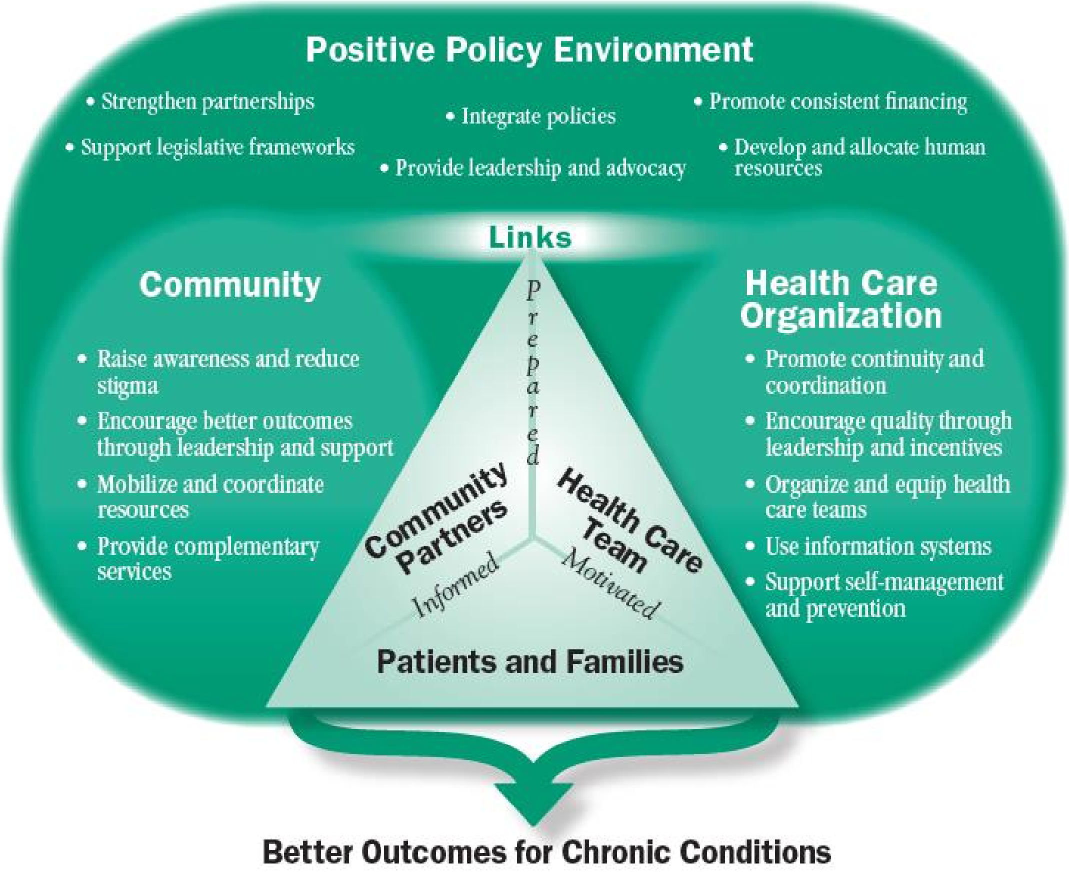

Figure 3.2: The Innovative Care for Chronic Conditions Framework[22]

Reprinted from Innovative care for chronic conditions: building blocks for action: global report. Report no. 9241590173. Pruitt, S., & Epping-Jordan, J. Chapter 3, Innovations in Care: Meeting the Challenge of Chronic Conditions, p.72 (2002). Access date - 29/04/20: https://www.who.int/diabetes/publications/icccreport/en/ (permission noted in Appendix 5)

The Person-centred Practice Framework [23]

While *The Innovative Care for Chronic Conditions Framework* provided a higher level conceptual guide in relation to health system redesign, a second framework was chosen to complement and extend the focus on the meso and micro levels of health care provision.

The Person-centred Practice Framework (2019 revision)[23] focuses on the delivery of person-centred care with specific attention on the prerequisites required for clinicians to deliver such care, supported by effective policy, a supportive practice environment and considered attention to person-centred processes. This Framework has evolved over the last decade from an explicit focus on nursing to inform multidisciplinary and interprofessional contexts[24] and more recently to incorporate the impact of the macro context in enabling person-centred outcomes.[23] Since its inception, this Framework has been grounded in concepts of caring and person-centredness, both critical when considering optimal inpatient palliative care provision. The key domains intrinsic to this Framework are: pre-requisites for person-centred practice; the care environment; person-centred processes; person centred outcomes;[24] and the macro context framing all such considerations (Figure 3.3).[23] The interrelation of these domains for enabling effective person-centred care has been validated through use in practice and research.[24]

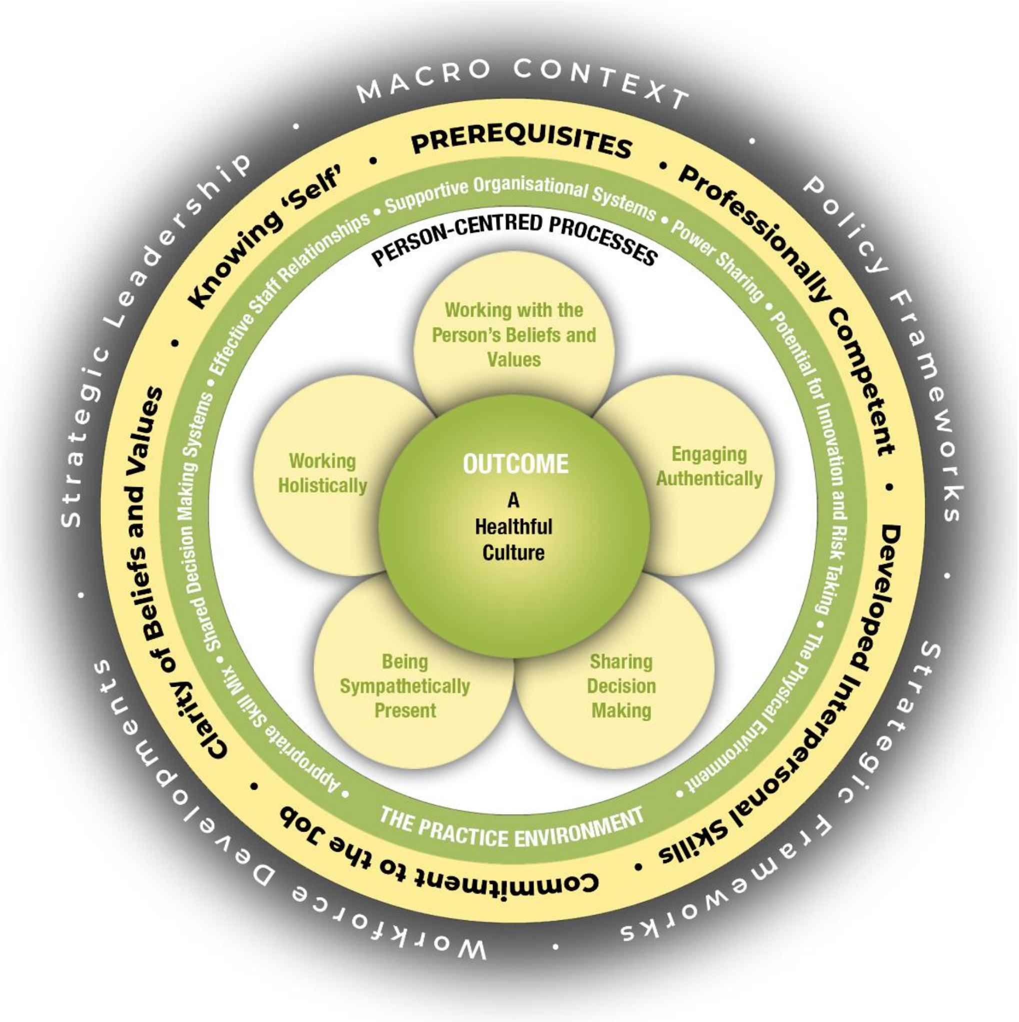

Figure 3.3:The Person-centred Practice Framework (2019 revision)[23]

Reprinted with permission from: The Person-centred Practice Framework (2019 revision). Access date - 29/04/20 https://www.cpcpr.org/resources Permission from Professor Brendan McCormack, Associate Director, Centre for Person-centred Practice Research (Appendix 5).

Person-centred outcomes in the context of this Framework are inclusive of both clinicians and patients and described as including a good experience of care, being involved, a feeling of well-being and the existence of a healthful culture.[24] A healthful culture is considered the ultimate outcome for teams at the micro level of care delivery and describes clinicians working collaboratively, inclusive leadership and encouraged innovation.[24] The OPAL Project's quest to optimise palliative care in Australian hospital settings aligned closely with all domains noted within this Framework and specifically considered what this means in practice for people with palliative care needs. Applying these person-centred domains to the design of the OPAL Project's Studies and analysis was important to enable outcomes that were both pragmatic and feasible for busy and dynamic clinical settings, alongside contributing to improved outcomes for patients and families.

Integration of both conceptual Frameworks within the OPAL Project

The Innovative Care for Chronic Conditions Framework informs how to reform health care systems charged with caring for people with chronic conditions*. The Person-centred Practice Framework* adds to this thinking by focusing more specifically on how to enable person-centred care in practice. In combination they provide a powerful conceptual frame to inform the design and analysis work within the OPAL Project.

The health triad within *the Innovative Care for Chronic Conditions Framework*[22] and the key domains within *the Person-centred Practice Framework*[23] are centred around patient and family outcomes. This was key for the OPAL Project, leading to overall Project design that prioritised the inpatient and family voice informing what was important for care (Phase 1 and 2), prior to working with clinicians and policy makers in combination with palliative care consumers, to develop actions for improvement based on such understandings (Phase 3). Table 3.4 outlines strategies used to prioritise patient and family perspectives throughout the OPAL Project.

Table 3.4: Strategies used to prioritise patient and family perspectives throughout the OPAL Project

Phase 1 – Scoping the problem	• Systematic review[2] (Study 1a) and meta-synthesis[3] (Study 1b) designed to analyse raw data from inpatients and families only (all other data excluded).
Phase 2 – Understanding importance	• Co-design of interview study (Study 2) with palliative care consumers informing optimal strategies for recruiting people with palliative care needs (and families), supporting their participation and communicating this work effectively.[25] • Study 2 participants being inpatients and families only.[4] • Data verification of early analysis work with palliative care consumers. • Mid-point meta-inference of Study 1a, 1b and 2 data to generate domains of importance informed by inpatient and family data only.
Phase 3 – Driving reform	• Involving palliative care consumers in the co-design study (Study 4) to identify actions addressing the outcomes from the mid-point meta-inference (inpatient and family identified domains of importance) with regard to strengthening palliative care within Australian hospitals.

The Innovative Care for Chronic Conditions Framework[22] articulates the need to consider driving change at macro, meso and micro levels, founded upon improving patient and family outcomes. The OPAL Project was guided by such direction, modifying accordingly for the inpatient context, through the presentation of final recommendations by macro (national policy), meso (health organisation) and micro (ward) level considerations. This Framework also provides a clear outline of the need to be cogniscant of: current and emerging policy initiatives including the consideration of paradigm shifts; service accreditation requirements and other work underway to drive sustainable change; integrated systems of care; and the effective use of healthcare personnel, all fundamental concepts to frame Project analysis and recommendations. Adding to this, *the Person-centred Practice Framework*[23] enhanced considerations relevant to the meso and micro levels focused on the concepts of a healthful culture enabling optimal outcomes for inpatients and families alongside a supportive and energising environment for clinicians and ancillary staff.

3.4 OPAL Project research methods by Phase and Study

The methods for each Phase and Study are described in detail below, excepting Study 1 detailed in Chapter 2.

3.4.1 Phase 1: Scoping the problem

Study 1: Identifying the domains of inpatient palliative care that patients and their families perceive as being most important: A systematic review and meta-synthesis

A full description of the methods used within the systematic review (Study 1a) and meta-synthesis (Study 1b) is provided within Chapter 2. Given the number of prior studies looking at areas of importance for optimal inpatient palliative care, a systematic review was considered to be the most appropriate design for understanding and appraising the quality of the existing evidence. Where prior studies are available, a well-designed and executed systematic review can inform practice and/or policy change[26, 27] as well as identify gaps and new research questions.[27] The systematic review and meta-synthesis identified key domains of care that are important from the perspectives of inpatients and their families from high income and mostly northern hemisphere countries.

3.4.2 Phase 2: Understanding importance

Study 2: Confirming key domains of importance for optimal palliative care in the Australian hospital setting: a qualitative study

Objective

To seek the perspectives of Australians living with serious chronic illness, who are considered to have palliative care needs, and their families, about their recent hospitalisation experiences to determine: i) the relevance of domains identified by international research to be important for optimal inpatient palliative care;[2, 3] and ii) how these elements might apply to their future care needs.

Design

An exploratory qualitative study using semi-structured interviews was used.[7, 15] This approach explores[28, 29] the domains identified in Studies 1a and 1b to be important and the specific ways in which these were experienced by inpatients and families. Despite being semi-structured, the interview questions were open-ended to encourage a depth of understanding from each participant and to allow points of interest to be followed as they arose.[30] This exploratory design allowed for the systematic collection, ordering, description and interpretation[31] of narratives generated from each interview. This approach also provided opportunities to explore and understand the meanings, values and experiences of a purposefully selected sample[31, 32] in relation to optimal inpatient palliative care. Reporting was guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.[33]

Participants

Participants were eligible if they were either an adult (age 18 years or over) patient with palliative care needs who had recent experience in the hospital setting, a current family member of such a patient or were a recently (past two years) bereaved family member of someone who had at least one hospital admission in their last 12 months of life. Palliative care needs were defined by having one or multiple life-limiting conditions in accordance with the Supportive and Palliative Care Indicators Tool (SPICT ™)[34] and an Australia-modified Karnofsky Performance Status (AKPS)[35] score between 30 and 70. Patients needed to be aware that they had a serious chronic illness and to be comfortable talking about this and related care needs over the telephone. Where patients had advanced dementia, and so were unable to speak for themselves, a family member was eligible to report on their behalf. All participants needed to be willing and able to give verbal informed consent and have sufficient English skills to participate in interviews.

Setting

Five hospitals (4 metropolitan and 1 remote) in New South Wales, Australia, recruited eligible patients and family members (current or bereaved). Bereaved family members who heard about the Study, irrespective of location, were also included.

Research team

The team consisted of experienced researchers with a background in oncology, palliative care and mixed methods research (supervisors) and a PhD candidate (CV) with a background in palliative care nursing. CV completed all the interviews and an understanding that her prior professional knowledge and interest in this research topic are likely to have an effect on the research process[29, 33] was planned for in order to limit bias as much as possible, detailed below within the reflexive account.

Recruitment

Given the vulnerable population involved, the recruitment process was co-designed with palliative care consumers (n=11) within five panel meetings held over an 18-month period.[25] These panel meetings focused on co-designing optimal strategies for identifying, approaching and recruiting people with palliative care needs, and their families, and supporting their participation throughout the proposed research. This co-design process informed changes to terminology used throughout Study paperwork, the screening and recruitment process and the process for enabling support for participants, as needed. Details about this work are published (Appendix 1).[25]

Non-probabilistic, purposive sampling was used to identify eligible participants at each recruitment site. This approach was chosen to ensure participants were competent to inform the Study's questions given their experience with inpatient palliative care.[7, 36] This decision was important to enable depth in data collected, based in real-world experience of care. The OPAL Project considered the six key principles noted to ensure that a credible qualitative sampling strategy was adopted.[37] Adopting these principles also ensured that the 'interpretive power' of the information obtained was enhanced,[37] so that Study 2 had the best chance of generating practical outcomes that were applicable within hospital settings. The six principles[37] and how these were applied within Study 2 are detailed below.

1. The sampling strategy should be relevant to the conceptual framework and the research questions addressed by the research.

Purposive sampling for patients with palliative care needs, their families or bereaved family members, with experience of hospital care, aligned with centering the focus and outcome of the Study directly on inpatients and families, in accordance with both conceptual frameworks and in direct alignment with the research question being addressed. Recruitment via one remote location in addition to four metropolitan locations also enabled perspectives from both metropolitan and rural settings to add richness and depth to information gained.

2. The sample should be likely to generate rich information on the type of phenomena which need to be studied.

Recruitment specifically screened for people with inpatient palliative care experience and therefore able to provide explicit information of interest. Interviewing with open-ended questions encouraged a depth of description and a richness in relation to how such data applies to clinical practice. Based on the premise that a sample size of 12 achieves data saturation for carefully selected participant samples,[38] this Study increased the projected number to account for the breadth of areas of importance noted in prior work,[2, 3] assuming patients and/or families may talk to a few areas of importance only (and not necessarily all). As a result, this Study aimed to recruit up to 30 patients and 30 family members aiming to achieve data saturation and rich information across all domains of importance. Sampling was reviewed throughout the Study in an attempt to enable as much diversity as possible to add to information richness. When cultural and socio-economic diversity was recognised to be limited, this was noted to screening sites so as they could keep this in mind for any potentially eligible participants.

3. The sample should enhance the `generalizability' of the findings.

Domains of importance revealed through the systematic review and metasynthesis of published data in relation to this area of enquiry (reported in Chapter 2) were used both within the question guide for the interview itself and within the integrated approach to data analysis (described below). This method enhanced the 'analytic generalisability'[37] by enabling the participant voices to be added to perspectives from all those included within prior published studies of relevance.

4. The sample should produce believable descriptions/explanations (in the sense of being true to real life).

The reliability of sources was ensured through carefully designed screening and recruitment processes. This ensured all participants had palliative care needs (patient or family member) and a recent experience of hospitalisation. The completeness of the data was maintained through the audio-recording and full transcription of each interview informing all data coded.

5. Is the sample strategy ethical?

The ethical nature of this work was carefully considered given the vulnerable population involved (people with palliative care needs). Firstly, the research protocol was co-designed with palliative care consumers, with their particular focus informing optimal strategies for identifying, approaching and recruiting people with palliative care needs and their families, and supporting subsequent participation.[25] Secondly, a full review by a Human Research Ethics Committee was completed including a specific focus ensuring informed consent through participant information sheet and consent form provision. There were no pre-existing relationships between the researcher (CV) and the Study participants recruited via the participating clinical sites. Snowballing occurred for bereaved family members and this did connect the researcher with some participants where there was an existing relationship (personal and/or professional). All participants were assured of complete anonymity and confidentiality in relation to interviews held. Participants who did have an existing relationship with CV, and approached the Study voluntarily for participation, were offered the opportunity of an interview with a different member of the research team (although no one chose to do so). Where an interview was held with a person known to CV, attention to ensuring consistency in interview approach was maintained so that the interview conduct mirrored that of all those held.

6. Is the sampling plan feasible?

The sampling plan was feasible, although it did require amendments from the initial planned approach to better articulate with clinical work practices. The resultant protocol (Appendix 6) stated the Study inclusion criteria were applied by a senior medical or nursing clinician known to each patient and/or family member. If eligible, the clinician provided Study information to the potential participant (face-to-face or over the phone) and gained verbal consent to provide the person's contact details to the research team. Once received, the researcher (CV) contacted the potential participant to discuss the Study in greater detail. This plan was feasible and successful.

Given the population of interest, the research team anticipated that recruitment might be difficult and planned for this through rapid response times to any identified potential participants (given the changing nature of their health) and the provision of interview times over the phone at the time of choice for the participant (inclusive of out of hours options). The competency of the interviewer was important as she was able to relate to informants and work with their changing circumstances. For example, on several occasions the interviewer phoned a family member and their loved one had died within the preceding 24 hours. Navigating this conversation was complex in terms of providing support to the person alongside staying within the bounds of the research and reason for the call.

Data collection

Telephone interviews were completed over a 12-month period, October 2018 – 2019, with only the interviewer and interviewee present. Telephone interviews were chosen so as to limit burden for this population given high levels of symptoms and disability (patients), as well as frequent medical and treatment appointments (patients and families) and to facilitate recruitment of a diverse inpatient population reflecting different demographic characteristics. Families / carers are often preoccupied with caring for patients and under considerable stress. Therefore, it was hoped offering phone interviews enabled less impact on time, energy levels (feeling one needed to be up and dressed) and facilitated changes as needed by patients or families on a day to day basis. That is, a quick call or text to cancel or reschedule the interview could occur (and frequently did) if the participant felt unwell or had other priorities to attend to. Interviews could be held with patients in any setting (home, hospital, specialist palliative care, aged care) and an option to interview together as patient and carer dyads was provided to each participant. Acknowledging phone interviews can be considered to generate less data depth than face to face,[39, 40] careful planning of the interview guide was completed to facilitate comfort, ease and depth of conversation.

An interview guide based on areas of importance for optimal inpatient palliative care[2, 3] was used in addition to a series of open-ended questions, to prompt in-depth discussions and facilitate greater understanding about key domains of importance previously noted, any new domains for consideration and implications for clinical practice (Table 3.5). This was not pilot tested but was reviewed after initial interviews were completed to ensure it was a useful tool to assist Study aims. No modifications were required. Topic areas covered what is important about the way care is provided within the hospital setting, what specifically enabled care to feel supportive or less so and what would have made a big difference to the quality of care experienced. Each interview was audio-recorded and transcribed verbatim as well as field notes taken at the time. When no new information emerged from patient or carer perspectives, data saturation was considered to have been reached. Demographic data including: age; gender; highest level of education; nationality; metropolitan or rural location and diagnosis, were collected to describe the Study sample. Transcripts were not returned to the sample, given their changing health status. However, an option to obtain a summary of Study results was provided to all participants at the time of their consent.

Table 3.5: Question guide for semi-structured interviews

Open questions with no prompting provided:

1. My first question is to understand a little about your illness - could you tell me about the serious chronic illness you live with?
2. Now I am keen to learn about the care you received the last time you were in hospital. I am wondering if you can think back and tell me what was most important for you about the way your care was provided?

Prompting in relation to previously noted areas of importance:

3. Other studies that have talked to patients about this have suggested (name one of the domains of care from previous work) is important – can you tell me what you think about that?

Focusing and extending understanding of key elements of importance described to inform practice:

4. You mentioned the importance of X a number of times and I am keen to understand that in a little more detail – what things made or make X feel like good X for you? What do you perceive could have been better in relation to X?
5. Overall, if you had to think of 1 or 2 questions you wish you were regularly asked about your care when you were an inpatient, what would these be? It can be hard to think about key questions perhaps, but if not questions – is there anything you think would have made a big difference to the quality of your care?

(NB: Language throughout was tailored to the participant – whether they were a patient or family member)

Reflexive account

It was important to consider and put strategies in place to facilitate reflexivity[29, 41] in relation to the conduct of this Study. Several strategies were put in place to address the impact of the researcher's (CV) personal characteristics and prior professional experience in relation to this work. Given CV's professional history in palliative care nursing, access to the field was potentially going to be positively affected.[41] Therefore, careful screening processes were designed to ensure rigour was maintained. In relation to the interview itself, a field notes template was developed and completed throughout each interview. This provided prompts informed by the outcomes from Study 1 – centering the discussion around patient and family centred domains of importance and thereby distancing the ability for CV to affect the research process and outcome.[41] At the completion of each interview, a reflexive journal was completed recording details about how the interview felt, the interaction flow, any noted areas of distress and any other relevant observations. This was important in considering any external factors which may have influenced the data and also specifically assisted growth for CV as a qualitative researcher through a conscious and deliberate review of each interview, reactions to respondents and potential changes for consideration.[41] This was particularly useful in uncovering some aspects that CV felt less confident to address within interviews. For example, upon review, it was identified that CV was less confident about discussing patients' feelings of burdening their families. After discussion with the supervision team, this was identified as an area for exploration with prompts articulated improving the quality of the research. Another example was CV's recording of feeling quite shocked and angry regarding some descriptions of poor care, particularly from her nursing perspective. Again, reflecting on this was important so as to ensure objectivity, non-exploitative responses[41] and impartiality to hearing and analysing this data appropriately. Discussions with the research team were critical in maintaining full engagement with and analysis of the data.

Palliative care nursing experience also assisted[41] with interviews, especially where communication was complex. Conducting telephone interviews with patients with a prognosis of approximately one year or less or with their family members (current or bereaved) to discuss experiences with inpatient palliative care provision included recalling and discussing some distressing events. Drawing on considerable palliative care communication capabilities developed during CV's 18 years in the field assisted navigating such conversations. These communication skills enabled CV to provide participants with support and comfort over the phone, divert the interview if needed (e.g. if a particular question led to content that was distressing for the interviewee) and also to attend to self-care throughout interviews held. The professional experience and comfort CV had with discussing issues pertaining to palliative care, death and dying may well have been an enabler to the richness of information gained.

A challenge related to CV's previous clinical background was in relation to her need to refrain from providing any feedback or clinical advice to questions or information divulged during the interview. For example, one patient asked about the best method for managing her home oxygen requirements, and CV had to ensure she did not provide advice but rather directed the patient back to her treating team to discuss this query in greater depth. To assist in maintaining these boundaries as a researcher, CV recorded field notes and contacted a member of her supervisory team for debriefing as required. Throughout this Study, CV openly stated to participants (both verbally and throughout provided paperwork) that she was a doctoral student and this work contributed to her PhD studies.

Data analysis

Content analysis was used to generate a taxonomy and themes through systematic organisation of data obtained into a format[33] able to inform optimal inpatient palliative care provision. The presentation of complex and multifaceted data into a formal system[42] develops a taxonomy that provides increased clarity to inform health policy and management.[32] Once ordered into a formal system, data were further analysed for recurrent concepts to enable a set of themes[32, 43] to characterise the noted areas of importance for optimal inpatient palliative care. The final set of themes within this Study were described as domains of importance in order to align with and build on outcomes from Studies 1a and 1b, with a clear focus on informing care provision in the real-world.

At the completion of each interview, transcripts were checked against audio-files and entered into NVivo 12 for management. Analysis then used principles of inductive reasoning alongside a predetermined coding structure.[32] Data immersion[32] was the first step, with each interview listened to and read twice before line-by-line analysis. Field notes were integrated onto the transcripts, to inform analysis. Coding followed using an integrated approach[32] allowing for both inductive and deductive analysis. Firstly, inductive coding of question 2 (Table 3.5) was completed independently by CV and a research assistant, before review and consensus discussions were held. This was completed to enable a distinct data-set that was entirely informed by participant data without any predetermined coding structure. Independent coding by two researchers attempted to limit bias from either coder to enhance credibility[33] in an attempt to articulate the voice of participants when first asked to describe what was important in relation to their inpatient care. Next, deductive coding of all data was completed. This involved structuring the parent codes with domains identified in the international literature (Studies 1a and 1b),[2, 3] with reference to confirmatory data, deeper insights and new knowledge. Emerging knowledge that did not fit domains was coded inductively. Coding was led by CV, with review by supervisors to gain clarity and resolve areas where consensus was needed, again maintaining credibility in relation to the rigour used within the coding process.[33]

Given the deductive coding was informed by prior research,[2, 3] the results reflect such domains. New domains are included in relation to data that did not link to earlier published work. This approach specifically addresses concerns related to conceptual generalisations from the local contexts of this Study[31] to a broader range of hospital settings, given the data from this Study adds to the voices of many other participants explored throughout Studies 1a and 1b.

Trustworthiness and rigour of the data and findings

In the qualitative findings, the researcher's interpretations have been reported alongside illustrative participant quotes (from either patients or family members) to enhance transparency and trustworthiness of data presentation.[33] Where patients and families have provided data relevant to a stated point, the term 'participants' is used and one illustrative quote provided. If only one group stated a point, this was explicitly noted by using the relevant term of either 'inpatients', 'families' or 'bereaved families'. Given areas of importance for optimal inpatient palliative care have been extensively reported on,[2, 3] the focus of the results reported in this thesis is on new and emerging content with the relationships to previous knowledge, referenced in the discussion. A broader representation of illustrative quotes for both confirmatory and new data is provided adding to trustworthiness and transparency.

Credibility was specifically considered to enable a comprehensive and complex understanding of what is important for inpatient palliative care provision.[33] Purposive sampling ensured collected data was from a population able to inform this area of research. Interview and reporting conduct ensured participant anonymity and utilised open-ended questions, probes and prompts to encourage depth in experiences shared. Field note use complemented the semi-structured interviews enhancing reliability, validity, and veracity of qualitative data collection.[44] Coding and theme development were designed to limit bias and enhance transparency as outlined. A full research team overview and consensus strategy from Study implementation to conclusion was maintained adding to the strength of conclusions drawn.

Ethics approval

Ethical approval was granted by St Vincent's Hospital Sydney, Human Research Ethics Committee Ref. No. 2019/ETH03307, October 2018 and consequently ratified by the University of Technology Sydney (Appendix 7). Site specific governance approval was obtained for the five participating hospital sites across NSW (Appendix 7).

This Study had considerable ethical considerations given the need to recruit and interview people who can be considered to be vulnerable (patients with palliative care needs and their families). Therefore, the process of submission for ethical review included the co-design of the Study protocol with palliative care consumers,[25] in addition to the research team, resulting in a protocol specifically designed for and considerate of the challenges inherent in interviewing people with palliative care needs and their family members (current and/or bereaved). Participants provided informed verbal consent to participate. Verbal consent was considered the optimal approach for gaining consent, as this Study was being conducted in a patient population with high levels of symptoms and disability, as well as frequent medical and treatment appointments. Families were often preoccupied with caring for patients and under considerable stress. The requirement to return a signed consent form via post could be burdensome for both patients and family members in this situation. Throughout screening, recruitment and the interview itself, it was made clear that participation was voluntary and that participants could withdraw from the Study at any time without affecting any relationships they might have with their treating teams and hospitals.

The risks associated with this Study were perceived to be low. The only foreseeable risk was one of discomfort or possible distress related to participation in the semi-structured interviews. Participants were asked about what is and has been important for their care and to describe good care and episodes where care could have been better. It was possible some of this discussion may have caused discomfort and/or distress especially if there were episodes of care that were distressing for the patient or family member. To minimise these potential Study procedure risks, the researcher provided details of free of charge support services that were available to all participants, offered a facilitated link back to their treating team as well as other relevant local/national support services (General Practitioner and phonelines – Beyond Blue and Lifeline). This information was included in the participant information sheet and given to participants again at the conclusion of the interview. Additionally, participants were advised that they were not obliged to answer interview questions and could end the interview at any time without giving a reason and with no consequence to their care. The interviewer, being an experienced palliative care nurse, ensured any distress was managed at the time, through support, linkage to clinical care as needed (via the original referring clinician who screened the patient for the Study) and ending any conversation that was causing distress. If distress was not the issue, but the patient appeared fatigued, the researcher offered to end the interview with the option to reschedule or finalise the interview at that time. Indeed, all patient participants were advised of how many more questions were remaining within the interview and asked whether they were able to continue in order to proactively account for possible fatigue.

Mid-point data integration and meta-inference

The integration of data is a defining element of all mixed methods research.[7, 15, 19, 20] Integrating the data from multiple linked studies provides a deeper understanding of the phenomena of interest through the meta-inference.[7, 15, 19] The meta-inference refers to the development of overall conclusions through the integration of inferences obtained from the qualitative and quantitative studies within the mixed methods study.[45] Consideration of this is required at the design, methods, interpretation and reporting levels throughout the Project.[19] The depth of understanding achieved through meta-inference cannot be achieved merely through an analysis of the individual study data sets.[7, 15, 20]

Data integration in mixed methods research needs to be both meaningful and deliberate, with consideration of the intent, the primary data analysis procedure, the presentation and interpretation of integrated results.[7, 19] In the OPAL Project, data integration occurred at two time points: 1) a mid-point meta-inference undertaken at the end of Phase 2, with the new insights and knowledge used to inform Phase 3 research; and 2) the end-point meta-inference involving all of the data sets, completed at the end of Phase 3, informing the Project's conclusions and recommendations. The approach adopted for the end-point meta-inferences is summarised later in this Chapter, coinciding with when it was completed. This section describes the mid-point meta-inference.

As the ‘patient and family voice’ underpinned all the OPAL Project’s research, identifying the *domains of care that are most important to inpatients with palliative care needs and their families* (Research Question 1) was a critical foundational step. The fully mixed sequential dominant design facilitated this through the mid-point meta-inference undertaken at the end of Phase 2. The mid-point meta-inference allowed the data from Studies 1a, 1b and 2 to be integrated through a series of joint display tables.[7, 46] The use of joint display tables allowed the data from the various Studies to be presented side-by-side.[7, 19, 46] This visual display facilitated the identification of data convergence and the meta-inference.[7, 46] Data convergence describes the process where data is analysed in the context of confirming (or not) the understanding from the initial data set(s).[7] When visualising data from all three data sets available for this mid-point meta-inference (Studies 1a, 1b and 2) the OPAL Project was looking for convergence (or not), enhanced understanding, non-convergence or lack of clarity achieved. Progressing from this, the meta-inference work was completed whereby Studies 1a, 1b and 2 data were analysed within the context of Research Question 1 to reveal the overall conclusions for the end of Phase 2. It was considered that answering Research Question 1 at the OPAL Project’s mid-point, (end of Phase 2), would provide the insights and knowledge critical to informing the Phase 3 co-design process. This final Phase of the OPAL Project was designed to generate recommendations to strengthen palliative care within Australian hospitals.

Design

This mid-point meta-inference was comprised of two key elements: 1) verifying data with palliative care consumers and clinical leaders; and 2) populating joint display tables to inform the analysis.[7, 46]

Participants - data verification

Palliative care consumers or an identified academic leader working in the field of palliative care research.

Setting - data verification

One workshop (3 hours) was held with palliative care consumer representatives at The University of Technology Sydney. In addition to this, a face to face individual meeting (3 hours) with an international academic leader was held.

Recruitment - data verification

Palliative care consumers were sent information about the data verification meeting by email and invited to attend. Identified key palliative care academic leaders were emailed and asked whether they would be available for a meeting. Response and attendance were voluntary with attendance noted as consent to participation.

Workshop – data verification

A modified nominal group process[47-49] was used. A nominal group process is a highly structured method for generating ideas and solutions within groups, with the aim of generating recommendations for best practice.[48, 49] This process is comprised of a number of steps that can generate both quantitative and qualitative data.[48] In the OPAL Project mid-point meta-inference the modified group process followed the following steps: a detailed introductory statement by the research team framed the context for the research; participants were asked to generate ideas individually; group discussion about generated ideas; group clarification of issues; generation of key priority areas for further analysis; and workshop conclusion.[48] Participants were asked to work independently before coming together as a group to provide consensus opinion in relation to the workshop objective (verification of data representation). Each participant was provided with data outlining key elements of optimal inpatient palliative care informed by Studies 1a, 1b and 2. Firstly, participants were asked to independently categorise the key elements into provided domains. Where they felt a point did not fit, this was placed into a domain titled ‘other’. All individual responses were collected for analysis. Secondly, the group were brought together for an overall discussion about the data and its impact on clinical practice to inform the development of key practice points. Field notes of this discussion were taken by two members of the research team to inform analysis.

Data analysis

Data analysis built on Study 2’s integrated analysis[32] approach. This used the domains from the initial quantitative data set (Study 1a) to inform the coding structures for subsequent qualitative Studies (Studies 1b and 2). To build on this, three key processes were used:[50]

1. Verification of the concepts described within the domains by palliative care consumers (workshop). Where three or more consumers agreed with the coding within one specific domain, this was felt to be verified. Where verification was not found, the research team further reviewed and discussed this key point and/or domain to identify how increased clarity could be obtained and how to best describe this in terms of clinical practice delivery;
2. Careful analysis of workshop outcomes (verification work and field notes review) and the relationships within and across domains and how these can inform clinical practice (research team and key research leader);
3. Meta-inference of all data using joint display tables.

Chapter 5 provides an overview of results from the OPAL Project’s mid-point meta-inference.

3.4.3 Phase 3: Driving reform

Study 3: National quality indicators and policies from 15 countries leading in adult palliative care: a systematic environmental scan.

Objective

To identify and describe national quality indicators and supporting policies used by countries leading in their provision of quality palliative care.

Design

A systematic environmental scan was undertaken from November 2016 to February 2017 of indicators available for use globally to measure the quality of palliative care provision as well as relevant policy and/or strategic frameworks to support their implementation. Environmental scans are commonly used to inform decision-making on policy, practice and programme development within the healthcare sector.[51, 52] However, despite their wide adoption, a working definition complemented by methodological guidance in relation to design and implementation is lacking and an area of current research.[51] Therefore, the OPAL Project was informed by relevant literature describing the utility of environmental scanning[51-53] and specifically adopted key principles noted to ensure quality of such an approach including: the examination of a broad range of issues within the context of the stated research; that information is gathered from a variety of sources; and that leading thinkers are involved in the information sourcing.[52]

Eligibility criteria

Data pertaining to a country listed in the top ten countries (n=15) ranked in the ‘quality of care’ category within *The 2015 Quality of Death Index study: Ranking palliative care across the world (‘Index’)*[54] were eligible for inclusion. This design allowed analysis of methods used to support system-wide palliative care improvements and the identification of indicators used by both specialist and/or generalist care providers.

Data sources

A systematic web search with predefined search terms and review of the first 10 webpages for each search was undertaken. This search was designed to identify peer reviewed publications, non-peer reviewed reports, policies, standards and/or resources relevant to measuring quality of palliative care. Once this was completed, additional details from the countries ranked in the top 10 of the ‘quality of care’ domain of the ‘Index’[54] were sought via: i) a systematic Google search to identify all relevant national policy and indicators, augmented with handsearching of retrieved documents to identify additional sources for review; and ii) listed key informants (‘experts’) named in the Index[54] who were emailed a set of standard questions about the availability and implementation of quality indicators in their country.

Experts identified in the ‘Index’[54] were asked to address the following three questions:

1. *Does your country have any quality indicators to measure palliative care?*
2. *Does your country have specific policy guidance in relation to measuring quality of palliative care?*
3. *Is there another key informant who works within this area whom I should contact?*

Follow-up emails were sent on two occasions, as needed. Snowballing was utilised if the initial experts suggested additional informants. Validation was assured by a review of country-specific summaries by each relevant expert.

Search

Seven systematic Google searches were completed using the following search terms: dying and acute care and/or hospital; palliative and quality; end-of-life care and quality; dying and quality; palliative and measures; end-of-life and measures; dying and measures. Within each website retrieved, a secondary search for all relevant references was completed, through accessing all appropriate hyperlinks (published documents and / or additional web content).

Data collection and items

The data collected for each of the 15 eligible countries included: all national policy guidance for palliative care; and national structural, process and/or outcome indicators used to monitor quality of palliative care by specialist and/or generalist care providers. Data were extracted into MS Word templates developed *a priori* that included: information from the Google search (date of search, search terms used, number of results, documents retrieved per webpage including URL link); information from key countries contacted (details of expert, date of emails and all related information categorised by country) and a handsearching overview (citation details, abstract and key points of relevance to this Study). Duplicate files were identified at the file management stage (saving files per country) and where a duplicate occurred, these were not saved a second time nor counted within the initial documents retrieved or screened. Where a country had updated reports or policies, the most recent policy informed indicator data for use (prior indicators were removed from analysis if no longer in use). However, where relevant, several policies informed analysis of approaches used for quality measurement of palliative care, given policy reform often continued to build on work from prior publications.

Reflexive account

When designing the semi-structured interviews (interviews completed exclusively via email correspondence), the team chose to engage the participant in a final check of the data summary (detailed as a vignette) for their review and approval. This maximised the opportunity for participants to impact the outcomes of the research and how it would be reported[41] and was an important reflexive check on CVs collation and interpretation of data obtained.

Data analysis and synthesis

Concurrent data analysis occurred via a two-step process:

1) Analysis of supporting policies and national approaches to quality measurement of palliative care within each participating country. Mapping was completed to identify availability of national standards, national quality indicators, whether they were designed for specialist palliative care or generalist care providers and whether they were supported by national policy and/or mandated for use. Information provided by Index experts was summarised to provide a country-specific overview and to describe identified measurement barriers and enablers.

2) Analysis of the nationally available palliative care indicators from participating countries. Identified indicators were categorised in accordance with the Donabedian model,[55] the US National Consensus Project Guidelines[56] ('US Guidelines'), mapped to a recent systematic review of available indicators[57] and summarised via descriptive analysis.

The Donabedian model focuses on the need to establish causal linkages between structures, processes and outcomes of care to inform a review of quality of health care delivery.[55] Additional constructs this model addresses include the need to consider how one would define optimal care and whether this is based on individual or social preferences,[55] aligning closely with the design of patient and family-centred perspectives prioritised throughout the OPAL Project. The mapping of indicator types (structure, process or outcome) was independently categorised by two researchers (CV & supervisor).

Adopting the approach used by two recent systematic reviews,[57, 58] all indicators were also mapped independently by two researchers (CV & supervisor) to the 'US Guidelines' domains.[56] This mapping provided an understanding about whether available indicators covered multiple domains of care or not. Mapping to indicators reported in a recent systematic review[57] was then completed (CV), with 10% of this work independently coded and checked for accuracy (supervisor). This work provided information about whether the indicators sourced through this environmental scan aligned with those available in peer-reviewed published work. Lastly, to summarise the content descriptively, indicators were grouped into measurement domains defined by the research team (CV & supervisor). Any disagreement in categorisation, mapping or grouping of indicators was discussed to ensure consensus.

Ethics approval

Ethics approval was obtained from the University of Technology Sydney (HREC ETH16-0939) in November, 2016 (Appendix 8). This approval was completed as a negligible risk application and particularly noted the ethical implications related to email correspondence with key informants. This research involved asking leaders in palliative care to provide information about policy and availability of quality indicators, via email. The informants were chosen from a group previously used to inform an international report that was published and freely available on the internet. Replying to the email was entirely voluntary and was taken as consent to be involved in this Study. Informing participants of the fact we planned to collate this information from across the world and publish our findings to assist others working to make improvements within palliative care was noted at the start. All contributors to this work were acknowledged within the resultant publication.

Study 4: Strengthening the delivery of palliative care in the Australian hospital setting: A co-design study to design actions for practice, policy, education and research

Objective

To identify actions required to strengthen the delivery of palliative care in Australian hospitals so that it addressed the domains of care identified as important for palliative care inpatients and their families.

Design

A co-design approach was used. Terminology within the health literature varies in relation to the co-design field of research, with some describing it as co-design, co-creation and/or experience-based co-design.[59-61] However, all describe approaches where the experience of end users (patients and families) are used in combination with relevant stakeholders to inform service improvements.[59-63] Co-design in this Study (and throughout the OPAL Project) is defined in accordance with that used by Boyd et al:[61]

> *It involves patients and staff exploring the care pathway and the emotional journey patients experience along it, capturing experiences, then working together to understand these experiences and improve them (p.4).*[61]

Several studies describe discrete steps involved within the field of co-design research, inclusive of proactive and meaningful engagements with patients / families and clinicians to enable understanding (opportunity identification); working together with all stakeholders to identify how to progress improvement work; understanding patient / family and clinician experience of services and how these may be improved (identification of needs and desires); turning ideas into explicit improvement opportunities; deciding which improvement priorities to take forward; and finally, taking such improvements forward through targeted actions.[61, 63] Not all steps need to be completed however, the experiences of end users and clinicians are vital components.[60-62] This Study focused on work completed to understand end user experiences and how these inform clinical practice, how these may be improved and explicit actions to optimise care in the Australian hospital setting.

Participants

Palliative care consumers, identified professional leaders in hospital based palliative care (either clinical or policy focused) or an identified academic leader working in the field of palliative care research. Clinical leaders from medical, nursing and allied health professions were all eligible to participate.

Setting

One workshop (four hours) held at The University of Technology Sydney.

Recruitment

Purposive sampling was used to identify eligible participants, given the need to ensure all participants were knowledgeable experts, to competently and efficiently inform Study outcomes.[36] This sampling approach also enabled recruitment reflective of all disciplines eligible to participate (medical, nursing, allied health, policy, academic and consumer representative). Each person was sent an invitation email with two reminders, after which a refusal was assumed. Interested participants were sent a participant information sheet and consent form with an opportunity to discuss the Study in greater detail provided. Signed consent forms were collected prior to workshop commencement.

Data collection

A modified nominal group process[47, 48] was used. In the OPAL Project the modified group process followed the following steps: a detailed introductory statement by the research team framed the context for the research; participants were asked to generate ideas individually; group discussion about generated ideas; group clarification of issues; generation of individual action lists; rating of the action list individually before a group consensus on the most important actions; group discussion, opportunity for a final pitch for a high priority action for consideration before workshop conclusion (Figure 3.4).[48]

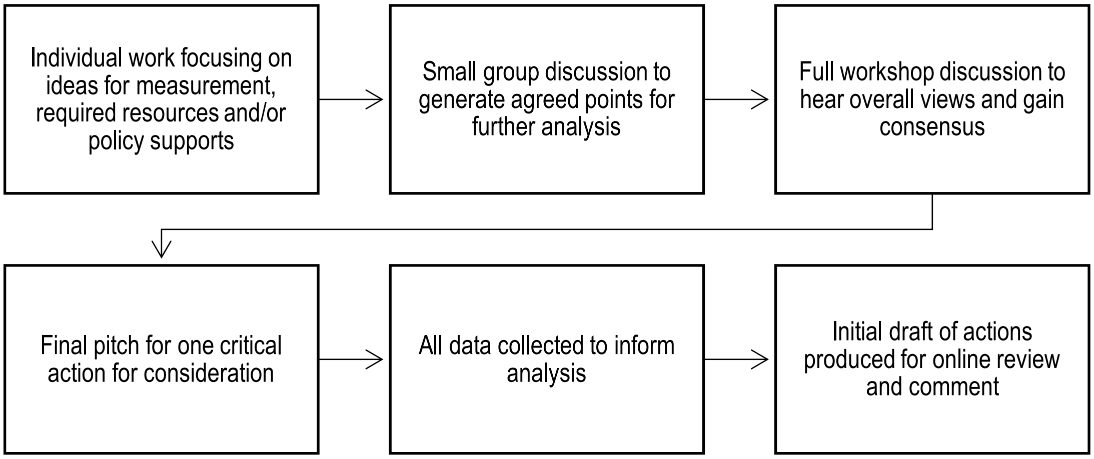

Figure 3.4: An overview of the modified nominal group process used

To facilitate the modified nominal group process, each invited participant was provided with an information pack detailing key domains of importance (including related practice points to guide clinical care) for optimal inpatient palliative care, based on the outcomes from the OPAL Project's mid-point meta-inference. Each participant was assigned to one of four specific groups designed to be reflective of all perspectives participating (medical, nursing, allied health, policy, academic and consumer). Groups were each provided with unique data packs focused on 2-3 domains of importance. Opportunities to contribute to other domains were provided through full workshop discussions. Three questions were provided to guide thinking and discussions:

1. *If these practice points were working well – how would you know / what would it look like?*
2. *What needs to be in place to enable this to happen?*
3. *What policy changes are needed (if any) to make sure this happens?*

Activity 1 asked all participants to work individually with their data pack in relation to the three provided questions writing their responses on their packs for collection at the end of the workshop. Activity 2 involved facilitated group discussion focused on hearing individual perspectives per domain, in relation to each of the three questions. Feedback then occurred from the allocated group facilitator to the full workshop enabling facilitated discussion to inform the final data set collected for analysis. Activity 3 asked each participant to consider and state to the workshop one critical point they want taken forward. The full workshop was audio-recorded as well as notes taken at the workshop itself. The intention of this co-design workshop was to enable the group to list all of the potential actions agreed to be important. Refinement of this action list and removal of redundant items occurred after the workshop. All data were collected to inform analysis and draft outcomes circulated for group review and comment prior to finalisation.

Reflexive account

The Study design was critical in accounting for the professional background of the lead researcher (CV) in this work, given attendees may have known or previously worked with CV. The co-design method adopted, inclusive of modified nominal group[47, 48] techniques, enhanced participation of all workshop attendees equally. An additional check was ensured by the appointing *a priori* of a group facilitator for each small group. These facilitators were drawn from the invited workshop participants, external to the research team, who agreed to this role ahead of the event, enabling members of the research team to perform the role of scribe and thereby limit influence on data collection. Attendance of four independent research team members further assisted veracity and credibility of data collection. Data informing all workshop activity came from the mid-point meta-inference of data from Studies 1a, 1b and 2. Therefore, patient and family data provided the platform for group discussion and subsequent co-design of actions, further limiting bias. Finally, the drafting of actions was circulated to all participants for review and agreement, providing a final check on the research team's analysis and interpretations.

Data analysis

The development of actions occurred through thematic analysis of collected data before circulating workshop outcomes to participants for feedback and relevant modifications. Thematic analysis was guided by the approach outlined by Thomas and Harden[64] and included: 1) line by line coding (CV); 2) descriptive theme development (CV and supervisors); and 3) analytical theme generation (CV and supervisors).[64, 65] Analytical themes were presented as actions. Line by line coding occurred with the data collected on butchers' paper and data packs from each participating group. Where linkages within concepts were evident, these were grouped into broad descriptive themes (described as actions) and discussed by the full research team for consensus. These actions were circulated to the participants (both those who attended and those who indicated interest in participating but were unable to attend the actual workshop) for review and comment. These comments were collated, analysed and reviewed to inform a final draft set of actions. This final draft was again circulated to the full list of participants until consensus was achieved. Consensus was defined as response by a given date, with a non-response assumed to be agreement with circulated content.

Ethics approval

Ethical approval was granted by the St Vincent's Hospital Sydney, Human Research Ethics Committee Ref. No. 2019/ETH03307 in October 2019 via an amendment to the Study 2 ethics approval process (Appendix 9). This amendment was noted by the University of Technology Sydney. Informed written consent was obtained prior to the workshop.

End-point meta-inference

The end-point meta-inference undertaken at the end of Phase 3 was designed to answer the final two research questions and generate a series of Project recommendations. This meta-inference utilised the data from across all four OPAL Project Studies and similar to the mid-point meta-inference, used joint display tables to assist with data integration.[7, 46] This occurred through multiple and sequenced phases of iterative analysis[66] informing new understandings about how optimal inpatient palliative care can be strengthened from a pragmatic viewpoint,[15] seeking to inform real and feasible change.

All inferences drawn from the integrated OPAL Project data were analysed in accordance with the key components described by the *Innovative Care for Chronic Conditions*[22] and *Person-centred Practice*[23] Frameworks to reveal recommendations at macro (national), meso (health care organisation) and micro (ward) levels to answer the Project aim of optimising palliative care within the Australian hospital setting. Chapter 7 reports the meta-inferences reached in relation to each stated research question along with recommended actions generated from the integrated OPAL Project data. Table 3.6 provides an outline of data integration in relation to each research question within the OPAL Project:

Table 3.6: Data integration and meta-inference within the OPAL Project

OPAL Project research questions	*Data included in meta-inference*
1. What are the domains of care that are most important to inpatients with palliative care needs and their families?	Mid-point meta-inference: Studies 1a, 1b and 2
2. Is there a suite of indicators to assist measurement of inpatient palliative care quality?	End-point meta-inference: Study 3 and mid-point meta-inference data
3. What are the key drivers for enabling improvement in palliative care provision within Australian hospitals?	End-point meta-inference: Mid-point meta-inference as well as data from Studies 3 and 4

3.5 Considerations for the fully mixed sequential dominant design

The OPAL Project's three-phase, sequential and pragmatic design was configured to understand the domains of importance for optimal inpatient palliative care from the patient and family perspectives, and to collaboratively identify the actions required to drive the necessary changes to enable these domains in practice. Undertaking a large three-phase Project of this scope required considerable time for execution due to the need to recruit a vulnerable population to inform the semi-structured interview study (Study 2) with these outcomes time-critical to inform the mid-point meta-inference. In addition, Phase 3 could not be fully planned until Phase 2 results were available making Project planning complex.[7, 67] Conducting such a large Project over a long-period of time (2013 - 2020) is risky given the temporal nature of the policy and operating environments and the global focus on improving palliative care. A number of strategies were used to manage these challenges, including regularly appraising these environments for signals of change along with the risks and opportunities that could potentially impact on the Project. Publishing Study outcomes contemporaneously enabled international peer review from leading scholars in the field, further strengthening risk mitigation. In addition, the need to consider potential barriers to timely completion of this work within the constraints of the doctoral candidature was important. To address this, co-design work for the qualitative protocol commenced early within the Project to allow for additional time relating to meaningful consumer involvement, resulting in ethics applications for Studies 2-4 being completed in a timely way. Opportunities to progress work where possible (for example progressing the global environmental scan when delays in recruitment for the qualitative semi-structured interviews occurred) ensured the overall Project remained on track.

Skills of the researcher

Within the context of a doctoral project, it is important to consider the skills of the researcher when undertaking a mixed methods research project.[9] The OPAL Project was a complex project that required skills in project design, research methodology design, the ability to conduct quantitative and qualitative data collection, analysis and integration[9] as well as the ability to communicate sensitively and effectively with a vulnerable population (patients with palliative care needs and their families, including those who were recently bereaved). In addition to this, understanding the nuances of an integrated mixed methods typology is complex and can prove difficult for the novice researcher.[1, 7, 9, 16]

In order to address these challenges, the doctoral researcher (CV) was supported to attend and engage with multiple learning opportunities including academic workshops, seminars and conferences (e.g. a meta-synthesis skills workshop; an eight-week qualitative research masterclass series; multiple research workshops aimed at academic literacies such as data management, statistical analyses, referencing and writing; webinars in relation to improvement within healthcare systems and relevant palliative care conferences). In addition to this, an interdisciplinary supervisory team with extensive experience in mixed methods, palliative care research and health system reform was convened to guide and support the researcher throughout the Project.[9]

3.6 Positioning of the researcher

Positionality refers to the researcher's positioning in relation to the social and political context of a study.[68] CV is an experienced palliative care nurse who has worked extensively in the hospital setting. The need to acknowledge this and plan to minimise bias that could occur in relation to this was critical. Accordingly, the research design initially focused exclusively on data from patients and families (Studies 1a and 1b), actively excluding data from health care professionals and/or authors. This was an important first step, as this informed the design for Study 2 and ensured the key domains being focused on were informed by patients and families, thereby limiting the potential bias related to CV's previous clinical roles.

In relation to Study 2, the positioning of the researcher was again closely considered to inform both optimal design and implementation of the Study. Co-designing Study 2's research protocol with palliative care consumers provided a powerful external check on the researcher's (CV's) positionality, particularly in relation to the social context of CV's comfort within palliative care (language and care provision). This step dramatically changed the approach to recruiting potential participants and the language used in recruitment paperwork.[25] It challenged the researcher to reflect on her high level of comfort with discussing death and dying and palliative care, and that this language so commonly used as part of being an experienced palliative care nurse was not necessarily language that was always acceptable for communicating with the broader community. As a result of this insight and the feedback from the palliative care consumers, the research design was able to be grounded in what was most acceptable and supportive for Australians with palliative care needs. Without the wise counsel of the consumers about how best to frame and position Study 2, recruitment of people likely to die within the next 12 months would have been much more difficult than it was.

Throughout Study 3 and 4, CV ensured her prior professional background and current focus on this work to inform doctoral studies was clearly noted to all participants. Carefully designed data analysis methods with oversight by CV's supervisory team ensured cognisance of potential bias and attempts to limit this throughout. The mid-point meta-inference informing Phase 3 design and analysis further limited possible bias. That is, careful consideration of CV's prior knowledge and beliefs was undertaken in an ongoing way throughout the Project to limit bias and maintain a consumer-centred approach to the development of overall conclusions and recommendations.

3.6.1 Reflexive account

Given the OPAL Project's mixed methods design had a dominant focus on qualitative data, it was important to consider and put strategies in place to facilitate reflexivity.[29, 41] The research team was acutely aware of CVs professional background and the impact this may have on the Project both in positive terms (access to the field, competence within complex communication) and negative terms (potential bias). Therefore, careful planning was completed to limit bias alongside the addressing of key components to enable reflexivity (logging field notes, consistent support from the supervisory team and repeated self-review).[41] The researcher also actively acknowledged[41] prior professional roles and considered how these may affect analysis. Ensuring this internal dialogue and critical self-evaluation[41] was important and was supported by discussion and consensus in relation to Study results with CV's supervision team. Strategies used to address the impact of CV's personal characteristics and prior professional experience included: basing design in patient and family data alone for Studies 1a, 1b and 2; careful design of a field notes template and reflexive journal for use after each interview held within Study 2; data verification work with palliative care consumers at the mid-point meta-inference; verification with participants in Study 3; and co-design of actions in Study 4. Details about these strategies have been provided earlier in this Chapter.

3.7 Ethical considerations

Study 1 of this Project involved a systematic review of all published literature pertaining to the noted research question. A formal application for ethics approval was not sought; however, rigour and quality for this work remained a clear focus of the research team. As such, data extraction and analysis were done by two independent researchers and standards in relation to publication of work were upheld. Ethical approval was sought for Studies 2, 3 and 4 as detailed above (Appendices 7-9). All phases of this research Project conformed to and were undertaken in accordance with the National Statement on Ethical Conduct in Human Research 2007 (updated 2018)[17] and the Australian Code for the Responsible Conduct of Research (2018).[18] In alignment with this, the OPAL Project addressed and reflects each of the following values.

Research merit

The OPAL Project sought to understand and develop recommendations to optimise palliative care within Australian hospitals. This represents a substantial body of knowledge that has not been available prior to this time, justifiable by its potential for wide-scale benefit.[17] Firstly, the research supervision team represents international academic leaders in palliative care and research, thereby providing rigour and appropriateness in design and implementation of the proposal. In addition to this, the Project has been presented at multiple fora, enabling peer review for research merit including: the Improving Palliative Care through Clinical Trials (ImPaCCT) Concept Development Workshop (August 11, 2014); the University of Technology Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT) Research Incubator (Aug 11, 2017); and all related University research fora and doctoral assessments.

Research integrity

The OPAL Project sought to understand the domains of importance for optimal inpatient palliative care, from the perspectives of inpatients with palliative care needs and their families. The commitment to developing this understanding was key within the conceptual frameworks, pragmatic assumptions and related designs chosen to amplify the voice of inpatients and families in Project recommendations. Honesty in conduct has been maintained throughout, supported by a comprehensive audit trail available for each Study. Dissemination of results has occurred through peer reviewed publications (n=5 with 2 under review), peer-reviewed oral presentations (n=17) and poster presentations (n=18), and invited presentations (n=7) permitting scrutiny and feedback.[17]

Justice

The OPAL Project accorded with the principles of justice noted by the National Statement on Ethical Conduct in Human Research 2007 (updated 2018)[17] through careful consideration of fairness in relation to inclusion and recruitment of participants. This was well supported through the co-design of the research protocol for Study 2 with palliative care consumer representatives. Unfair burden on participants was carefully considered across all Studies, given participants were either people with palliative care needs or busy clinicians and policy experts. The careful and judicious use of time was a priority, no exploitation occurred and access to the benefits of this research internationally available through peer reviewed publications.[17] Furthermore, research outcomes were made available to participants for each Study at the conclusion and reporting stage of each, enhancing accessibility in a timely way.[17]

Beneficence

The careful design and implementation of this Project ensured that the likely benefits of system-level improvements in palliative care would outweigh any risks related to the conduct itself.[17] The key area of potential harm was in relation to the interviewing of people with palliative care needs, given they are so unwell, can be considered vulnerable and may be distressed in discussing their care. The co-design of the protocol for this work with palliative care consumer representatives was an important piece of work contributing to the minimisation of this risk. Benefits and risks related to each Study were also articulated clearly for participants and no coercion was placed in relation to participation.[17]

Respect

In addition to the key principles noted above, demonstrating respect for the intrinsic value of all participants[17] was prioritised through consideration of each person's perspective and ensuring their confidentiality throughout all data management. This was particularly important given participants disclosed very personal thoughts and experiences throughout Studies 2, 3 and/or 4. Respect to each of these was given and all were included into the full data set to contribute to final Project conclusions and recommendations.

3.7.1 Data management and storage

Studies 1a and 1b worked with data from previously published work. Extraction and analysis of such data were stored on a password protected UTS endorsed Cloud storage.

Study 2 involved the collection of data from patients with palliative care needs, and their families, via semi-structured interviews. Data were collected, used, stored, accessed, archived and to be destroyed according to the National Statement 2007 (updated 2018).[17] Ethical considerations in relation to collection and use of data were closely reviewed to ensure collection of data specifically in line with stated research aims only. Consent data were stored within a locked file within a password-protected location. All other Study data were collected using unique identifier codes and kept in a different file location.

Study 3 worked with data published online as well as data obtained through semi-structured interviews conducted via email. All data obtained was in soft copy format and was filed within a password protected UTS endorsed Cloud storage.

Study 4 involved the collection of data from consumer representatives, clinicians and policy experts via workshop participation (field notes), notes collected onto butchers' paper and audio-files. Butchers' paper was photographed and stored on Cloudstor along with workshop audio-files.

Data storage included:

- soft copies of data stored on a password protected UTS endorsed Cloud storage;
- hard copies of research data and associated record keeping metadata stored by the research team in a locked filing cabinet with all identifying information removed, and independent from the administrative files for the Study. Only authorised members of the research team had access to these materials;

- all identifiable data (e.g. consent forms, etc.) kept in a separate locked file, away from the Study documents. On completion of the Study, these data were archived with the Study material, in a separate file with no link between these data and the Study materials.

At completion of this Project, all data collection forms and Study materials (both hard copy and electronic) were prepared for collation and archiving consistent with the jurisdictional regulations regarding the retention and disposal of research data, as advised by the National Statement.[17] This included retention, archiving and disposal controls as outlined by the University of Technology Sydney Records Management Policy and the policy *The General retention and disposal authority: higher and further education records (GA47)* as approved by the State Archives and Records Authority of NSW.

3.8 Conclusion

This Chapter has outlined the rationale for a fully mixed sequential dominant design underpinned by the philosophical assumption of pragmatism and two complementary conceptual frameworks[22, 23] to answer the stated research questions for the OPAL Project. Furthermore, the contribution of each Study, its design, data collection and analysis methods were detailed. Finally, the integration of all Project data (mid-point and end-point) to inform overall Project conclusions and recommendations was described.

Chapter 4 reports the results of a semi-structured interview study (Study 2) seeking to inform the Australian perspective in relation to the domains of importance for optimal inpatient palliative care and their implications for clinical practice.

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Chapter 4 Phase 2: Understanding importance

Study 2: Confirming key domains of importance for optimal palliative care in the Australian hospital setting: a qualitative study

4.1 Chapter preface

A systematic review and meta-synthesis reported in Chapter 2 identified key domains of importance for optimal inpatient palliative care from an international perspective. Important domains include: expert care (inclusive of physical care, symptom management and integrated care), optimal communication, respectful and compassionate care, valued family involvement in care planning and delivery, maintenance of self-identity for patients, environmental privacy for families, ensuring patient safety, supporting patient choices, preparing families for death and providing contact for families after a patient has died. It is unclear if these identified domains of importance reflect Australian inpatient perspectives and also what specific clinical practices enable inpatients to experience care in line with such noted domains. For example, inpatients describe the importance of being treated with care, respect and with a focus on dignity. In order to use these insights to inform clinical practice improvement, understanding what enables this care is crucial.

This Chapter reports a qualitative study completed to better understand how to enable care in line with noted domains as well as Australian perspectives in relation to work completed to date.

4.2 Publication reference

This manuscript was submitted to Palliative Medicine on February 27, 2020. The first review by two peer reviewers and the editorial team has been completed, with helpful comments to strengthen the manuscript provided. An updated manuscript was resubmitted on May 30, 2020. Palliative Medicine is a peer reviewed journal, with an impact factor of 4.956, focused on improving knowledge and practice in palliative care. This Chapter provides an edited version of the submitted work, noting the submitted manuscript concentrated on inpatient data exclusively, with this Chapter reporting the data from all Study participants (inpatients, family members and bereaved family members).

> **Virdun C,** Luckett L, Davidson P, Lorenz K, & Phillips J. (2020) Hospital patients' perspectives on what is essential to enable optimal palliative care: a qualitative study *Palliative Medicine*, 34(10), 1402-1415.[1]

4.3 Overview

As described in the preceding Chapters, the majority of expected deaths in high income countries occur in hospitals,[2-8] where optimal palliative care cannot be assured.[7, 9-13] People with palliative care needs are also often hospitalised within the last year of life, even if they do not die in this setting,[14-17] so hospital clinicians provide care intermittently to this population from diagnosis through to death.[5, 18, 19] Hospitals can and do provide excellent palliative care.[7, 18, 20, 21] However, there is persisting evidence that optimal inpatient palliative care is not always provided.[11, 22-26] The reasons for this are both varied and complex,[22] but largely relate to ineffective communication, too little input into decision making and poor symptom management.[7, 11, 27-29]

The OPAL Project's systematic review and meta-synthesis (Chapter 2) has facilitated an understanding of 15 key domains of importance ('domains') for optimal hospital-based palliative care from the perspectives of inpatients and families,[9, 10] including those listed above. However, it is unclear how these domains might be operationalised in clinical practice. Furthermore, data informing recent systematic review work are predominantly derived from the northern hemisphere[9, 10]. Therefore, more research is needed to build on the previously reported domains of importance for optimal hospital-based palliative care, with a particular focus on how to enable such care in practice, as well as to build the evidence base from a country outside of the northern hemisphere.

4.4 Objective

To seek the perspectives of Australians living with serious chronic illness, who are considered to have palliative care needs, and their families, about their recent hospitalisation experiences to determine: i) the relevance of domains identified by international research to be important for optimal inpatient palliative care;[9, 10] and ii) how these elements might apply to their future care needs.

4.5 Methods

The methods for this qualitative study have been described in Chapter 3. A series of semi-structured interviews were undertaken with inpatients, family members and bereaved family members. The term 'participants' is used in the findings where an illustrative quote(s) has been provided by patients and families. The terms 'patients', 'families' or 'bereaved families' are used if only one participant group contributed to a specific theme or stated point. A broader representation of illustrative quotes for both confirmatory and new data is available in Appendix 10.

4.6 Findings

Seventy-six participants were eligible for interview, with 50 (66%) completing interviews (Refer Figure 4.1), including: patients (n=21); current family members (n=16); and bereaved family members (n=13) (Refer Table 4.1).

The patient sample tended to be female (n=12, 57%), White Australian (n= 13, 62%), metropolitan based (n= 18, 86%) and with a fairly even split between malignant (n= 10, 48%) and non-malignant (n= 11, 52%) diagnoses. The family sample tended to be female (n= 11, 69%), White Australian (n= 19, 56%), metropolitan based (n= 11, 69%) and also reflecting views of those with both malignant and non-malignant diagnoses. The bereaved family member sample were also predominantly female (n= 10, 77%), White Australian (n= 9, 69%) and metropolitan based (n= 11, 85%). The bereaved family member sample were also highly educated with 85% (n= 11), having a Bachelor’s degree or higher, and predominantly reflected experiences of those dying from a malignant diagnosis (n= 13, 85%). Interview lengths ranged from 17 minutes (patient interview) through to 126 minutes (bereaved family member interview) with average interview lengths for patients being 51 minutes, family members 57 minutes and bereaved family members 73 minutes.

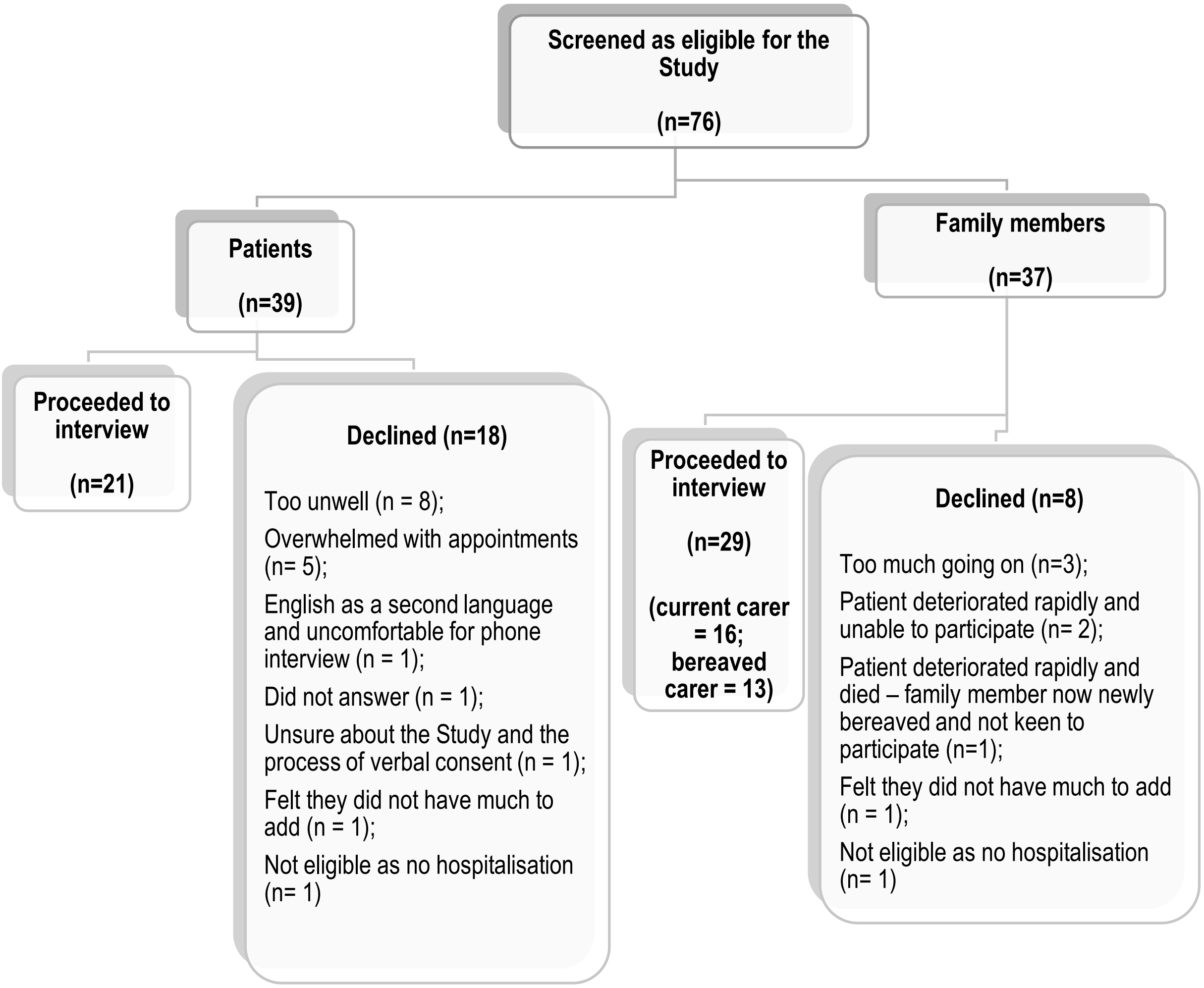

Figure 4.1: Overview of participation for those screened as eligible for this Study

Table 4.1: Sample characteristics

	Age (Yrs)	Gender	Highest level of education	Nationality	Metropolitan or rural	Diagnosis
Patient sample (n=21)	Median: 69 Range: 45-82	Male: n=9 Female: n=12	Post school education: n=8 Yr 12 schooling: n=9 Yr 9 schooling: n=4	Australian: n=13 Indigenous Australian: n=1 New Zealander: n=1 Sri Lankan: n=1 Filipino: n=1 South African: n=1 Austrian: n=1 Maltese: n=1 Italian: n=1	Metropolitan: n=18 Rural: n=3	Malignant n=10 Non-malignant n=11
Family sample (n=16)	Median: 54.5 Range: 30 - 78	Male: n=5 Female: n=11	Post school education: n=11 Yr 12 schooling: n=2 Yr 9 schooling: n=3	Australian: n=9 Indigenous Australian: n=1 Filipino: n=2 English: n=1 Chinese: n=1 Scottish: n=1 Sri-Lankan: n=1	Metropolitan: n=11 Rural: n=5	Malignant n=8 Non-malignant n=5 Both n=3
Bereaved family sample (n=13)	Median: 56 Range: 33 - 69	Male: n=3 Female: n=10	Post school education: n=12 Yr 12 schooling: n=1	Australian: n=9 Indigenous Australian: n=1 English: n=3	Metropolitan: n=11 Rural: n=2	Malignant n=9 Non-malignant n= 2 Both n=2

Participants both confirmed and added depth of understanding to what has been reported in the international literature,[9, 10] as summarised below:

4.6.1 Domain: Effective communication and shared decision making

Participants unanimously confirmed the importance of effective communication and shared decision making. They desired compassionate communication that was honest, clear and used layman's language. They stressed the importance of active listening, adequate information provided in an unhurried manner and the need for engaging both inpatients and families in care planning. Consistency of messaging, accurate documentation across teams and departments and pulling together complex information are important. Participants also highlighted the importance of clinicians being fully present and focused on the patient's current situation. Connection was considered critical:

> *Well, I think it's somebody looking at you, speaking to you. Not appearing thinking about something else or thinking about the next thing they have to do. But they're absolutely focused on what we're talking about. They're mindful. In the moment, and that they had done their homework and know what they're talking about (Patient 3, 80yr female with non-malignant illness)*

Families highlighted the importance of providing opportunities for inpatients and families to speak separately with clinicians:

> *Because we go see the doctors together, but that one time I wanted her to freely discuss her feelings or her needs, because of course, as a daughter and if I'm a little bit controlling or she doesn't want to reveal things when I'm around, something like that. At the same time, I have thoughts and I have observations about her that I wish I could share, and I'll consult the doctors about (Family 3, 52yr female carer for mother with malignancy)*

Participants described the importance of acknowledging and tapping into the inpatient's own knowledge in relation to their health condition:

> *They think well they've done the training, they know what they're talking about and whatnot. They don't ask the patient "How are you managing and what you're doing yourself" (Patient 22, 75yr female with non-malignant illness)*

Participants appreciated clinicians often had to break bad news but preferred that this information be delivered in an honest and compassionate manner, ideally by a senior clinician:

> *We only saw Consultant X once…he was really good, he speaks very fast, but he sat on the edge of the bed, and absolutely directly, spoke to Dad for about five minutes. It was a pretty confronting conversation about the fact that you know this was terminal, and Dad said "This means I'm not going to get better?" Yes, that's right. And then turned to me and asked me what I thought, etc, etc. And I thought, because often you don't see consultants that will do that. They often send their 2IC in. Or they talk over the patient, to either relatives or to their team. And I was very impressed when I saw that (Family 9, 64yr female carer for father with non-malignant illness)*

Families stressed the importance of asking directly about inpatients' preferences:

> *No one in this busy general hospital asked, what do you want? Every one of them framed it in, what would your mother or your father want in this circumstance? They did a superb job, an unbelievable job (Bereaved family 13, 54yr male carer for both parents with non-malignant illness)*

Participants described their need for adequate information throughout a hospital admission to assist decision making and development of trust and confidence in the team:

> *So just her talking to me and telling me what we were going to do, and that I needed to be in a hospital…I think that that changed for me that I went right, okay, I trust her so I'll go into this as long as it's her, I'll be okay (Patient 4, 54yr female with malignancy)*

Participants would appreciate additional depth of information from their health care team and noted the need for extra time and compassion from the doctors leading their care.

> *Basically, if you need to know anything, what's going on with your treatment, the doctors, they don't actually come forward and tell you straight away. You have to actually ask the nurse and then when the doctor comes around again, she asks what's going on and then the doctor tells you limited amounts of the information that you want…And not knowing is probably half the problem of being in hospital (Family 14, 49yr male carer for wife with malignancy)*

Clinicians being mindful of inpatients with cognitive impairments when providing information to them without a family member present was discussed. Furthermore, the availability of a team member to pull complex information together was noted to be helpful:

> *And then you're telling my mum who at that time the brain cancer was really affecting her and all she wanted to do was get home and they sort of kept telling her different things and that was hard for me to handle on that side as well (Bereaved family 10, 43yr female carer for mother with malignancy)*

> *everybody was there with their bit but there wasn't anybody to pull all the bits together, if you know what I mean. That would be helpful (Patient 13, 61yr female with non-malignant illness)*

When an inpatient is close to dying, bereaved family members specifically noted their need for clinicians to be explicit about likely prognosis and for practical information about physical changes one may expect:

> *I think it'd be better off them saying, "Look, we think she may pass away" or, "she's extremely unwell. I'd suggest that it will be in the next week or whatever" so that you're prepared (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)*

> *The nurses in particular were really practical. So they and probably the palliative care specialist, said things like, "Okay, in the next 24 hours, this is likely to happen." So the breathing will change. Mum's extremities, her fingers got really cold and became almost black because of the blood supply. So we could openly say, "Why is this happening?" And they'd say, "Oh, the body's starting to shut down. The blood's being diverted to the brain, because it's the last... So they're the control mechanism." So it was really practical. It wasn't disrespectful. It was all very... It was great, because it gave us a real... things to look out for. Things to watch. Things to alay any concerns (Bereaved family 5, 56yr female carer for mother with malignancy)*

Participants spoke about wanting clinicians to be positive and maintain hope within the context of living with a serious illness. Highlighting their need to understand the reality of their situation before focusing on how to live as well as they could occurred:

> *Well, don't just give me the bad news, now I'll give you the good news about what I can do that is positive…what we can do, in the meantime, is make sure that you live in the best possible manner to reduce... to keep this at the slowest rate of progression possible, and enjoy as much quality of life as you can (Patient 16, 60yr male with non-malignant illness)*

Finally, the importance of cross-cultural awareness to prevent misunderstanding and negativity amongst both inpatients and clinicians was described:

> *in many cases the language doesn't transfer well, in other cases then that creates confusion and possibly I think a cross cultural component, just making people aware that cultures are very different and people react very differently in different cultures, not necessarily meaning offense, which could be taken by offence. And that it definitely, that triggers a reaction, which is a negative reaction and that creates its own another negative reaction (Patient 11, 72yr female with malignancy)*

4.6.2 Domain: Expert care (good physical care, symptom management and integrated care)

Physical care

Participants confirmed the importance of personal care needs being met, with a compassionate, empathetic and willing approach appreciated:

> *When I, like, I had trouble with my bowels also, because I'm on special medication and I get embarrassed. They said, "Patient 8, don't worry about it," you know? They're very, yes, they made me feel at ease (Patient 8, 77yr female with malignancy)*

Patients understood the multiple competing priorities for nurses and appreciated open communication and responsive attention accordingly:

> *I understood if I needed my diaper changed they couldn't come immediately because they were doing other things, so that was the reason. Like they'd say "We'll be back in five minutes," or something like that, and they were (Patient 17, 66yr female with malignancy)*

Families spoke of the importance of sufficient nursing levels to enable adequate physical care, with some noting their willingness to assist under clinical guidance:

> *… and for 13 days I could not get anybody to give him a shower until the last day when he was going home. That's terrible…And I tried chasing them, and they're too busy… (Family 12, 78yr female carer for husband with non-malignant illness)*

> *It's the personal hygiene stuff. I think more of that. If not done by the nurses, at least enabling family to do it, and giving them some ideas of things, they can do, because I think a lot of people are scared to touch the person (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)*

Symptom management

Participants confirmed the importance of effective symptom management as well as the need for prompt, individualised assessment and management of pain and breathlessness in particular. Patients also spoke of the importance of effective communication with regard to symptom assessment and management in relation to three areas:

1) Clinicians to be mindful of clarity of message, as multiple drug names can be confusing for people who are unwell and may have cognitive effects from illness or pharmacology:

> *They say it's anti-nausea that's fine. It's for the pain, that's fine. But if they say always MS-Contin and then they say Oxycontin and then they say, I don't know all these different names, then you get confused… One form, one function. The function is pain, you're giving a pain killer. The function is stomach, you give whatever (Patient 11, 72yr female with malignancy)*

2) Patients understanding that asking for medication assists the clinical team to optimise their analgesia:

> *At first, I thought asking for more pain relief it seemed a little bit wussy on my part, but that was my head space. And they just kept reassuring me and saying, "Don't be afraid to ask. You need to ask because that's how we're going to measure your dosage" … So, I thought that was really good (Patient 4, 54yr female with malignancy)*

3) Exploring why patients may be reluctant to take analgesia:

> *When I was younger I had two really good mates and they started taking tablets and pills and stuff like that, and then their lives just changed and they ended up getting all the other drugs and one of them died and the other one, I don't know what happened to him. And it was through just taking... I just hate taking tablets (Patient 1, 48yr male with malignancy)*

Families added to this, describing the importance of using critical thinking to ensure a comprehensive and accurate assessment and management plan:

> *Well, there was no connection. It was literally, "I'm just taking your temperature, I'm taking your blood pressure, and now out of 1 to 10." There was no thought in it, no critical thinking behind why am I doing this and does this scale actually mean anything to this person? How do I engage with them to actually get them to give me an honest, a deeper answer and an answer that's actually a real answer, rather than trying to please the nurses so that they don't make a fuss? That kind of thing (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)*

Frustration with hospital processes for medication provision was expressed, noting distress caused by delays in access due to an 'as required' order's maximum limit and/or the need to double-check all analgesia:

> *Actually, one thing that would've made a big difference for us - the doctors prescribed the medication and the max limits and that was a thing where we needed that changed and we couldn't actually get a doctor for almost an hour and a half to have that changed. But once those pre-approval or pre-authorizations are in place from the doctor for the nurses, you know, the nurses can more easily hand out that medication.*

> *If that whole process was somehow improved… And I suppose the other frustrating thing is, and I know they have to do it because it's too open to abuse otherwise, but the having to wait for second nurse or a doctor to go and sign off to give meds. I mean, but having to do that even to just give Panadol and Nurofen is just a bit much (Bereaved family 11, 33yr female carer for father-in-law with malignancy)*

Accurate assessment and responsive attention were emphasised as crucial, with adequacy of nursing clinicians noted to enable this:

> *Look, the important thing, I think is to know there's somebody there. And very often, they're not. Not because they don't want to be, but there's not enough staff. We know that. The nurses are absolutely run off their feet. They are so good, but they can't do everything…… And I mean if you are in the toilet and you press the button, they do come eventually, but if you're not breathing or something like that, it's not fun (Patient 10, 82yr female with non-malignant illness)*

> *I thought these people have been here all night and nobody had noticed that that this person looks absolutely dreadful this morning, and that there's obviously something wrong…And then when they came they just gave her 1 endone or ½ an endone I think and then went away and never came back again to check whether it had worked or not, and it obviously didn't work. So that didn't seem to be a priority, they weren't really anticipating pain or assessing it well at all I didn't think (Bereaved family 4, 69yr female carer for friend with malignancy)*

Patients described the challenges of managing breathlessness in the hospital when fans, fresh air or cooling are not easy to access:

> *Because what happens when you can't breathe... You sort of hit a panic button. And you get all hot, very very hot and flustered. You want cooling blowing on you. You start to wheeze because you've got no control because you're panicking…And they can't always find a fan for me (Patient 23, 69yr female with non-malignant illness)*

The importance of non-pharmacological care to relieve distress was noted:

> *But the thing about pain relief for me is they focus on the drugs, which is really important, but what they didn't focus on was on the other stuff that relieves pain. I was doing things like getting bowls of warm water and soaking Patient X's hands and feet in those bowls of water, which she just thought was fantastic (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)*

Integrated care

Participants confirmed the importance of clinicians being knowledgeable about their specific condition and working as a team both within and across departments:

> *So they knew what Professor X was doing as her treatment, and the oncology team were checking in with that. So they all knew. Everybody was talking to each other… Which was great. If you don't have your staff talking to each other, you can get a gap in the hole (Patient 4, 54yr female with malignancy)*

> *Because it's not just one person, it's a team of people. And they really put all their ideas together, what would work best. So, you're looking at more than one person's knowledge. So, to pool people's knowledge and get the best of care I think is a great approach (Family 11, 61yr female carer for mother with malignancy)*

Participants expressed frustration about care that was provided in silos with poorly coordinated communication:

> *Communication between departments is nil. It is absolutely off the tree, and that is very important, because you need that communication between departments…And that's got nothing to do with the patients. That's the department. If the departments cannot communicate, god help the bloody patients (Patient 10, 82yr female with non-malignant illness)*

> *It was very piecemeal. It was very "This is my discipline, this is what I look at" … So there was no combined discussion of goals of care, of a treatment plan. Everybody in their little silo did their own thing and focused on their little bit of it (Bereaved family 6, 68yr female carer for brother-in-law with malignancy)*

Frustration was expressed at the fact that access to advice from departments outside of their admitted location could be difficult to manage. An example was provided of an elderly patient with advanced respiratory disease admitted with an exacerbation of breathlessness. She wanted to arrange a dental review for a sore tooth whilst an inpatient, as arranging this from home with related transport, care and oxygen needs was difficult. However, this was not enabled across her admission of over one week.

> *Once you're in hospital, getting anybody in another department is ... forget it. It's impossible. Communication between departments is not on. It is one of the worst things to try in the hospital... You know, that's annoying because you can't get hold of the people you want to get hold of (Patient 10, 82yr female with non-malignant illness)*

Patients confirmed the importance of effective discharge planning, with one participant noting her discharge summary never makes it to her General Practitioner (GP) and her medication changes need to be self-managed:

> *The only thing is, when you're discharged from hospital, only once have I had a sheet given to me on the discharge summary. And, my GP has never got summaries from them. She's always complaining. I have to take my list of medication in and explain what medication I'm on (Patient 3, 80yr female with non-malignant illness)*

Participants described that nursing handover is problematic, with complex needs not always translated between shifts:

> *"It's changeover time." … I don't want to listen to that, because it's hard. Because they've got to change over, and then they don't know who you are. And then we're back to square one (Patient 10, 82yr female with non-malignant illness)*

Families discussed the difficulties in relation to timely integration with specialist palliative care providers. They acknowledged their lack of understanding of what this service offers and their fear of accepting a referral:

> *I was horrified when they said the palliative care team should come and speak to him, but the other side of that was they were absolutely amazing and wonderful, and so professional and so good to be around (Bereaved family 7, 56yr female carer for husband with malignancy)*

A perceived rivalry between treating teams and palliative care was described, resulting in poor integration between services:

> *I'm probably naive, I thought we've moved on a lot. Thinking of the palliative care being more ingrained in our care process, but that certainly wasn't what we experienced. It was still like it was the alternative, out of the box sort of... The oncologist was set on the outcome, but processes are a big part of care. It seemed to be really missing in the oncology team… Having the oncology services and palliative care service working as one. Working in unison. Working together. It would have made a massive difference for mum. From day one, she would have, yes... Mum still would have passed away, I know that, but we might have had a little bit longer. (Bereaved family 5, 56yr female carer for mother with malignancy)*

The ability for inpatient teams to work with community palliative care providers was also described, noting that the lack of this impaired effective care planning:

> *The pathway to his care, it became difficult for us to advocate for him, because, what the hospital was seeing, and what we were seeing was quite different. There wasn't much interaction between the community based palliative care teams, and the hospital, so once he went to hospital he was admitted under an ED consultant initially, and then obviously under the relevant team based on what his care needs were, but it was difficult to get palliative care involved, because from what the hospital was seeing, they weren't seeing a palliative care patient, they were seeing someone in liver failure who was having seizures, so there was very different focuses on the care (Bereaved family 3, 43yr female carer for brother with non-malignant illness)*

Finally, a patient with a cognitive impairment noted the difficulties she experienced as her medical history and care plan were not accessible within the Emergency Department:

> *... in the emergency, they... Isn't it, our profile, is in the system already, in the computer? So, why is it that they need to repeat all over and over again... the interview before they go in to cure you? (Patient 21, 50yr female with malignancy)*

Other – clinical competence and access to senior clinical support

Participants also described two additional areas of care that are relevant to the domain of expert care: clinical competence and access to senior clinical support.

> *I think the most (important) thing is the competency of the people that are looking after you. I mean that's obviously number one. And then that probably breaks it into two areas; the nursing staff, and the professional staff with the doctors (Patient 9, 75yr male with non-malignant illness)*

Participants described that when living with complex illness, access to competent practitioners is required, with particular examples provided in relation to intravenous cannulation and pleural effusion drainage.

> *When they have to have their cannula in, they get prodded to such an extent to get that cannula in, that it is unbearable to watch, never mind about experience… I said, 'I would really be very grateful if you could send an RMO1 or 2 who has had a bit more experience, because he's in for a long trot and an unpleasant one, let's make it as easy as possible.' And he did, he sent me an RMO1…who was very experienced, and while he was chatting, the cannula went in and no one even knew it went in (Family 12, 78yr female carer for husband with non-malignant illness)*

Competence to appropriately manage an implantable device when someone is imminently dying was noted as highly important:

> *What do you do with a defibrillator in someone who has a Glasgow coma score of three and is dying…what should have been an absolutely routine 30 seconds visit from a technician was blown up into something where that whole process was actually delayed by 36 hours and just causing such needless angst, such absolutely needless angst…what should have been very, very simple and straightforward palliation was compromised by two people, both of whom should have known better and both of who had this as their core business (Bereaved family 13, 54yr male carer for both parents with non-malignant illness)*

4.6.3 Domain: Adequate environment for care

The concept of space was personal, with a variance in preferences in relation to private and shared rooms noted. Some participants described a preference for a shared room to enable company and helpfulness of fellow patients:

> *As a matter of fact, it's better, because if you're in a shared room, first of all you can help somebody else if they need it. And secondly, they can help you if you need it. It is much better that you are in a shared room. I'm not really that keen on being in a private room, because you are stuck like a shag on a rock, like I am here at home (Patient 10, 82yr female with non-malignant illness)*

> *In the single room, it's quieter, but in those rooms the doors have got to be shut because the air pressure's different for infection control. So it's really isolated as well. The happy medium is when she's in a two bedded room, and there's another female in the bed, who's not so advanced in age that they actually can have a conversation or a conversation with the family (Family 5, 50yr female carer for mother with malignancy)*

However, difficulties in sharing included being disturbed by noise, having to tolerate different smells, and feeling confronted by other people's illnesses:

> *...the lady next to me ... she used to bring in her own food and the smell was not the best. And also her visitors used our toilet, which is a big no, no ... I'm very sensitive to smells (Patient 19, 69yr female with malignancy)*

Participants described their bed being moved as disorientating and distressing:

> *The point is, I want to be left alone. I want to say, "This is my bed. This is where I belong." Once you're there, you want to belong somewhere not feel, "This is where I belong until they think of something else this afternoon at four o'clock." (Patient 10, 82yr female with non-malignant illness)*

Families spoke of their discomfort with mixed gender wards and that shared rooms limited their ability for privacy and important conversations:

> *There was only once that I didn't agree with it, there was three ladies altogether and then they put a gentleman in the same room…And I don't agree with that. Not that I had anything against him, I just don't think that men should be in the same room as women because it's a personal thing and they shouldn't be (Family 18, 59yr female carer for mother-in-law with non-malignant illness)*

> *I know when dad was in there when he had his stroke, I'd be sitting there and just wanting to talk to him about lovely things that we had done or whatever, and the whole room is listening in because they've got nothing to do but ... They're not being rude or anything, but yeah. So it's very hard in that kind of situation. You just want privacy (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness)*

Participants described the importance of a restful environment that was quiet and enabled sleep:

> *to be in a place where you can be in a room or something without much disturbance (Patient 5, 72yr male with malignancy)*

Cleanliness was valued by participants, noting the relevance of this for infection control:

> *everything was cleaned every morning… So I knew if I got out and I had my bare feet, I could walk on the floor and I knew that I wasn't going to get... they talk about the hospital bugs and that you can get? Staph and all that. I don't think I had any chance of getting any of that (Patient 1, 48yr male with malignancy)*

Patients with breathlessness spoke about their need for adequate ventilation, particularly in the bathroom, to assist with showering:

> *... there's no exhaust fans in hospital toilets, all that, in the showers. They're that small ...Yeah, you can't leave the door open. You can't shut the door, because of the steam, and you can't breathe in there. There's no windows to open. If there is a window, it*

> *only opens about three or four inches at the most anyway (Patient 23, 69yr female with non-malignant illness)*

Window access was described as important to: enable a connection to the day/night cycle; feel connected to the world; feel warmth from sunlight; and prevent feeling claustrophobic.

> *Light and sky, is correct. Probably the only thing I always look for. I grew up on a farm…the sky is be all, and end all really. It gives you time, tells you what time it is (Patient 12, 65yr male with non-malignant illness)*

Bereaved family members described the importance of a private room when someone was imminently dying:

> *When we were actually, he was very, very close to dying. We had to really beg them, "Please, can he just die in a room by himself, please? Can you not die in a four bedded room?" (Bereaved family 3, 43yr female carer for brother with non-malignant illness)*

The importance of dedicated space for families to enable comfort, rest and private conversations was described:

> *We could use a microwave and a kitchen area. Any sort of bedding would be nice, because to sleep on a concrete floor for a night or to put two chairs together, and then try to be a reasonable human the next day is pretty hard (Bereaved family 5, 56yr female carer for mother with malignancy)*

> *but there was nowhere that you could go other than in the room… It's kind of like either you're in the room or you have to go to the cafeteria with everyone else. There was no private space where you could go and get a cup of tea, nothing like that (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)*

Families also talked about their need for access to nutritious and affordable meals:

> *there was a cafeteria in the bottom of the hospital that was then atrociously expensive, and they were your only two options, so there was nothing else around the hospital that you could walk to. And we did, I think we did uber eats at one stage, but I mean, that week we must've spent hundreds of dollars on cafeteria food that was horrible…Its just, it'd be good if the quality was better and price wasn't so exorbitant (Bereaved family 11, 33yr female carer for father-in-law with malignancy)*

Patients spoke about their need for comfort whilst waiting in the Emergency department and also their need to be appropriately triaged and quarantined if immunosuppressed. They are aware of how busy it is, but found being left in a chair for long periods distressing:

> *not have to sit and wait. Which has happened every single time. I have not had to wait. They got me through straight away, which is brilliant…It's just that I'm so sick that I need to go and lie down basically (Patient 19, 69yr female with malignancy)*

Two practical concerns were described by patients:

(1) The practicality of the hand-held TV audio-control:

> *The worst part of being in hospital is having to hold the thing to listen to television. That's a nuisance, because you can't eat and hold that at the same time. So you can't watch the news in the evening, while you're eating your dinner (Patient 10, 82yr female with non-malignant illness)*

(2) Arriving at hospital without basic toiletry items:

> *I understand now that they don't supply you with shampoo and proper soap and deodorant… but it is very difficult when a person has an emergency situation, you're going to the hospital, and you need that stuff, and you haven't got it (Patient 18, 71yr male with non-malignant illness)*

4.6.4 Domain: Family involvement in care provision

Participants confirmed that company and family connection are vital in providing comfort and emotional healing for patients, and the importance of families feeling respected as partners in the care of their loved one when in hospital. In addition to this, participants described family involvement as supportive for understanding of information, given a patient's cognition may be affected by illness or medication:

> *My role was to be his advocate and his interpreter…Dad's 91 and a bit deaf and he was below par... obviously a little bit confused, I think, because of the renal failure. So it was very important that he had a go-between (Family 9, 64yr female carer for father with non-malignant illness)*

Participants valued flexible visiting hours. Simple comforts to support families when staying overnight would be appreciated:

> *Well, it is very important for him to sleep well so that he will kind of care for me... You can just imagine the whole day, the whole week, he's looking after me. He's assisting*

> *me… Even going to the toilet because I'm so weak (Patient 21, 50yr female with malignancy)*

Participants expressed frustration with being unable to find out when medical ward rounds occurred, leading to lengthy periods of sitting by the bed, hoping to see the team:

> *I think it would help if when the doctors doing their rounds…if they could give you some sort of indication of when they'd be in the ward so that you're family member wouldn't have to get there at eight and stay until midday, and the doctor comes at 11:30. It's a strange world the hospital world… it's like working on another planet. Everything else in the outside world just gets turned off. People don't have appointments, everything that happens in the hospital is the most important. Which it probably is, but you still need to realize that people need to go to work and have that appointment to talk about their mother (Patient 13, 61yr female with non-malignant illness)*

Families also spoke of their need for a clear process for communicating with a senior member of the team to enable regular updates about the care plan:

> *It would be fantastic ... after doing a round, it would be excellent, because then you're getting the latest of what's going on there…I'd be very happy with the registrar involved to do that…I think the registrar, from the team I ran into, I think was more able to do that. I think the resident was very nice, actually, but I think the registrar was much more savvy (Family 9, 64yr female carer for father with non-malignant illness)*

Bereaved family members outlined what was important for their support at the time of and immediately after their loved one's death. Firstly, the importance of respectful care of the body, not feeling rushed to leave the ward and for timely, accurate death certificate completion was described:

> *…certainly even at the time of his death, we weren't given much time to spend with him after he died. You could see that there was a pressure for us to wrap things up, and get going. We as a family, we laid out his body, and we washed him. And I stayed till he was put in the body bag, and I never felt beyond that point that his body potentially was treated respectfully. Because once the wardsmen came to pick him up, you could see that, he sort of threw him onto the trolley… He very much fell into the pattern of being a job, rather than a person requiring care, if that makes sense…It was very much about a task; collect the patient in bed 27 sort of thing, rather than respectfully care for someone who's just passed away (Bereaved family 3, 43yr female carer for brother with non-malignant illness)*

> *…she continued to decline, and died on the Sunday night… twenty to eight. And just to add to this, my sister and I, waited until 1 o'clock that morning for somebody to come and pronounce her dead… we waited in the room with her and we were told several times, that we're very busy and nobody could come. Then at the time when the poor young registrar came to call it. She then said, "Oh, your mum's... I'll call the death at well at 1 o'clock this morning." And we said, "She actually died at twenty to eight last night." To which they said, "Oh, well does that really matter?", Yes, that really matters (Bereaved family 5, 56yr female carer for mother with malignancy)*

Secondly, they spoke of their need for information about what happens after a person's death in relation to death certification and removal of the body:

> *that's definitely an area that I think could be improved, is when someone dies in a hospital, what happens, what's the paperwork, what's the process. There was nothing on that end. We had a bit of trouble finding out what the process was, especially in terms of when does the funeral home take the body and all that sort of thing, like the chain of custody and documentation (Bereaved family 11, 33yr female carer for father-in-law with malignancy)*

Finally, bereaved families described that they would appreciate a follow-up contact from a clinician who had been connected to their loved one's care, to check in with them and offer information about additional supports. The provision of a bereavement letter from a service separate to those connected to their care felt less supportive and somewhat tokenistic:

> *If it was a quality control thing, like, "Hey, give us some feedback," no. That wouldn't be appreciated. But if it was a, "Hey, we just want to see how you're doing. Let us know if you need anything. You know, here's an offer for counselling should you need it," that would be amazing….Like it would've been so nice to hear from the nurse that was, you know, the nurses that were there from us, that were there with us at the end. If they had sent an email saying, you know, "We're just thinking of you. If you need anything, let us know," etc, etc. I mean, that would be really lovely (Bereaved family 11, 33yr female carer for father-in-law with malignancy)*

> *The Cancer Unit X do things like they send a letter acknowledging mum's death and saying, how sorry they were, they did have a brochure in there if we needed assistance… I think once again it feels a little tokenistic (Bereaved family 5, 56yr female carer for mother with malignancy)*

4.6.5 Domain: Financial affairs

Participants noted the supportive health system in Australia where a lot of healthcare is provided at little or no cost. However, they noted the need for improved processes and supports in relation to hospital parking costs, supported accommodation for those requiring this, access to carer payments and subsidies for relevant clinical equipment required to enable transition home:

> *Was it the social worker that had said, "Have you accessed the Carer's Payment yet?" I already knew about these, so I'd already started applying for them because I've just retired from work, from teaching. (Family 11, 61yr female carer for mother with malignancy)*

> *There is a thing at that hospital where once a day, if you have got a pension card and if you're visiting a patient, they stamp your ticket and it costs $5 then for parking rather than $35, which that's been a really big help for dad….it's taken three years to find out about that….Someone just randomly mentioned it on the ward to him (Family 5, 50yr female carer for mother with malignancy)*

4.6.6 Domain: Maintenance of sense of self / identity

Patients confirmed prior research that outlined the profound impact of living with a terminal illness and the need to live as well as possible within the context of life limiting illness. Of note, only patients spoke of the importance of this domain (no family members). Patients spoke about wanting to maintain wellness, within the context of their illness, and wanting to isolate their illness from their full life – not to *become* their diagnosis:

> *I like to be treated as a normal well individual. Because that's where I keep my consciousness, my self-view of myself. Is that I am well, all is well, in terms of keeping myself positive…I've found a way to be very... to live very well, in the state that I'm in. Which is now fairly rapidly deteriorating (Patient 16, 60yr male with non-malignant illness)*

Patients talked about wanting to maintain independence through exercise and supporting their sense of self through connections with others:

> *I may go through emails and the telephone and all the connections I've got…Sometimes it just too tiring, but I try, I try not to let it go, because it is myself…..It helps me still feel Patient 11 with my interests, with my friends, with what I have always done (Patient 11, 72yr female with malignancy)*

Taking control of the daily routine was important to patients, with a focus on physical activity:

> *As soon as I'm in a hospital, whatever time I wake up, I get out of bed and I'll sit in the chair or go for a walk up and down the passage. The nursing staff will say "You think you're well enough to do that?". I was like "Yes I'm doing it to get well". And a lot of them can't understand that (Patient 22, 75yr female with non-malignant illness)*

The notion of becoming institutionalised was discussed by patients as something to be avoided:

> *I think it would be easy... it would be very easy to just relax and buy into it, and be the helpless renal patient who everyone has to look after. It terrifies me. It absolutely terrifies me that that could happen to me (Patient 3, 80yr female with non-malignant illness)*

The importance of humour and having a laugh was discussed in relation to helping patients cope with living with serious illness:

> *Oh, man, if you stop laughing, you might as well give up (Patient 16, 60yr male with non-malignant illness)*

Patients talked about their need to engage in meaningful activity, with several describing their days as long, and their need to occupy themselves to assist in wellbeing:

> *It allowed me to be me too, because I could go and get those things to them, because I was making a nappy baby for one lady, and I bought a present in the chemist for her, and I bought another present. So I was able to sort of, yeah, be a little bit of me. And that was good (Patient 4, 54yr female with malignancy)*

Patients provided some suggestions of how to enable meaningful activity centering around the provision of reading materials or puzzles/games, access to information about what is available across the hospital, visits from pastoral care workers and encouragement to get out of bed and engage in an activity:

> *There used to be a library that a volunteer would bring around a trolley and it had games on it like Checkers or things like that... To do stuff like that…If they had a thing on the TV ... like an information pack that didn't get too into the nitty gritty of it. It just said do you know that you can ... there's a podiatrist service and this is the number. There's a hand clinic, this is their number... Just listed the things that are available (Patient 13, 61yr female with non-malignant illness)*

Finally, patients talked about their spirituality, noting the support their beliefs provide, that they wanted to maintain positivity and hope in line with such beliefs, and pray to support their clinical team to provide optimal care:

> *… I mean I am a Christian, I always believe that there is always hope and we have gone through that – we want to overcome this problem (Patient 5, 72yr male with malignancy)*

4.6.7 Domain: Minimising burden

Previous research found patients noted minimising physical or emotional burden as important. When discussing this with participants, several noted feelings of being burdensome on family members or friends but they did not talk about needing to minimise this *per se*, rather describing the fact that they felt burdensome due to their care needs:

> *I think most people feel that way…That's a personal thing within yourself and it's just thoughts. I mean, I feel that way and it will eventually it will get worse. So, you can't help feeling that way (Patient 19, 69yr female with malignancy)*

One patient described working to limit the time required to care for him and actively trying to delineate between 'carer' time and time being husband and wife:

> *She owns her time, and I own my time, but we share time together. But, she shouldn't be sharing my illness time, right, we should be sharing good time. That's how I feel about it (Patient 12, 65yr male with non-malignant illness)*

4.6.8 Domain: Respectful and compassionate care

Participants unanimously confirmed the importance of respectful and compassionate care, with specific reference to people feeling welcomed; inpatients being treated with care, respect and dignity; clinicians anticipating inpatient/family needs, being responsive and demonstrating cheerfulness and care for their work; and clinicians being compassionate and supportive. Participants noted the tone of communication as being important, the need for clinicians to connect with each inpatient and the need for simple acts of care and kindness:

> *Well, a nurse gets to know their patients, I suppose, and needs to know their needs, and I think when a new nurse comes on, the first thing she can do, besides introducing herself, which she should be doing anyway, she might just say, "Are there any things you need? Anything special that I've got to look after for you?" Just get to know your patient… And I'm not talking about having to give her a whole life story.*

> *Just maybe one minute or two minutes to find out my personal needs while I'm there. (Patient 18, 71yr male with non-malignant illness)*

> *It is the simple stuff. This is not about whether you had side effects from drug X, or drug Y would have been better. This is simple humanity (Bereaved family 13, 54yr male carer for both parents with non-malignant illness)*

Participants spoke of the impact of friendliness, a nice manner and common courtesy:

> *Just a general attitude to the nurses on the ward. I don't have to be your best friend, but a bit of common courtesy, I suppose, would be better. (Patient 13, 61yr female with non-malignant illness)*

Participants appreciated clinicians who ensured they were comfortable before leaving the room and who listened. One patient recalled how difficult it was when she was told not to buzz as the nurses were writing reports. This same patient noted the importance of clinician friendliness, particularly for those who have an extended hospital admission:

> *I was in there for nine weeks, in March, you're in there a long time. It's a long time to be alone. Not alone, but separate from your family and spend days with ... If you don't get a visitor, it's a long day. You would like the staff to not necessarily notice you don't have a visitor, but just be that little more pleasant on a day to day basis. (Patient 13, 61yr female with non-malignant illness)*

Participants spoke of noting a ‘vibe’ from clinicians in relation to whether they were happy to be at work or not. The impact of being cared for by someone who appeared happy to be at work, who was engaged and deliberately made an effort to connect with patients and families, was important:

> *I never got that feeling if someone helped me and they're thinking "Oh look, she doesn't want to do this or he doesn't want to do this." I never got that. I never got that vibe at all with any of them (Patient 1, 48yr male with malignancy)*

> *Some of them were just there, doing their jobs. They don't particularly care, had obviously seen everything, were just kind of fed up, you know, maybe burnt out, sick of their jobs, didn't want to be there … when you're the family member of someone who's passing away, you feel that. You can feel that they don't want to be there, that they don't really care. At first, it was their body language and the way they talked. They were more, I suppose leaning in, whereas those that didn't really care, they didn't really show eye contact. It was just kind of coming in, check-in, doing the bare minimum, not really engaging in conversation except where necessary…You know, just very clinical. Whereas ones that you could tell actually cared, they deliberately*

> *showed empathy and engaged in conversation and would ask, "How are you doing? Are you okay? Do you need anything?" Those kinds of things (Bereaved family 11, 33yr female carer for father-in-law with malignancy)*

Participants spoke of wanting to be treated as a human, the importance of empathy and the need for care to be less mechanical and more compassionate:

> *Yeah, it's lack of compassion. She's just like a woman with answers- You know, you ask question and she going to answer it just like reading books… It's too mechanical. It's yes or no. And well, with a patient like me, I need more explanations and more compassions on what to do (Patient 21, 50yr female with malignancy)*

> *I just felt that there was a deep empathy and there was just a compassion that was palpable, so it didn't feel that it stepped over the professional boundaries at all. It was still within those boundaries, but it was very gentle and very life-giving for the families. And obviously, the character of the individuals involved in creating that safe soft space was just outstanding, you know? And we were very blessed to be carried, because that's essentially what we were, we were carried by these beautiful people through just an absolutely horrendous experience (Family 8, 52yr female carer for father with malignancy and bereaved family for daughter with non-malignant illness)*

A patient also described how she felt she had little power when trying to provide feedback:

> *Oh, it's the power. Patients feel they're at the bottom of the power-triangle. They shouldn't feel like that but I'm sure a lot do just from stuff I've done…. It changes, and I know that, but it's interesting as a patient, you do feel like that (Patient 3, 80yr female with non-malignant illness)*

A bereaved family member also spoke of their need for respectful care that was not judgmental or stigmatising:

> *... If health professionals could change in any way they could change, that part of themselves to show empathy despite people circumstances, and really put themselves in someone else's shoes, and just listen to the journey that these families have been on. Because for most families, it hasn't been easy, and it will never be easy for my parents. They've buried their son. They've buried their only son. And it will never be easy, but it just is nice to think that, there isn't a stigma attached to the fact that he was alcoholic (Bereaved family 3, 43yr female carer for brother with non-malignant illness)*

4.6.9 Domain: Trust and confidence in clinicians

Participants confirmed the importance of trust and confidence in clinicians and described that effective communication assisted them in relation to this:

> *I get confidence from the medical staff when they talk to me and they tell me exactly what's going on. Obviously, I have to trust what they say because they're the doctors … But it's good that the doctors don't just talk. They've got to follow-up (Patient 18, 71yr male with non-malignant illness)*

> *…that they listen to you, number one and that they look you in the eye and they have the body language of being present is all. Yeah. And that they're looking to you and they might relay back what you said that you can hear that they've heard you, and be caring to the patient (Family 13, 56yr female carer for mother with non-malignant illness)*

Participants spoke about the importance of being able to communicate openly with their teams without feeling clinicians are being defensive:

> *Confidence, preparedness to listen. Preparedness to take questions. A sense that they're not being defensive when questioned and queried about something (Family 9, 64yr female carer for father with non-malignant illness)*

A clinician being attentive, responsive and mindful in their care delivery was noted to help in the development of trust and confidence:

> *Isn't looking at other things or checking her mobile or something else. Just being attentive, I suppose, being in the moment. Being mindful (Patient 3, 80yr female with non-malignant illness)*

> *I guess if you ask a question, they knew the answer to that, and if they didn't know, they said they'd go and find out about it. They didn't try and make some crap up. The ones that actually came in and asked about how we were going, how's patient X going, when they came in and did things, actually explaining what they'd done, and what the outcome of what they'd done was (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)*

A good clinical outcome (feeling better), feeling safe and that everything that could be done was being done, engendered confidence, as did feeling the clinician is confident, competent and efficient in their care delivery:

> *Well, people should be sure what they're doing, and know you have to have confidence in them. Not to feel that they are doubtful and they're asking you (Patient 11, 72yr female with malignancy)*

> *We felt safe, and we knew that everything that could be done was being done, and we knew that potentially that wasn't going to be enough. But just the comfort of knowing that everything that can be done has been done is just ... You know, you can't ask for more than that (Family 8, 52yr female carer for father with malignancy and bereaved family for daughter with non-malignant illness)*

Families noted the importance of a team in building trust and confidence, speaking about the fact that they knew team members may have different levels of expertise but as a collective would enable the required care:

> *But you've got a team of people who do, so it's almost as if there's this kind of critical mass that if you have a team of people that by and large have got the skills, that can carry those who perhaps don't, but they might be great clinicians in other ways (Family 8, 52yr female carer for father with malignancy and bereaved family for daughter with non-malignant illness)*

Finally, the approach to care was noted as being important to enable trust and confidence, with helpful approaches being those that are strong, caring, compassionate and professional:

> *...being strong and caring, but not overdoing it ...Strong… definite… Yeah. And that strength follows like … connects you know (Patient 19, 69yr female with malignancy)*

4.6.10 Domain: Maintenance of patient safety and prevention of harm

This domain was previously described as important by families, where they noted that hospitalisation did not always improve care outcomes; sub-optimal care adversely affected clinical outcomes and families needed support to speak up without fear of repercussion. This research confirms such data and adds the patient voice to this understanding.

Participants spoke of the need to feel their care is safe and well managed without needing continual oversight, given they are so unwell:

> *Where it lacked is that unless you were always on the ball for your own case, there could be a lot of mistakes because ... they are put down on computers, you don't know what is written there so you'll have to constantly be on the ball. But if somebody's very ill, or very tired or uneducated, it's not easy to be on the ball (Patient 11, 72yr female with malignancy)*

They discussed the importance of their clinical team being knowledgeable about their specific health care needs within the context of their broader health issues (not focused purely on one component of care / organ):

> *The lack of safety was, I thought, with medication being prescribed by the urology team, that he didn't need. And Dad had had two episodes of melaena in there, and had a massive drop in haemoglobin. And the team continued the input of some oral aspirin, and I was at home here thinking "Oh, I'm not happy about that." Because, you know, he was transfused, had three units of blood and until I actually brought up the issue, this aspirin's still here, I felt a bit of danger in that regard. Not ultimate danger, but I just thought, "This is not ideal management." (Family 9, 64yr female carer for father with non-malignant illness)*

Medication management was discussed by participants with a focus on accuracy in prescription and administration, with particular concerns noted in relation to: translation of complex medication regimes in the home setting to the hospital setting (and vice versa), accuracy in timing of administration, and managing an error in the computer system once entered:

> *And also, the hospital constantly gets the medications wrong. That is terrible. I check every tablet I take, and they get it wrong. Then they tell me I don't take this. Then we get into screaming arguments. And then they bring up pharmaceuticals again. They say, "Yes, you do, but they didn't believe you." You know things like that or it's not on the computer, because somebody forgot to put it down (Patient 10, 82yr female with non-malignant illness)*

> *…the medication dispensing is such a stuff-up, excuse my language, that they could kill a patient. They could kill a patient, easily…But basically, my concern was from the day go, the way they distribute the medication. I don't blame the nurses, it's the system, and it is horrendous…One nurse looking after five patients, she comes in with her computer and she starts dishing out pills. She dishes out one or two pills and then her buzzer rings or whatever, she runs away, and she comes back half an hour later. She has no idea, she can't remember what she dished out (Family 12, 78yr female carer for husband with non-malignant illness)*

One patient noted the lack of pressure injury prevention provided and the impact this continues to have on her wellbeing:

> *It was just a bedsore...If I'd been rotated or my ankle would have been elevated or a couple of nurses just sort of stuck the bandage back on even though it was a bit wet ... Which the wound care for that was shocking. I have a wound on my right stump at*

> *the moment caused from the same problem... At the moment, I've got quite a problem to live the best life I can (Patient 13, 61yr female with non-malignant illness)*

Optimal care was described as being adversely affected by understaffing. This meant inpatients could not always get assistance with simple tasks, could not communicate in any depth, and care felt mechanical, task orientated and not responsive to their needs:

> *… you don't always get attention immediately but I totally respect and understand that because it's usually because they're busy, not because they're ignorant or don't want to do what you ask them. So, it's about lack of staff. That's what it's about and that's a huge problem (Patient 3, 80yr female with non-malignant illness)*

Two new domains that had not previously been reported in the literature were described as important by participants.

4.6.11 Addressing nutritional needs – the impact of good food, hot drinks, nutrition and supportive kitchen staff;

Food within the hospital setting was described as important in relation to nutrition, wellbeing (including diabetic management), recovery and comfort:

> *My diet in the hospital is a big drama because I don't eat meat. I have to be on a dialysis diet and a diabetic diet so really getting down to not many very choices on the diet front. The food front. Then at breakfast time you might get a lukewarm cup of supposedly hot water and a tea bag, and I don't drink tea. Then you ask someone, could you have a coffee satchel. By the time they get back with the coffee satchel the hot water's cold. It just sort of ... it's a bad way to start the day…. It's just a shocker. I find that quite depressing actually (Patient 13, 61yr female with non-malignant illness)*

Participants noted the need for inpatients to maintain their weight across an admission:

> *This is going to sound petty, but that the food I was given was okay... was what I normally eat and what I wanted…it's things I prefer and I don't have much appetite…And, I'm only 55 kilos, so I need to maintain my weight if I can, because you lose a lot of protein and stuff, and I've always been fairly thin. I just need to keep my weight up (Patient 3, 80yr female with non-malignant illness)*

Comfort provided by good food that is at the right temperature, fresh and in line with patient preferences was noted:

> *The kitchen at the hospital is one of the most fabulous things. People do not realize what that kitchen does for the hospital. Their food is bloody good…Now, morning and*

> *afternoon tea…. They're the important things in life (Patient 10, 82yr female with non-malignant illness)*

The impact of diet aides and kitchen staff was noted:

> *even down to the women that come and take your order for your food. I think we forget about those people. Yeah. Like I might've been in the shower and they would come back. It's just those little things that, they come back to take my order. They could have just given me anything (Patient 4, 54yr female with malignancy)*

> *The dietician's aid came in with a computer and with a menu to ask what you want to eat the next day…She would come in, and if he had somebody attending to him, or there was a doctor in, she'd turn around and she'd walk away, and she would never come back. This ended up, out of his nine days, for three or four days he had no breakfast at all. No breakfast at all, I would have to go downstairs and buy something for him, to take his medication. (Family 12, 78yr female carer for husband with non-malignant illness)*

The need for assistance in managing food trays was noted as important and an area that was often missed:

> *The nurse stood there and opened the packet so I could... it says on my plate every time 'needs help with opening packages because of my strokes'. Yet, I think one out of every second week, one person would help me. Then you're sitting there trying to open packets with your teeth, which is very undignified (Patient 13, 61yr female with non-malignant illness)*

4.6.12 Comfort provided by access to medical and nursing specialists.

Participants described the comfort and reassurance felt by having easy access to clinical specialists. They specifically described the positive impact of having access to a nurse specialist, given their prompt attention to noted concerns, answers to questions, time for support and planning, ongoing support on discharge home, continuity in care and high levels of expertise:

> *… because the nurses from the PD clinic, the peritoneal dialysis clinic there, come and see you every day as well. They're so... across your particular case, because I see them at least monthly. They are like angels. They're just absolutely tops in terms of nurses. So, they would come up daily and they'd always check with the staff on the ward. I don't know that that's so in all chronic disease but certainly renal dialysis at Hospital X, we are incredibly lucky (Patient 3, 80yr female with non-malignant illness)*

> *And so Clinical Nurse Specialist X, who was just such a great clinician but also ... her dedication to her job, her competence and the way that she just enabled us to all feel so comfortable because she was onto everything. If there was any little thing, she was across it straight away, not in an overbearing way, in the most appropriate and life-giving way. (Family 8, 52yr female carer for father with malignancy and bereaved family for daughter with non-malignant illness)*

4.7 Discussion

This qualitative study confirms and adds depth to understanding of domains previously identified in the international literature as important for optimal inpatient palliative care, namely: Effective communication and shared decision making; Expert care; Adequate environment for care; Family involvement in providing care; Financial affairs; Maintenance of sense of self / identity; Minimising burden; Respectful and compassionate care; Trust and confidence in clinicians and Maintenance of patient safety and prevention of harm. [7, 9, 10, 18] Two additional domains were noted to be important by the Australian informants in our study: Nutritional needs; and Access to medical and nursing specialists. Our study also provides new insights on how the above domains can be operationalised in inpatient palliative care. Integrating data from this study with prior published work is important to inform progress in supporting acute care clinicians in their efforts to improve on and deliver optimal palliative care. There is significant literature available to answer the question of what is important from the inpatient and family perspectives for good hospital palliative care,[7, 9, 10, 18] to which this Study accords and further develops. Understanding how to enable this care within the busy and varied environments of hospitals across metropolitan and rural contexts, and caring for diverse populations remains elusive.

The emergence of two new domains within our results is notable. The importance of food and nutrition to enable optimal inpatient palliative care was not identified in previous international literature.[9, 10] This may reflect cultural differences or be explained by the fact that palliative care provision is gaining greater prominence for people with chronic and complex illness who are seeking to live as well as they can despite their diagnosis. The role and meaning of food and nutrition for people with palliative care needs is an under-reported area, with current literature focused mostly on cancer cachexia.[30] This study reports the importance of nutrition for physiological reasons, such as to maintain wellness, strength and weight, in addition to the psychosocial aspects of food in relation to comfort and pleasure. How to enable this uniformly within hospitals warrants further investigation. Working with dieticians to design optimal models to address this for inpatients would be a valuable first step.[30]

The importance of access to clinical specialists is also described as a new domain in this study. Two Canadian studies previously reported the importance of the availability of medical clinicians who can communicate in a way the patient understands.[31, 32] Participants in this study extended this further, describing the importance of both accessibility and effective communication as important and distinct elements of optimal care. Participants spoke of the value of accessing nurse specialists in addition to medical clinicians. The emergence of the nurse specialist role[33, 34] is highly valued by those with advanced chronic and complex illness and is therefore a priority to further investigate in relation to future improvements in models of care and patient outcomes. It is noted that uniform access to nurse specialist support is not available across Australia and is highlighted as a ready solution for system-level healthcare improvement.[34]

Work focused on enabling optimal inpatient palliative care has commenced, with one recent study outlining the need to consider a compassionate model to inform care provision.[18] Study 2 within the OPAL Project suggests that a more comprehensive approach is required, whilst not disputing the noted importance of compassionate care provision to enhance patient and family experience. Another recent study[7] has provided an example of how to use data from bereaved families to inform improvement efforts within a hospital environment, complemented by structured committees, with noted executive and quality improvement professional involvement. Whilst not disputing the value of this approach, maintaining an ability for the inpatient voice in addition to bereaved family experience is both possible and important.

There are many examples of excellent palliative care within the hospital setting.[7, 18, 20] To enable this experience to be possible across all wards irrespective of location or population is the challenge. An initiative involving ward-based palliative care champions was tested without resulting in improved experience for bereaved family members.[35] Similarly, the implementation of a framework to support clinicians in their care provision (the AMBER care bundle) has shown mixed results, specifically noting challenges in relation to identification of patients,[36] enabling improved experiences once implemented, particularly in relation to effective communication,[37] and the complexities inherent in standardised package use across such varied clinical contexts where some wards may engage with this work regularly and others infrequently.[38] Given the complexity both in relation to the care of those with palliative care needs and the hospital environments in which such care is delivered (ranging from intensive, critical and high-dependency care units through to all ward areas and emergency departments), it could be argued that a standardised approach to care provision cannot succeed. Rather, tailoring to the local context will be important, albeit underpinned by evidence-based resources, tools and quality processes.

4.8 Strengths and limitations

The strength of this Study lies within the engagement of palliative care consumers in co-designing the research protocol,[39] with their specific focus on defining the sampling approach and methods to support participant experience within the research. The integrated data analysis enabled the voices of this Study's participants to be compared and contrasted with the voices of other patients and families,[9, 10] adding a richness and depth that could not have otherwise been achieved. A limitation of this Study is that the sample is not representative of the broader Australian population, with the views of people from culturally and linguistically diverse backgrounds and Indigenous Australians underrepresented. Recruiting through clinicians also raises the potential for sampling bias through ‘gatekeeping’. In an attempt to limit such bias, clinicians were encouraged to refer people with a full range of experiences. Of note, participants were often critical of their hospital care, suggesting that selection was not biased towards encouraging a favourable report. Finally, given participants were describing past care experiences (within 12 months), it is possible some recall bias may have occurred. On the other hand, participants had an opportunity during the intervening time to reflect on and distil the personal meaning of their hospital experiences, lending weight to the importance of issues they identified as most salient.

4.9 Summary

These findings provide a starting point to building more person-centered models of care for inpatient palliative care. Translating the care priorities defined by patients and families into a series of feasible and actionable strategies and/or practice points will be critical to driving the policy reforms required at a national, organisational and local level, and enabling clinicians and managers to implement the practice points in each ward. Research to date suggests a fairly substantial level of reform is required to improve care and outcomes for inpatients and their families. Developing a framework for involving palliative care consumers in informing ongoing improvement work across the sector will be critical to ensuring this reform process remains aligned with patient and family priorities. Chapter 5 reports a mid-point meta-inference of data across Studies 1a, 1b and 2 in order to articulate the domains of care that are most important to inpatients and their families, and how these can be achieved in practice.

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Chapter 5 Phase 2: Understanding importance

Mid-point meta-inference: Studies 1a, 1b and 2 data

5.1 Chapter preface

The perspectives of inpatients with palliative care needs, and their families are key to developing strategies to optimise palliative care within Australia's diverse hospital settings. The systematic review and meta-synthesis, reported in Chapter 2, focused on the domains of care that are most important to inpatients and their families, as reported in the international literature. The mixed-methods design and approaches adopted by the OPAL Project were presented in Chapter 3, including the rationale for undertaking a mid-point meta-inference. Chapter 4 reported on the perspectives of Australian inpatients and their families, and explored what they considered to be the most important domains of inpatient palliative care (Study 2). This Chapter reports on the findings of the midpoint meta-inference, undertaken at the end of Phase 2.

5.2 Methods

5.2.1 Objective

To confirm the domains of care that are most important to Australian inpatients with palliative care needs and their families.

5.2.2 Design

A mid-point meta-inference, as detailed in Chapter 3. This meta-inference sought to: 1) verify Australian palliative care consumer and research leader perspectives in relation to data presentation; and 2) integrate the data from Studies 1a, 1b and 2. The integration is presented in a series of joint display tables, which assisted with generating the mid-point meta-inference (Appendix 11).[1, 2]

5.3 Findings

5.3.1 Part 1 - Workshop: verifying the data with palliative care consumers

The consumer representatives (n=6) who participated in the three-hour November 2019 workshop were provided with a summary of domains of importance (n=12) generated from the Study 1a, 1b and 2 patient data. Family data were not included at this initial stage, to prioritise the patient voice. The summary of the patient data included 12 patient-identified domains, which contained a total of 131 key points considered essential for enabling optimal inpatient palliative care (Appendix 12). Consumer representatives were asked to work individually with the 131 key points and allocate each one into the domain they felt they best aligned with, to verify the mapping completed by the research team. Results from this individual mapping revealed strong group consensus (100%) regarding four domains, majority group consensus (>50%) regarding 8 domains and minority group consensus (<50%) regarding four of the 12 domains (Table 5.1).

Table 5.1: Consumer agreement with coding to domains completed by research team

Inpatient identified domains of importance (N=12)	Number of key points in each domain	Degree of consumer agreement* on the key points (N=131)	Suggested alternative domains
1. Addressing nutritional needs	5	5/5 - **100%**	Not applicable
2. Comfort provided by easy access to medical and nursing specialists	2	2/2 - **100%**	Not applicable
3. Family involvement in care provision	4	4/4 - **100%**	Not applicable
4. Minimising burden	1	1/1 - **100%**	Not applicable
5. Adequate environment for care	13	12/13 - **92%**	Maintenance of patient safety
6. Maintenance of patient safety	5	4/5 - **80%**	Not applicable
7. Maintenance of sense of self	17	12/17 - **71%**	Expert care
8. Respectful and compassionate care	18	11/18 - **61%**	Effective communication and shared decision making; and Maintenance of sense of self / self-identity
9. Effective communication and shared decision making	22	11/22 - **50%**	Expert care; and Respectful and compassionate care
10. Expert care (good physical care, symptom management, integrated care and other)	35	17/35 - **49%**	Effective communication and shared decision making; Maintenance of sense of self / self-identity; Respectful and compassionate care; and Trust and confidence in clinicians
11. Financial affairs	4	1/4 - **25%**	Family involvement in care provision; other - not coded consistently
12. Trust and confidence in clinicians	5	1/5 - **20%**	Effective communication and shared decision making; and Respectful and compassionate care

**Consumer agreement with mapping completed by the research team*

The key points (n=131) articulating what patients stated enabled optimal care within each domain (n=12) were perceived to be comprehensive and a good overview of areas of importance. The degree to which participants verified the classification of key points into domains was variable, suggesting that further synthesis was needed to enhance clarity and reduce duplication. Group discussion revealed that the taxonomy of domains (n=12) was perceived to be unclear, with significant overlap in concepts, especially in relation to what key components of care informed effective communication, expert care, trust and confidence in clinicians, and what was understood to inform the financial affairs domain. Participants made a distinction between Person-centred care (encapsulating for example communication, compassion, respect) and Expert task-oriented clinical care, and felt this distinction was not reflected in the current domains. They recommended that Person-centred and Expert care ought to be two separate categories to reflect the type of care that is required for optimal inpatient palliative care provision. Based on this advice, the 12 domains and 131 key points were reviewed before undergoing further synthesis and consideration of the viability of adopting these recommended changes.

5.3.2 Post workshop data synthesis and consensus: verifying the data with palliative care research leaders

The consumer representative workshop outcomes reported above guided the next stage of the analysis. The suggested changes along with the 12 patient reported domains were initially reconsidered by the research team before being discussed with an international palliative care and research academic expert with measurement expertise (FM). During this three-hour meeting, held in November 2019, the team considered the domains of importance and their degree of alignment within the suggested new overarching categories of ‘Person-centred care’ and ‘Expert care’. The team also considered the synthesis and renaming of the domains to enhance clarity of meaning. Whilst consensus with the consumer-recommended changes was secured, the research team identified that the integrated data also highlighted the need to consider the environmental needs of inpatients with palliative care needs. At the end of this process were two outcomes: 1) three overarching categories were agreed to, namely: 1) Person-centred care; 2) Expert care; and 3) Optimal environment for care; and 2) synthesis and renaming of inpatient-described domains of importance for optimal palliative care, with a final set of 14 domains noted (Refer Figure 5.1).

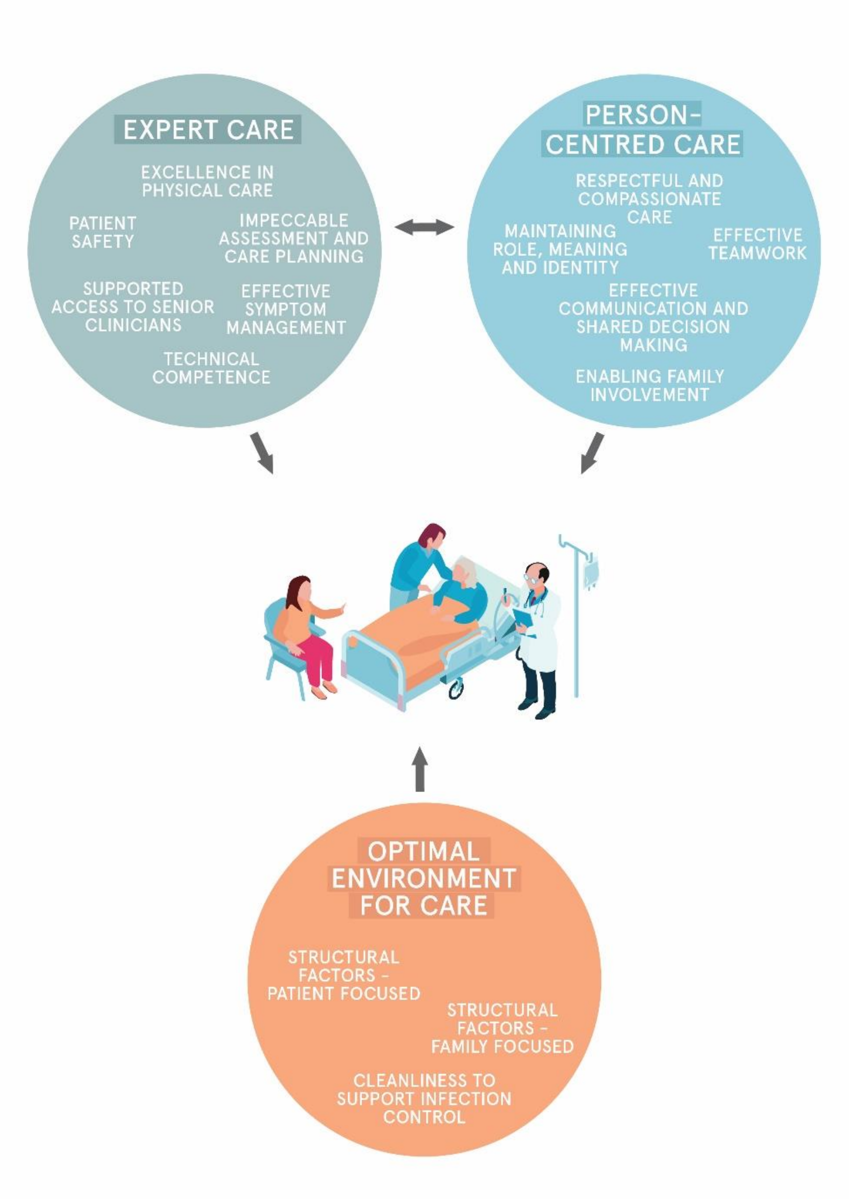

Figure 5.1: Categories (n=3) and domains (n=14) of importance for optimal inpatient palliative care

Having confirmed these three categories and their 14 related domains, the next stage of the mid-point meta-inference sought to: integrate all data inclusive of inpatient and family participants; and develop key practice points for potential use by hospital managers and clinicians to strengthen inpatient palliative care. This mid-point meta-inference was also designed to inform the third and final Phase of the OPAL Project, focused on opportunities to drive improvements and wider-systems reform.

5.3.3 Part 2 - Meta-inference outcomes

The first step of the mid-point meta-inference was to integrate all data inclusive of both patient and family-identified domains of importance from the systematic review and meta-synthesis (Studies 1a and 1b) and the qualitative study (Study 2), in a series of joint display tables (Appendix 11). Collectively, these data reflect the perceptions and desire for change over the past 30 years from a large number of inpatients (n=1233) and their families (n=3818) living in various high income countries, including Australia.[3-5] Integrating these data facilitated identification of 15 domains of importance, with an additional three domains evident from family data alone (Table 5.2). The integration of these three data sets (Studies 1a, 1b and 2) confirmed that 10 of the 15 domains were considered relevant to Australian inpatients and their families, but was unable to confirm the relevance of the other five domains (i.e. financial affairs; minimising burden; enabling patient choice at the end of life; nutrition; and access to senior clinicians). These unconfirmed domains warrant further investigation.

Table 5.2: Domains of importance for optimal inpatient palliative care derived from meta-inference of data from Studies 1a, 1b and 2

Domains of importance (n=15)	Identified within patient data (n=12)	Identified within family data (n=13)	Confirmed by Australian data
Effective communication and shared decision making	✓	✓	✓
Expert care	✓	✓	✓
Respectful and compassionate care	✓	✓	✓
Trust and confidence in clinicians	✓	✓	✓
Family involvement in care provision	✓	✓	✓
Adequate environment for care	✓	✓	✓
Financial affairs	✓	✓	X
Maintenance of sense of self / self-identity*	✓	X	✓
Minimising burden*	✓	X	X
Maintenance of patient safety and prevention of harm;	✓	✓	✓
Preparation for death*	X	✓	✓
Duty of care extending to the family after patient death*	X	✓	✓
Enabling patient choice at the end of life*	X	✓	X
Nutrition	✓	✓	X#
Access to senior clinicians	✓	✓	X#

*Domain unique to either patient or family data only; #Unconfirmed on meta-inference as these domains are new data from the Australian Study (Study 2) and warrant further investigation

The mid-point meta inference confirmed that:

- Person-centred care; Expert care; and Optimal environment for care (identified during the consumer representative and research leader verification process) were relevant and appropriate categories; and
- The newly described domains (n=14) reflected all patient and family data, with data alignment fitting well within each of the three categories (refer Figure 5.2).

This process also facilitated identification of key practice points (n=68) as illustrated in the joint display tables (Refer Appendix 11), and described in the next section.

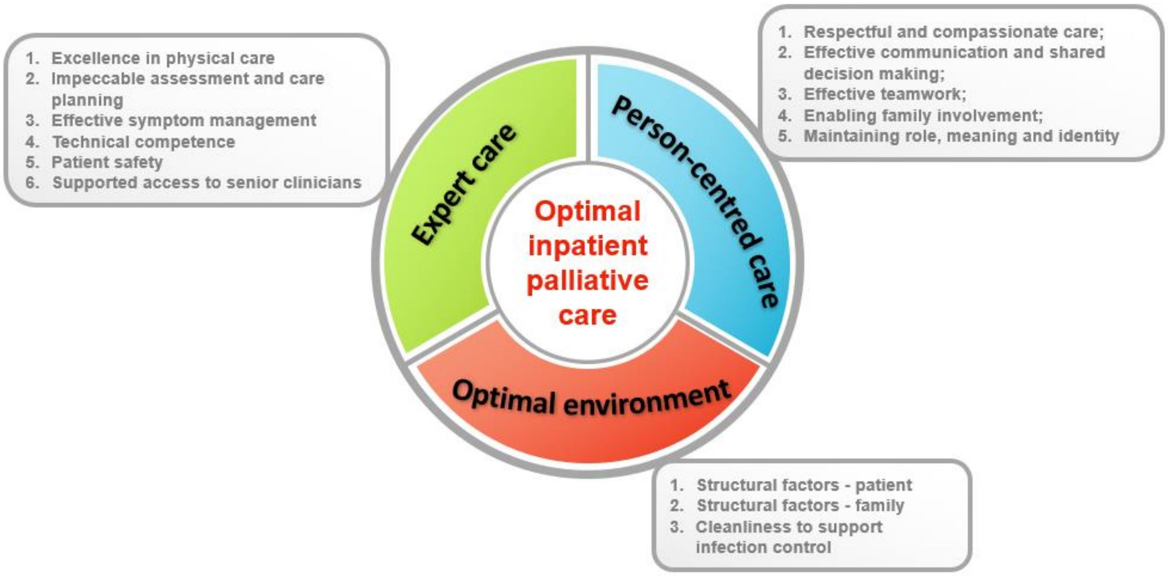

Figure 5.2: Key domains of importance for optimal inpatient palliative care from both patient and family perspectives

Person-centred care

The five domains identified as being important within the category of Person-centred care are: 1) respectful and compassionate care; 2) effective communication and shared decision making; 3) effective teamwork; 4) enabling family involvement; and 5) maintaining role, meaning and identity. The type of care provision that will enhance the person-centred care experience for inpatients and their families in each of these identified domains is described in the next section, along with a series of key practice points that are considered as being important to guide clinical practice, policy and research in each domain.

Respectful and compassionate care

Respectful and compassionate care for inpatients resonates with many areas noted as important for the non-palliative inpatient population, including the need for compassion, empathy, kindness, personalised care, clinicians being happy and willing, as well as clinicians who are knowledgeable, efficient and connected to the unique needs of each inpatient.[3] Additional requirements in relation to respectful and compassionate care for those with palliative care needs relate to care provision when someone is imminently dying, noting the importance of clinicians checking in with family members, even when there is no clinical task to be completed, and talking with patients about care provision even when unconscious or after death. Furthermore, consideration of the comforts provided from access to food and beverages is important, with kind and empathetic kitchen staff enabling the provision of good food, at the right temperature and, in line with preferences, supportive. Table 5.3 describes what patients and families consider enables the quality of care received in hospital to feel respectful and compassionate.

Table 5.3: What contributed to respectful and compassionate care: key practice points (n=11)

1. Clinicians who provide care in a compassionate, empathetic, personalised, kind, friendly, supportive and willing way, who are professional and appear happy to be at work
2. Clinicians who are honest, trustworthy, knowledgeable, able to anticipate needs, and confident, efficient, attentive, responsive and mindful in their care delivery
3. Clinicians who connected to their particular situation and circumstances, were unhurried, non-judgmental and acknowledged them as a unique human being
4. Preservation of dignity described in relation to physical care*, consideration of quality of life,* and through the tone of communication used (particularly noting the need for use of names and not terms such as 'darling'*, and not talking down to the patient or family member)*
5. Use of humour throughout an admission to assist a patient to cope and have a laugh
6. Feeling welcomed and deserving of a hospital admission, and where they may have experienced multiple admissions, to be acknowledged by clinicians and ancillary staff, assisting a feeling of homeliness
7. Kind and empathetic kitchen staff and diet aides who return to talk with patients about dietary choices if they are not available on their first visit (asleep, at a procedure, in the bathroom etc.)
8. Provision of good food at the right temperature, in line with preferences, that aides in wellbeing and a sense of comfort (E.g. a hot cup of tea or coffee in the morning) as well as timely assistance with accessing food items on the tray when unable to manage independently
9. *Gentleness and kindness from ancillary staff, particularly noting the impact of cleaners, catering staff and those working in hospital cafes*
10. Checking in with family members when their loved one is dying (prognosis of days only), even when there are no clinical tasks to be completed, to show kindness, support and care and to understand if they have any concerns at this time*
11. Talking with patients when unconscious and after death, in relation to their care provision*

Normal font = data from patients and families; Italics = data from family members only (current and bereaved); * data from bereaved family members and specific to the care in the last days of life and at the time of death.

Effective communication and shared decision making

Effective communication and shared decision making for inpatients also reflects the expressed needs of the non-palliative inpatient population,[3] noting the need for honest, mindful, informed and clear communication that enables a shared understanding and feels unpressured by time. However, those with palliative care needs also require clinicians to acknowledge and work with their expertise in relation to managing their own condition and they have also stated that it is important for difficult conversations to be led by a senior clinician. Furthermore, additional requirements when a person is imminently dying are noted including, the need for: clinicians to be explicit about the fact the patient may die within the next few days/a week, to enable important conversations and preparations as much as possible; and for clinicians to ask family members whether they are wanting explicit information about the physical changes that occur as a patient nears death (E.g. breathing and circulatory changes). The need for clinicians to support patient choices either through informal discussions or formal advance care planning processes is also noted as important. Of note, a recent study investigating the most common complaints for health professions in Australia found that a lack of effective and respectful communication ranked highly, and that this resonated with prior published work and highlighted the need for targeted professional development.[4] Table 5.4 describes what patients and families consider enables effective communication and shared decision making.

Table 5.4: What contributed to effective communication and shared decision making: key practice points (n=16)

1. Communication that is honest, clear, uses layman's language, *demonstrates understanding of the current situation* and is delivered in a compassionate, connected and mindful way *(including sitting at eye level, near to the person, and managing hearing impairments effectively)*
2. Communication that enables a shared understanding *and feels unpressured by time*
3. Communication that works with a patient's/ family's own knowledge and expertise about their condition
4. Listening to the patient *and family member* and using this information to guide clinical assessments and care planning, especially in relation to symptoms*, being mindful of the fact patients and family members might want to meet separately with clinicians at times*
5. Communication that maintains positivity and hope within the context of their illness
6. Communication that focuses on the bigger picture in relation to their care, not just the immediate day-to-day issues
7. Accurate documentation of communications held with patients, families and across teams and departments
8. *Difficult conversations should be led by a senior clinician and held directly with patients, as appropriate*
9. Acknowledgment and support for the requirements within cross-cultural communication to prevent misunderstanding and negativity across patient, family and clinician groups
10. Regular updates throughout an admission about the patient's current condition and plan of care
11. Consistent messages across teams and departments, with a lead clinician to pull complex information together *and a key contact who can address any noted concerns*
12. Clinicians that explain what is likely to happen with the patient's physical condition over time, to enable planning
13. When the patient is close to death, clinicians being explicit about the fact that the patient may die within the next few days/a week, to enable important conversations and preparations as much as possible*
14. When the patient is close to death, clinicians checking with family members about whether they are wanting explicit information about the physical changes that occur as a patient nears death (e.g., breathing and circulatory changes) *
15. Being engaged in care planning and supported in making decisions, in line with personal needs to be able to live as well as possible
16. *Discussion of patient choices with family members supported informally or more formally through advance care planning processes, advance care directives, and nomination of preferred decision makers*

Normal font = data from patients and families; Italics = data from family members only (current and bereaved); * data from bereaved family members and specific to the care in the last days of life and at the time of death.

Effective teamwork

Effective teamwork evidenced through care integration within teams and across departments resonated again with expressed need from the non-palliative inpatient population.[3, 5] The additional area described by families of those with palliative care needs was that of a greater need for effective integration with specialist palliative care services in relation to timing of consultation, how this service is described to family members and then how their advice is integrated into care planning. Table 5.5 describes what patients and families consider important in relation to effective teamwork.

Table 5.5: What contributed to effective teamwork: key practice points (n=5)

1. To see clinicians working together in relation to the patient's care, both within the ward environment and across different teams and/or departments, *and also with generalist care providers or lead clinicians from other hospitals*
2. To ensure complex care needs are accurately handed over in depth between shifts to enable good care and prevent continual repeating of needs by patients, *and where possible to roster the same nurse to a patient to support continuity in care*
3. To enable access to multidisciplinary expertise to help patients be as well as they can be, with specific noting of the need for increased access to physiotherapy support, *and a key clinician to support inpatients with dementia*
4. Efficient discharge planning and management with specific noting of timely provision of paperwork, accurate medication management, with this information also provided for the GP, physical supports such as a wheelchair and/or wardsperson to assist with getting to the car, *and integration with generalist care supports as required*
5. *Effective integration with specialist palliative care services in relation to when they are consulted, how their service is described to families (to enable understanding of their expertise and role) and how their advice is integrated into care planning*

Normal font = data from patients and families; Italics = data from family members only (current and bereaved);

Enabling family involvement

Enabling family involvement is valued to ensure inpatients' needs are understood, to advocate for optimal care and promote emotional wellbeing for inpatients with chronic and complex healthcare needs.[6-8] Patients specifically articulate the importance of family involvement to assist understanding of complex information whilst so unwell and potentially with affected cognition related to illness or medication provision. Families of people with palliative care needs also specifically noted wanting to connect with clinicians in a way that respects their knowledge, enabling them to feel part of the care team. They value a clear process for communicating with a senior member of the team able to make an impact on care planning and provision, as well as opportunities for family conferences to guide planning at complex points of care. Supportive care and processes at the time of an inpatient's death, such as respectful care of the body, adequate information provision, not being rushed from the ward and timely and accurate death certification are appreciated. Finally, a follow-up contact (call or email) by a clinician connected to their loved one's care to check in and provide information about options for counselling or other supports is valued. Table 5.6 describes what patients and families stated to be important in enabling family involvement.

Table 5.6: What enables family involvement: key practice points (n=9)

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1. Family inclusion *to advocate for optimal care and* help patients understand complex information provision, given they are so unwell and their cognition can be affected by illness and/or various medications
2. Family inclusion to provide comfort, emotional healing and ongoing sharing as part of a long-term partnership
3. Supportive hospital processes to enable family members to fully participate, including:
    - understanding the timing of medical ward rounds (to prevent having to sit all day waiting)
    - *supporting families to be part of the team, respecting their knowledge of their loved one's care needs (enhancing patient safety) and inviting them to participate in care if they are wanting to*
    - enabling access for visits at any time
    - comfort when staying overnight (to enable rest) *and consideration of the family member's wellbeing*
4. *A clear process for communicating with a senior member of the medical team, in charge of the care plan*
5. *Opportunity for a family conference to guide care planning at complex points of care*
6. Explicit information and guidance on admission about:
    - how to best manage parking costs
    - *availability of Wi-Fi*
    - *supported accommodation options for those who are from rural locations*
    - *access to carer's payments*
    - *access to subsidies for clinical equipment required for transition home (E.g. Incontinence pads)*
7. Supportive care and processes at the time of an inpatient's death (respectful care of the body; not feeling rushed; timely and accurate death certification completion) *
8. Supportive information provision (verbal and written) about processes of care after death (death certification, removal of body) *
9. A follow-up contact (call or email), conducted in a compassionate and kind manner, by a clinician connected to their loved one's care to check in with the family and provide information about options for counselling or other supports (with routine bereavement letters from a separate service noted to be less supportive and feeling somewhat tokenistic)*

Normal font = data from patients and families; Italics = data from family members only (current and bereaved); * data from bereaved family members and specific to the care in the last days of life and at the time of death.

Maintaining role, meaning and identity

Maintaining role, meaning and identity is articulated as important by inpatients. Across multiple studies and for over two decades, patients have noted this as important for the hospital setting, but families have not mentioned this at all - the only domain of importance where this is the case. Inpatients want to be supported to live as well as they can, within the context of their illness, to isolate their illness as much as possible and to engage in meaningful activities on a day-to-day basis. They also emphasise their need to retain a sense of control and to avoid becoming institutionalised whilst an inpatient. The need to connect with each patient and value their individuality is well noted in policy and research across healthcare;[3, 9, 10] however, this need is accentuated for people with palliative care needs, where the notion of maintaining one's role and identity is considered especially important in the context of declining health and functioning. Table 5.7 describes what patients stated they wanted to support their sense of role, meaning and identity.

Table 5.7: What enables the maintenance of role, meaning and identity: key practice points (n=3)

1. To be supported and encouraged to maintain independence and live as well as possible, within the context of life limiting illness, minimising feelings of being powerless and burdensome#
2. To isolate their illness from life and engage in meaningful activity on a day-to-day basis to assist in wellbeing, even whilst in hospital, suggesting the following would assist in this: access to reading materials (papers/magazines) or puzzles/games, access to information about what is available across the hospital and encouragement for inpatients to get out of bed and engage in an activity#
3. To feel a sense of control and avoid becoming institutionalised noting the importance of access to technology to support social connections, beauty treatments for those who require it (waxing and hair for example) # and the need to maintain a focus on work where able

data from patients only; normal font = data from patients and families

Expert care

The Expert care category for inpatients includes six domains of importance: excellence in physical care; impeccable assessment and care planning; effective symptom management; technical competence; patient safety; and supported access to senior clinicians. Aspects of care provision that enhance care experience are noted below in relation to each identified domain, followed by the key practice points to guide clinical practice, policy and research.

Excellence in physical care

Excellence in physical care, with specific attention to the maintenance of personal hygiene, responsive attention and care provided in a compassionate, empathetic and willing way is important. In addition to this, attention to a patient's nutrition is important for this population who noted their need to access a diet that enhances wellbeing, maintains weight and assists management of chronic conditions. Table 5.8 describes what patients and families stated to be important in relation to physical care.

Table 5.8: What enables excellence in physical care: key practice points (n=2)

1. Excellence in physical care that is responsive and provided in a compassionate, empathetic and willing way
2. Attention to the inpatient's nutrition to maintain weight throughout an admission and assist in management of chronic conditions (E.g. diabetes) and overall recovery/wellbeing

Normal font = data from patients and families;

Impeccable assessment and care planning

Impeccable assessment and care planning, highlighting the need for clinical teams to pay attention to a person's holistic health care needs, inclusive of their physical, social, emotional and spiritual wellbeing, are vital. In addition, inpatients with palliative care needs want clinicians to be knowledgeable about specific health care needs within the context of broader health issues, enabling an accurate assessment of the current situation and related care requirements to achieve a good clinical outcome. That is, inpatients and their families seek care that is not purely focused on one component of care or one organ system only. Finally, families articulated the importance of identifying when an inpatient is in their last days of life and ensuring their comfort. Table 5.9 describes what patients and families stated to be important in relation to assessment and care planning.

Table 5.9: What enables impeccable assessment and care planning: key practice points (n=3)

1. That the clinician is knowledgeable about their specific health care needs *within the context of their broader health* issues, enabling them to accurately assess the current situation and related care requirements to achieve a good clinical outcome
2. That the clinical team pays attention to a person's holistic health care needs, inclusive of their physical, social, emotional and spiritual wellbeing
3. Identification of when a patient is in their last days of life and ensuring their comfort *

Normal font = data from patients and families; Italics = data from family members only (current and bereaved); * data from bereaved family members and specific to the care in the last days of life and at the time of death;

Effective symptom management

Effective symptom management, including the need for regular assessment and rapid management (pharmacological and non-pharmacological) of any symptoms causing discomfort or distress, especially in relation to pain and breathlessness, is important. Responsive attention to symptom distress was highlighted and families specifically noted the need for rapid management of distress for an imminently dying person, with medication orders available for nurses to act immediately. Table 5.10 describes what patients and families stated to be important in relation to symptom management.

Table 5.10: What enables effective symptom management: key practice points (n=2)

1. Regular assessment and rapid management (pharmacological and non-pharmacological) of any symptoms causing discomfort or distress, especially in relation to pain and breathlessness
2. Responsive attention to any forms of distress identified for a patient who is imminently dying, with medication orders available for nurses to act immediately (not have to wait for medical review) *

Normal font = data from patients and families; * data from bereaved family members and specific to the care in the last days of life and at the time of death;

Technical competence

Technical competence in relation to specific procedures such as cannulation and pleural effusion drainage is valued. Distress was caused by multiple cannulation attempts. In addition, the need to proactively discuss and appropriately deactivate an implanted cardiac device for an imminently dying person is important from the perspective of families. Table 5.11 describes what patients and families stated to be important in relation to technical competence.

Table 5.11: What is important in relation to technical competence: key practice points (n=2)

1. That their clinician is an expert in procedures such as cannulation (insertion and care) or management of a pleural effusion
2. Ability to discuss and appropriately deactivate an implanted cardiac device in a timely way *

Normal font = data from patients and families; * data from bereaved family members and specific to the care in the last days of life and at the time of death;

Patient safety

Patient safety with respect to care being well-managed without the need for continual oversight by the patients themselves, given the unwell status of this population, is important. Medication management was also discussed as an area of critical importance and of great concern for patients and families alike in relation to accuracy in medication prescription and administration. Table 5.12 describes what patients and families stated to be important in relation to patient safety.

Table 5.12: What enables patient safety: key practice points (n=2)

1. To feel their care is safe and well-managed without them needing to continually have oversight of the care given the patient is so unwell
2. Accuracy in medication prescription and administration, with particular noting of translation of complex medication regimes in the home setting to the hospital setting (and vice versa), *accuracy in timing of administration* and managing an error in the computer system once entered

Normal font = data from patients and families; Italics = data from family members only (current and bereaved)

Supported access to senior clinicians

Supported access to senior clinicians with high levels of expertise to enable prompt attention to noted concerns, answers to questions, time for support and planning, comfort in relation to ongoing support on discharge home and continuity of care is valued and supportive. Table 5.13 describes what patients and families stated to be important in relation to access to senior clinicians.

Table 5.13: What do patients and families state to be important in relation to access to senior clinicians: key practice point (n=1)

1. Access to senior medical and nursing clinicians with high levels of expertise (email / mobile phone numbers) enabling prompt attention to any noted concerns, answers to questions, time for support and planning, comfort in relation to ongoing support on discharge home and continuity of care

Normal font = data from patients and families

Optimal environment for care

Environmental factors also impact on inpatient and family experience of palliative care and feelings of wellbeing,[11] hence being represented as a third category of importance for optimal care. This category includes three domains of importance: patient focused structural factors; family focused structural factors; and cleanliness to support infection control. For inpatients, an optimal environment aligns with many of the person-centred design principles recommended for hospital environments, including: the built environment takes a holistic approach to health and wellbeing; the built environment is welcoming and feels safe; spaces are designed to facilitate patient and family engagement; design of spaces promotes partnership and equality between patients and care teams; physical barriers are minimised to promote communication; and the environment empowers patients and feels like ‘their own’.[5] Aspects of the inpatient environment that enhance care experience for people with palliative care needs, are noted below in relation to each identified domain, followed by the key practice points to guide clinical practice, policy and research.

Patient focused structural factors

Specific attention to providing a restful environment is desired, inclusive of minimal noise, soft lighting and comfortable temperatures. Access to a window is important to enable a connection to the day/night cycle. It also enables inpatients to feel connected to the world, feel warmth from sunlight, and helps to prevent feeling claustrophobic. The preference for a shared or private room varied, suggesting that each inpatient, where possible, ought to be provided with choice. This discussion would be helpful even if choice is not available, as understanding the key concerns for either option could enable clinicians to tailor care accordingly – for example, where someone is particularly concerned by smells, use of an odour neutraliser in the room could be helpful. Discomfort with the use of mixed gender wards was a frequent concern for both inpatients and their families, who felt vulnerable and questioned the appropriateness of such a policy. Preventing frequent bed changes is important for inpatients who try to develop a sense of belonging to their bed area. People living with breathlessness spoke of their need for greater environmental supports for their symptom control, such as the provision of fans, cooling air and adequate ventilation in bathrooms specifically. Patients also spoke of practical supports that enhanced their care experience, such as the provision of a bed whilst waiting in the Emergency Department, given how unwell they are, and the opportunity to access emergency supplies of toiletries if needed. Table 5.14 describes what patients and families stated to be important in relation to the inpatient environment.

Table 5.14: What do patients and families state as important in relation to the inpatient’s structural environment in the hospital: key practice points (n=7)

1. That the bed area is restful to enable sleep and recovery, including the need for quiet, appropriate lighting and temperature$^{\#}$
2. Access to a window to enable a connection to the day/night cycle, to feel connected to the world, to feel warmth from sunlight and to prevent feeling claustrophobic
3. Prevention of frequent bed changes, as patients try to develop a sense of belonging within their space and feel disorientated when moved regularly (the loss of personal items when moved was also noted) $^{\#}$
4. To consider comfort when waiting in the emergency department, through the provision of a bed to wait in (rather than a chair only), given they are so unwell
5. To consider practical supports such as emergency access to toiletries for unplanned admissions, and more practical audio-visual controls for the TV (not to be handheld if possible) $^{\#}$
6. Consideration of supports for people with breathlessness, including the provision of fans, cooling air and adequate ventilation in bathrooms specifically to assist with showering$^{\#}$
7. To consider the implications of a shared room, with positives noted in relation to the company and helpfulness of fellow patients but challenges noted in relation to being disturbed by noise, having to tolerate different smells/odours, feeling quite confronted by other people’s illnesses, *discomfort with mixed gender wards and lack of privacy for both care and important conversations*

Normal font = data from patients and families; Italics = data from family members only (current and bereaved); $^{\#}$ data from patients only

Family focused structural factors

The provision of simple comforts, such as seating for family members and preferably a place to lie down at night, alongside the patient’s bed, was important to ensure rest and wellbeing whilst providing care on a day-to-day basis. Families described how supporting people with palliative care needs can be exhausting, and the profound benefits comfortable sleep provides. In addition, simple kitchen items (water, ice, microwave) are helpful to enable family members to provide care for their loved one, as well as food and drinks for themselves. Dedicated space to enable private conversations, a break from caring or for quality family time away from the bed-space (inclusive of the inpatient) were also highlighted as supportive. In addition, access to affordable meals onsite was said to be important, with the suggestion that subsidised hospital cafeteria food be made accessible for families. Finally, bereaved family members noted the fact a private room is essential for someone who is very close to dying to enable privacy for meaningful conversations and quality time. Table 5.15 describes what families stated supported their stays and time in the hospital.

Table 5.15: What do families state as important in relation to the structural environment in the hospital in order to facilitate their support: key practice points (n=4)

1. *Access to seating and preferably a place to lie at night, alongside the patient's bed, as well as simple kitchen items (water, ice, microwave)*
2. *A dedicated space or room to enable private conversations to be held, a break from caring or for quality family time away from the bed-space (inclusive of the patient)*
3. *Access to affordable meals onsite (a suggestion of subsidised hospital cafeteria access for this population)*
4. A private room for someone who is very close to dying to enable privacy for meaningful conversations and space for families to be present *

Italics = data from family members only (current and bereaved); * data from bereaved family members and specific to the care in the last days of life and at the time of death

Cleanliness to support infection control

Cleanliness to support infection control was emphasised as important, specifically in relation to feeling safe in the bed and ward area. Patients especially described their need to limit exposure to infections if they are immunosuppressed. Table 5.16 describes what patients and families stated as important in relation to hospital cleanliness.

Table 5.16: What do patients and families state as important in relation to cleanliness in the hospital: key practice point (n=1)

1. Cleanliness, specifically in relation to infection control and managing the unique requirements of those who are immunosuppressed, in a timely and efficient way

Normal font = data from patients and families

5.4 Discussion

This mid-point meta-inference has confirmed three categories of care that, when considered from the perspectives of inpatients and their families, would ensure optimal palliative care within Australian hospital settings, namely 'Person-centred care'; 'Expert care'; and 'Optimal environment for care'. The meta-inferences have revealed specific domains (n=14) and practice points (n=68) that when implemented would potentially strengthen and improve inpatient palliative care delivery. To be effective, all of the categories and domains will need to be considered in their entirety. That is, a focus on excellence in physical care alone will not enable optimal inpatient palliative care. The meta-inference described in this Chapter is reflective of the views of a large cohort of inpatients living in high income countries and is a robust contribution from which to move forward in informing practice evaluation and subsequent improvement.

Given the studies included in the systematic review and meta-synthesis (Studies 1a and 1b) were published up until April 2015,[12, 13] an updated search was completed in February 2020, with three additional studies identifed.[11, 14, 15] These three studies confirmed data already outlined within the mid-point meta-inference. However, there was one additional component for consideration from a more recent New Zealand study[14] centering on the need to consider ‘traditions and culture’. This emphasis is consistent with New Zealand’s bicultural society and reflected in its national policy and practices. The participants of most included studies are predominately White Europeans, Americans, Canadians and Australians, suggesting that culture other than Anglo-Celtic may be a neglected factor.

There is considerable evidence outlining that person-centred care contributes to improved outcomes and experiences for both inpatients and their families.[5, 9, 16-18] While the OPAL Project has identified that ‘Person-centred care’ and ‘Expert care’ are two separate but important categories of care, this distinction is at odds with traditional person-centred frameworks, which tend to encompass both clinical competence and technical skills.[5, 9, 16, 18-21] While *The Person-centred Practice Framework,*[22] notes professional competence as a prerequisite to enable person-centred outcomes, it does not give it the emphasis that palliative care consumers believe good care demands. This change in thinking is also consistent with a recent review of the key attributes of high-performing person-centred healthcare organisations undertaken by the Australian Commission on Safety and Quality in Health Care, which identified the two key influencers on experience of care were the way a person is treated as a person and the way they are treated for their condition.[5] This distinction speaks to the importance of differentiating between the person and the technical capabilities of the clinician and confirms the consumer representative argument presented in the OPAL Project.

Importantly, there is considerable cross-over in relation to what is important to the non-palliative inpatient population in relation to person-centred care[3, 5, 9, 16, 19, 20] and what is important for those with palliative care needs. The need for respect, compassion, effective communication, shared decision making, holistic care, engagement and coordinated care is well stated across both populations.[3, 12, 13, 23] Maintaining role, meaning and identity is not specifically discussed within the broader discourse about person-centred care,[3, 5, 9, 19] but it is noted within literature focused on working with older people.[20] This suggests that maintaining role, meaning and identity may be of specific importance to people living with life-limiting illnesses. Important areas of care articulated by inpatients with palliative care needs that are not evident in current person-centred care discourse include enabling family involvement, valuing of time with senior clinicians and the importance of food and nutrition. Furthermore, there are specific requirements that are supportive for people who are imminently dying, and their families, that are not evident in the broader person-centred care literature.[3] These include the care and communication required when a person is close to dying and immediately following their death. Understanding such distinctions is important when considering evidence to inform indicators of quality that may be accessible from non-palliative inpatient population data, to drive reform. That is, there may well be data currently available to inform aspects of care noted to be important across all inpatients (palliative and non-palliative), such as respectful care, compassionate care and/or effective communication. However, consideration ought to be given to areas noted to be important specifically to those with palliative care needs (e.g. enabling family involvement, food and nutrition, and access to senior clinicians). A different process is also likely to be needed to obtain data from people who have recently experienced a death in hospital of a close family member.

Given the busy hospital environments caring for diverse populations, the number and frequency of indicators used for quality assurance processes is critical. Therefore, driving improvements in inpatient palliative care will benefit from a review of possible use of: existing data sources;[24] prioritisation of tools that assess patient-identified areas of importance;[25] tools that can be implemented into routine clinical practice[26, 27] and which preference patient-reported outcome and experience data.[27-29] The insights generated by this meta-inference can be used to inform and influence the use of current data and available indicators with the most potential of informing improvements, as well as identifying where new indicators are required.

5.5 Summary

The mid-point meta-inference in the OPAL Project has identified and confirmed three categories of care that enable optimal inpatient palliative care, namely: 1) Person-centred care; 2) Expert care and 3) Optimal environment for care. Within these three overarching categories are 14 domains of importance for inpatients with palliative care needs and their families. Many components within each domain are also likely to be important for other inpatient populations. However, there are some unique requirements for inpatients with palliative care needs that warrant careful consideration, particularly in relation to the inpatient who is imminently dying. In relation to the imminently dying patient, families want: their dying to be identified and explicitly communicated; their symptoms or related distress to be identified and responded to in a timely manner; to be allocated a private room; to ensure access to supportive care at the time of their death, and bereavement follow-up.

The OPAL Project's mid-point meta-inference provides a clear set of practice points aligned to each domain and category to inform optimal inpatient palliative care. Understanding how to drive reform to enable this care, within the busy and varied environments of Australian hospitals caring for diverse populations across metropolitan and rural contexts, is an important next step. The next Chapter reports on the final two Studies conducted within the OPAL Project. Study 3 reports on an environmental scan of global quality indicators and policies used to drive improvements in palliative care provision. Study 4 reports on a co-design process configured to enable key stakeholders to generate a series of actions to strengthen Australian inpatient palliative care.

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Chapter 6 Phase 3: Driving reform

6.1 Chapter preface

Phase 1 of the OPAL Project identified the need to: develop a deeper understanding of the domains noted to be important for optimal inpatient palliative care; and how this information could assist clinical practice. During Phase 2 a qualitative study sought the perspectives of Australian inpatients to explore what they considered to be the most important domains of inpatient palliative care and how these impacted on care provision (Chapter 4). The mid-point meta-inference (Chapter 5) confirmed three categories of care that enable optimal inpatient palliative care, namely: 1) Person-centred care 2) Expert care and 3) Optimal environment for care. It also facilitated the identification of the key domains within each of these categories and identified the key practice points required to deliver on these areas of importance. This Chapter reports the two Phase 3 studies (Studies 3 and 4) undertaken to understand the feasibility and acceptability of the identified practice points, the strategies required to drive their implementation, and how in doing so they can inform optimal inpatient palliative care.

6.2 Study 3: National quality indicators and policies from 15 countries leading in adult palliative care: a systematic environmental scan

6.2.1 Publication reference

This environmental scan was published in 2018 in *BMJ Supportive and Palliative Care,* a peer reviewed journal, with an impact factor of 3.208, focused on connecting disciplines and specialties across the globe with high quality and clinically relevant research related to supportive and palliative care. This Chapter provides a lightly edited version of this published systematic environmental scan.

> **Virdun, C.,** Luckett, T., Lorenz, K. A., & Phillips, J. (2018). National quality indicators and policies from 15 countries leading in adult end-of-life care: a systematic environmental scan. *BMJ Supportive & Palliative Care*, 8(2), 145-154.

6.2.2 Overview

The importance of measuring the quality of palliative care is well established and central to informing better clinical care, research, policy reform and service commissioning.[1-5] For over two decades, there have been recommendations to measure the quality of palliative care through clinically meaningful standards,[5] indicators and data collection tools.[6] These terms have sometimes been used interchangeably, but in this Chapter the following definitions apply:

- ‘standard’ is an agreed and preferably evidence-based process that should be undertaken or outcome to be achieved for a defined circumstance, symptom, sign or diagnosis;[7]
- ‘indicator’ is a measurable statement ‘*with explicit criteria for inclusion, exclusion, time frame and setting’*;[7](p79) and
- ‘tool’ is a method and/or instrument used to gather data to inform a quality indicator and standard;[7, 8] and
- ‘measure’ is used only as a verb to avoid ambiguity.

Progressing measurement of palliative care quality would benefit from: collation, analysis and adaptation of current indicators for use across different societies and health systems, cultures, care settings and diagnoses;[2, 3, 9, 10] development of indicators where gaps exist; [2, 3, 11] decreased variation in indicators to enable greater comparative and collaborative opportunities;[3, 9] and that indicators used align with areas noted to be most important to inpatients and their families.[8] Given palliative care complexity, there is a need for suites of indicators that reflect multiple domains of care[1, 2, 5] as well as measuring structures, process and outcomes to elucidate the relationship between these.[10, 11] Attention to measurement feasibility for inpatient palliative care is important, with due consideration of both data informing what matters most for people with palliative care needs and burden of collection within busy and varied ward settings.[8]

An international review of quality indicators for palliative care was published in 2013 and concluded that the large number of indicators developed over the preceding years had been subject to limitations in quality and capacity for clinical implementation.[10] The OPAL Project’s Study 3 went beyond this work by examining each included country’s national supporting policies.[10] Better understanding how countries are undertaking national quality measurement of palliative care to drive improvements and commissioning of new services is critical to improving care experiences for people with palliative care needs, inclusive of inpatient care.

6.2.3 Objective

To identify and describe national quality indicators and supporting policies used by countries leading in their provision of quality palliative care.

6.2.4 Methods

The systematic environmental scan methods have been described in Chapter 4. This study included a systematic web search and semi-structured interviews with key stakeholders to identify indicators available for use globally to measure the quality of palliative care provision, as well as relevant policy and/or strategic frameworks to support their implementation.

6.2.5 Findings

Systematic web search

Seven Google searches, generated 10 items per webpage across 10 webpages per search, resulting in a review of 700 items, with 99 items meeting the inclusion criteria, including:

- 28 peer reviewed manuscripts;
- 40 policy / report documents from: United Kingdom - UK (n=15 – includes UK n=11, England n=2, Scotland n=2), Australia (n=14), US (n=6), Ireland (n=3), Canada (n=1), Global (n=1); and
- 31 webpages – US (n=16), Australia (n=7), UK (n=6), Canada (n=2) – resulting in an additional 89 documents downloaded for review.

Handsearching generated another 68 documents for inclusion. Targeted searches of the 15 countries participating in this Study led to an additional 49 documents for review, a total of 274 documents included overall (Refer Figure 6.1).

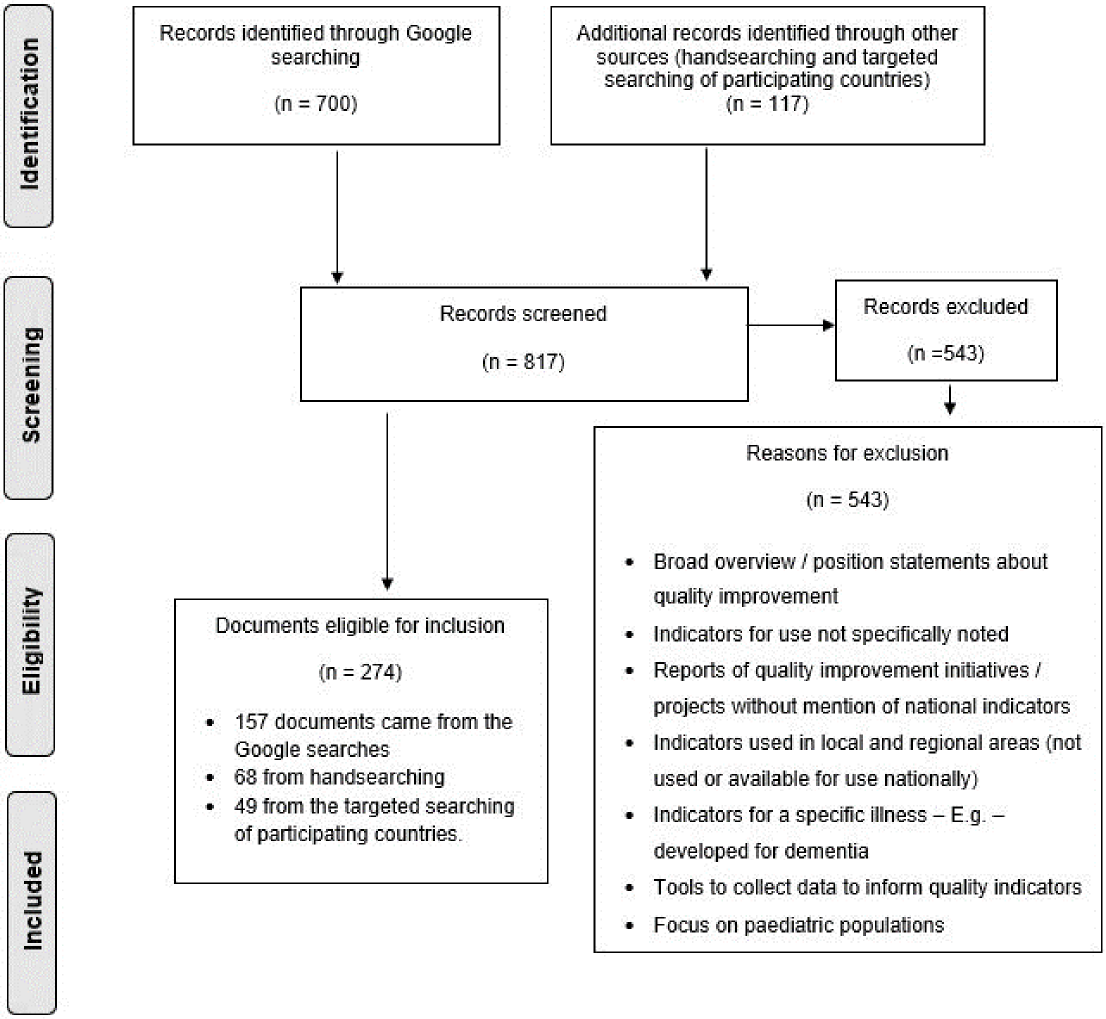


Figure 6.1: Data sourcing, screening and inclusion

Semi-structured interviews with experts

Of the 39 experts identified from the 15 included countries, 18 responded (46% response rate) with an additional 46 nominees contacted, with 27 providing additional data (59% response rate). Comprehensive responses were obtained for all 15 countries. Verified summaries for each participating country providing an overview of national approaches to quality measurement of palliative care (including indicator availability, enablers to their implementation, policy and standard frameworks and contributing expert details) are presented in Appendix 13.

National approaches to quality measurement of palliative care across 15 countries

Two thirds (n=10, 66%) of participating countries have current national policy supporting the use of quality indicators to measure palliative care (Table 6.1). These policies vary considerably. Policies from New Zealand (NZ) and Singapore focus predominantly on specialist palliative care provision. England, Australia, NZ and Singapore have national standards for palliative care. Sweden, Australia, Belgium, The Netherlands and the US each have indicator sets available for national palliative care measurement. While the Australian and Belgian indicator sets are for specialist palliative care services, the Swedish indicators are for generalist care services and the Dutch and US sets are applicable for use by all services. Involvement of consumers in the development of indicators is rarely, if at all, described by those countries with indicator sets.

None of the included countries mandated the implementation of their national quality indicators, with all relying on policy guidance to spur measurement of the quality of palliative care. In 8 (53%) of the 15 included countries, policy guidance has not led to indicator development. Australia is the only country with a: national policy supporting measurement of quality palliative care; national standards for optimal palliative care; and a national indicator set available for use. However, these 20 indicators do not directly map to all 13 Australian palliative care standards[12] and are only applicable to specialist palliative care services.

Table 6.1: Availability of national policies, standards and/or indicators to ensure quality palliative care across 15 countries

'Index'[13] ranking/ Country	National policy supporting use of quality indicators for palliative care	National standards available for quality palliative care	National palliative care quality indicators available for use by specialist palliative care providers	National palliative care quality indicators available for use by generalist care providers	Use of quality indicators for palliative care mandatory for specialist palliative care providers	Use of quality indicators for palliative care mandatory for generalist care providers
1. United Kingdom: **England**	✓	✓ *	X	X	X	X (Hospital accreditation notes palliative care)
1. United Kingdom: **Scotland**	✓	X *	X	X (under review)	X	X
1. United Kingdom: **Wales**	✓	X *	X	X	X	X
1. United Kingdom: **Northern Ireland**	✓	X *	X	X	X	X
2. Sweden	✓	X *	X	✓	X	X
3. Australia	✓	✓	✓	X	X	X
4. New Zealand	✓ (focused on specialist palliative care)	✓	X	X	X	X

Table continued... 'Index'[13] ranking/ Country	National policy supporting use of quality indicators for palliative care	National standards available for quality palliative care	National palliative care quality indicators available for use by specialist palliative care providers	National palliative care quality indicators available for use by generalist care providers	Use of quality indicators for palliative care mandatory for specialist palliative care providers	Use of quality indicators for palliative care mandatory for generalist care providers
5. France	X	X *	X	X	X	X (Hospital accreditation notes palliative care)
6. Canada	✓	X *	X	X	X	X
7. Belgium	X	X *	✓	X	X	X
8. Netherlands	X	X *	✓	✓	X	X
8. Singapore	✓ (focused on specialist palliative care)	✓ **	X	X	X	X (Hospital accreditation notes palliative care)
8. Switzerland	✓ (expired)	X *	X	X	X	X
8. Taiwan	X	X	X	X	X	X
8. United States	X	X *	✓	✓	X (Some payment incentives linked to indicator use)	X (Some payment incentives linked to indicator use)
Totals	**10/15**	**4/15**	**4/15**	**3/15**	**0/15**	**0/15**

* National guidelines for quality palliative care available; **Singapore's standards are called 'guidelines' but written in a very similar way to standards from Australia and New Zealand and therefore have been classified as standards for this Study. To see referencing for each policy informing the above table, please refer to Appendix 14.

Enablers and barriers to implementing national palliative care quality indicators

Significant work is under way to strengthen the measurement of quality palliative care provision globally (Appendix 13). A narrative synthesis of the country specific summaries articulated four key enablers for development and implementation of national palliative quality indicators identified, namely:

1. National project / program work (Australia, Belgium and The Netherlands);
2. Use of mandatory accreditation frameworks (England, France, Australia and Singapore);
3. Availability of a national palliative care data registry (Sweden); and
4. Incentivising quality indicator use (US).

Three main barriers were identified by experts that prevent quality measurement of palliative care, including:

1. Lack of a national data collection system focused on quality of palliative care (England);
2. Legal and regulatory constraints in relation to data access (England); and
3. Policy frameworks that focus on availability, access and activity, rather than a more holistic understanding of quality palliative care (England and France).

However, these results are presented with caution as articulation of barriers and enablers was not an explicit question asked of the experts. Therefore, the above is reflective of data that emerged unprompted within semi-structured interviews only.

An overview and analysis of nationally available palliative care indicators

There are 128 indicators identified from five countries: The Netherlands (n=43), Belgium (n=31), US (n=25), Australia (n=20) and Sweden (n=9) (Appendix 15). The majority (62%, n=79) are outcome indicators, with the remaining (38%, n=49) classified as process indicators. No structural indicators were identified (Figure 6.2).

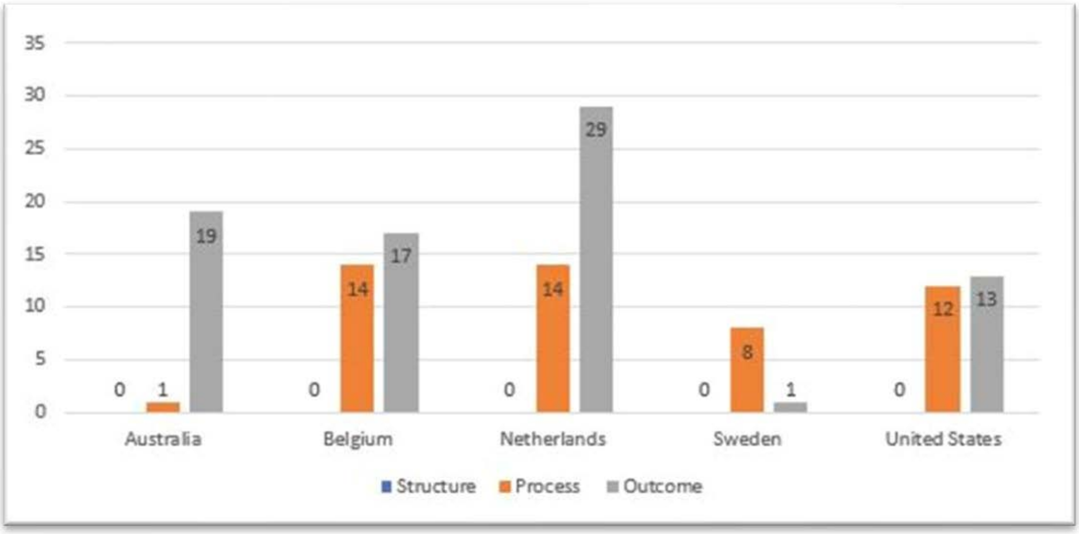


Figure 6.2: Available indicators mapped to indicator 'type' – Structure, process or outcome

The majority of indicators, when mapped to the 'US Guidelines' domains,[14] refer to physical care (n=48, 38%), social care (n=41, 32%) or processes of care delivery (n=35, 27%). There is a smaller number of indicators measuring psychological (n=21, 16%), spiritual / religious care (n=21, 16%) or the quality of care throughout the dying process (n=17, 13%). Few indicators measure cultural (n=9, 7%) or ethical and legal aspects of care (n=9, 7%). Belgium and the Netherlands are the only countries with a set of indicators that map to all domains. Physical aspects of care are the major focus for Australia (n=15, 75%) and Sweden (n=6, 67%). Cultural aspects of care are never explicitly referred to, with indicators mapped to this domain measuring either quality of life, how a patient or family member was feeling, degree of preparedness for saying goodbye and perceptions of the quality of death.

Mapping the 128 national indicators (Appendix 16) to the 2013 systematic review of quality palliative care indicators,[10] found: 32 (18%) were listed, considerable overlap in indicator availability (e.g., multiple indicators measuring aspects of pain screening, assessment and/or management), with 'similar' indicators used on 73 occasions. There are 390 distinct quality indicators listed across the systematic review[10] and this Study. Three of the five participating countries with national indicators sets (Australia, The Netherlands and US) were within the published review's indicator set.[10] Appendix 16 provides an overview of this mapping work, including visibility of all such indicators.

The descriptive summation of the 128 national indicators reveals: 36 key measurement domains; 13 occasions where a single country is measuring a key area in isolation (e.g. nausea measured by Australia and pressure ulcers measured by Sweden); and 23 occasions where two or more countries are measuring the same key area using different indicators. There are 37 indicators measuring symptom management with 15 specifically for pain (inclusive of screening, assessment and / or management). There are 9 indicators for psychological / spiritual / religious aspects of care and 8 measuring information provision to the patient. There are 11 occasions where the indicators measure multiple components of care and could not be mapped to one domain. Figure 6.3 provides an overview of the mapping of indicators to key domains, Table 6.2 notes the mapping in line with each participating country and Appendix 15 at each indicator level. All five countries with national indicators for measuring the quality of palliative care have indicators relating to general symptom management and pain. No other key area is measured by all five participating countries. All available indicators have relevance to inpatient palliative care.

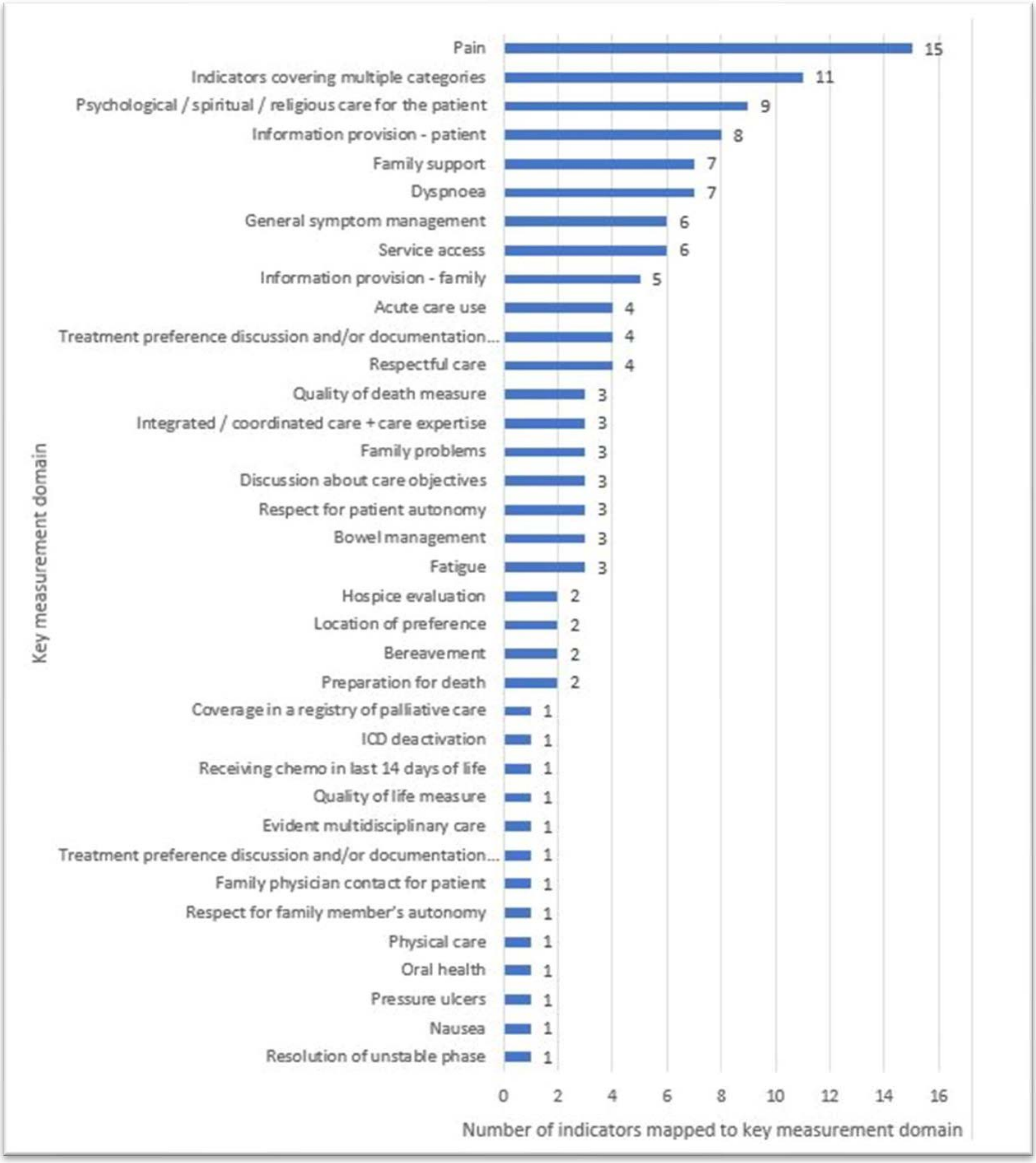


Figure 6.3: Key measurement domains of the indicators (n=128 – Appendix 15) used by participating countries

Table 6.2: Number and type of indicators available for national use to measure quality of palliative care listed by country of origin, mapped to the 'US Guidelines' domains[14] and key measurement domains

Indicators available by participating country	Type of Indicator	Domains*: 'US Guidelines'[14]	Key domains of measurement
Australia – 20 indicators for use by specialist palliative care providers	1 Process 19 Outcome	Domains 1, 2, 3, 4 and 5	General symptom management; Pain; Fatigue; Dyspnoea; Nausea; Bowel management; Psychological / spiritual / religious care for the patient; Family problems; Service access; Resolution of unstable phase.
Belgium – 31 indicators available for specialist palliative care providers	14 Process 17 Outcome	Domains 1 – 8	General symptom management; Pain; Dyspnoea; Quality of life measure; Respect for patient autonomy; Information provision – patient; Information provision – family; Family support; Evident MDT care; Treatment preference discussion and/or documentation – patients; Treatment preference discussion and/or documentation – families; Discussion about care objectives; Family physician contact for patient; Quality of death measure; Service access; Acute care use; Indicators covering multiple categories.
Netherlands – 43 indicators available for generalist and specialist palliative care providers	14 Process 29 Outcome	Domains 1 – 8	General symptom management; Pain; Fatigue; Dyspnoea; Bowel management; Physical care; Psychological / spiritual / religious care for the patient; Respectful care; Respect for patient autonomy; Preparation for death; Quality of death measure; Location of preference; Integrated / coordinated care and care expertise; Information provision – patient; Treatment preference discussion and/or documentation – patients; Service access; Family support; Respect for family member's autonomy; Information provision – family; Bereavement; Indicators covering multiple categories.
Sweden – 9 indicators available for generalist providers	8 Process 1 Outcome	Domains 1, 2 and 7	General symptom management; Pain; Oral health; Pressure ulcers; Psychological / spiritual / religious care for the patient; Discussion about care objectives; Coverage in a registry of palliative care; Acute care use.
United States – 25 indicators available for generalist and specialist palliative care providers	12 Process** 13 Outcome**	Domains 1, 2, 3, 4, 5, 7 and 8	General symptom management; Pain; Dyspnoea; Bowel management; Psychological / spiritual / religious care for the patient; Respectful care; Treatment preference discussion and/or documentation – patients; ICD deactivation; Information provision – family; Family support; Service access; Acute care use; Receiving chemotherapy in last 14 days of life; Hospice evaluation; Indicators covering multiple categories.

***Domain headings from the United States Clinical Practice Guidelines for Quality Palliative Care, Third Edition:** Domain 1: Structure and Processes of Care; Domain 2: Physical Aspects of Care; Domain 3: Psychological and Psychiatric Aspects of Care; Domain 4: Social Aspects of Care; Domain 5: Spiritual, Religious and Existential Aspects of Care; Domain 6: Cultural Aspects of Care; Domain 7: Care of the Patient at the End of Life; Domain 8: Ethical and Legal Aspects of Care
****** The United States note their indicator 'type' on each published indicator. Therefore, this was recorded and used.

6.2.6 Discussion

This systematic environmental scan identified wide global variability in progress towards establishing national approaches to robust, feasible and sustainable mechanisms for measurement of the quality of palliative care provision.[15-18] Belgium and the Netherlands currently have the most comprehensive indicator sets available at national levels. However, Belgium's set is currently only for specialist palliative care providers and the Netherlands' indicator set was made available as part of a five-year project, due for completion in 2017. Whilst all available indicators have relevance to the inpatient setting, close analysis of: the number used in total; providers included; and whether the indicators measure what matters most to inpatients and families is needed.

Indicators are currently only used by a third of countries identified as leading in palliative care provision, and none of the countries mandated indicator use. Two of the five indicator sets identified were designed for use by specialist palliative care services, rather than more generally measuring palliative care provided by generalist care providers; and only two addressed all of the 'US Guidelines' domains.[14] While hospital accreditation requirements in Australia, England, France and Singapore incorporate aspects of palliative care, no national indicators have been developed specifically to support this process in acute care.

Enabling system-wide improvements for inpatient palliative care provision requires: the integration of indicators into existing healthcare systems; and indicators that are relevant to generalist care providers and specialist palliative care providers. While Sweden reports improvements in palliative care resulting from integration of indicators across all care settings, for all care providers,[15] their current indicator set does not cover all care domains; or consider structural, process and outcomes and subsequent causal linkages. No participating country had a comprehensive set of national palliative care indicators, relevant to all care providers across care settings. The development and implementation of a comprehensive set of indicators would support wide-scale improvements in inpatient and family experiences. Given the increasing number of people living with complex illnesses, focusing indicator development on specialist palliative care services alone reinforces the status quo and does little to highlight the need for all health systems to prioritise palliative care.

Debate continues as to whether indicators should be mandated or voluntary, with a recent US publication proposing that a nationally mandated approach will enable progression in measurement of, and improvements within, patient safety.[19] Without a mandated approach, data from Study 3 suggests that implementation is inconsistent and/or reliant upon project funding affecting sustainability and usability of data for comparative purposes. However, mechanisms to mandate need careful consideration, with a specific focus on whether incentivising is useful, whether public reporting of data assists performance and whether data should be used with a punitive intention.[20] Given the aim for such reporting is to drive system-wide improvements, policy makers and standard enforcers are advised to consider such approaches in line with best practice for performance management.[20] However, the complexity of this work should not be underestimated. Each country has unique data collection, data regulation, policy and population requirements to consider. Nevertheless, development of national data registries, incentivising indicator use, appropriate utilisation of accreditation processes and commencing work through funded national programs have all been highlighted as mechanisms for enabling progression in quality measurement of palliative care (Appendix 13).

Current development and implementation of quality indicators for palliative care falls short of key recommendations from a recent systematic review.[10] No national indicator sets include structural indicators with recommendations highlighting the need for structure, process and outcome indicators to truly inform a review of quality palliative care; and advice to adapt indicators across countries to limit development of new indicators and enhance opportunities for benchmarking has not been implemented, with all countries having unique sets of indicators with both duplication and heterogeneity evident. There are opportunities to learn from different approaches and indicators used, to share successes and challenges in the measurement of optimal palliative care and for policy makers, researchers and service commissioners to use this information in line with cultural and contextual factors at the national level.

Given the focus on person-centred care and consumer-driven healthcare, it is time that the healthcare sector also partnered with consumers: to identify a set of indicators that can assist optimal palliative care provision across all care settings (acute, community and aged care); and to implement these nationally, so that service commissioning is in line with best practice. Driving such work from a consumer perspective will ensure that all system level improvements are in line with patient and family expectations of what constitutes good palliative care.[21, 22] It is also timely to develop an international repository of available indicators to limit ongoing development of 'similar' indicators and inform development of indicators where these are not available (E.g. cultural care). Such work could lead to international consensus on specific indicators that are of shared importance – for example, in relation to symptom management. Opportunities for collaboration and learning from other countries will flow directly from such an approach.

Crafting a set of national quality indicators that draws together key information from multiple tools in a feasible and sustainable way is complex. For an indicator set to be feasible for hospital settings, the number and frequency of measuring is an important consideration. It also requires a commitment to: utilise existing data sources;[23] carefully consider tools that inform quality indicators and standards;[1-3, 5, 6, 24] prioritise tools that assess consumer-identified areas of importance,[24] can be implemented into routine clinical practice[1, 25] and preference patient reported data.[1, 9, 26] Enabling quality measurement of inpatient palliative care also requires assessing the validity and usefulness of available national data sets[2] and better understanding how to use information from proxies when patients are unable to self-report.[2] Finally, ensuring a pathway between indicators and improved patient and family experience is fundamental to successfully effecting system level improvements.

6.2.7 Strengths and limitations

The involvement of key experts from all participating countries is a strength of this Study. Their contribution has ensured a realistic view of practice within the context of future plans that would not have been available from the published literature only. Furthermore, the use of standardised questions for experts and the systematic approach we used to search for and collect data limit the risk of bias. We adhered to standards for reporting a systematic environmental scan to the degree possible, recognising that such standards do not currently account for internet-inclusive searches.

The Study's main limitation is that we restricted participation to the 15 countries ranked in the top 10 countries delivering quality palliative care according to the 'Index'.[13] Other countries may be working in this area and may have national quality indicators not included in our review. Focusing on the countries ranked in the top 10 for quality of care was intended to instill at least some confidence in the quality of policies in the absence of research evidence. Limiting our inclusion to national indicators rather than those used at local or regional levels means we have not identified quality indicators currently used by some services. This approach enabled reviewing in line with national policy guidance and reduced contextual heterogeneity, at least to some extent. Whilst the 'US Guidelines'[14] had previously been used to map indicators to key domains,[10, 11] these were hard to separate at times (E.g. significant overlap between domain 1 – structure and processes of care and domain 4 – social aspects of care) and this led to our taking an inclusive approach. As a result, the mapping may over represent availability of measures in some domains. Similar to other reviews, this Study has focused purely on quality measurement, without inclusion of safety.[3, 5, 10] Despite some progress noted in healthcare safety measurement over the past 15 years, considerable work is required to enable this in a systematic way[19] for people with palliative care needs.[27]

In addition, since this study was completed in February 2017, further advances have been made. While neither the English Palliative Care Outcome Scale (POS)[28] or Gold Standard's Framework (GSF)[29] are mandated for use, these tools are available for use at the national level by generalist English palliative care providers across care settings. The POS has been updated and validated as the integrated palliative care outcome scale (IPOS), and translated into a number of languages.[28] The IPOS is reported to be feasible to implement and captures useful data that ought to inform clinical care. Importantly, the IPOS captures inpatient concerns inclusive of: symptom needs, informational requirements, practical concerns and psycho-social concerns.[28] The GSF provides a structured approach to identify inpatients with palliative care needs, offer advance care planning conversations (including understanding where the patient would prefer to die) and encourages ward cultures to provide evidence-based palliative care through training, quality assurance and support.[29] Interested inpatient units can implement quality improvement strategies to gain ward-based GSF accreditation.[29] To date, 99 hospitals (49 acute and 50 community hospitals), reflecting 364 wards across England, have implemented the GSF program, with 49 (13%) being accredited.[30] Finally, while the Netherlands time-limited project[28] reported in the environmental scan has since been completed, its findings are yet to be published in the peer reviewed press.

6.2.8 Summary

Measuring the quality of palliative care is a global priority, as it is key to ensuring access to high quality care across all settings. The collaborative development of a person-centred set of quality indicators, mapped to available standards and data sources, to inform local, regional and national understanding of palliative care provision is a good starting point to strengthen the safety and quality agenda. This suite of indicators must align with patient and family-stated domains of importance for optimal care, including in the hospital setting. In addition, indicator development that supports system-level improvements in palliative care provision will need to consider generalist care providers as well as specialist palliative care providers, and all care settings. A collaborative approach will reduce duplication of effort, facilitate rapid transfer of learnings from key successes, and provide the foundation for future benchmarking.

Study 3 has provided foundational knowledge about national policy frameworks and quality indicators available to support measurement of palliative care quality from countries leading in their palliative care provision. Understanding such policy frameworks is helpful for considerations at the national (macro) level. It is recognised that quality measurement in isolation will not drive improvements in inpatient palliative care. A systematic review of quality improvement models in health care identified a number of key elements necessary for successful implementation of improvement work, including active engagement of health professionals, middle and senior management and the hospital executive; multifaceted interventions; alignment of quality improvement with organisational strategic goals and the integration of quality improvement work into everyday activities.[29] Understanding how to apply such understandings to the Australian hospital context is the next focus for the OPAL Project to inform overall Project conclusions and recommendations. The next section reports on the co-design study (Study 4) undertaken with national Australian palliative care stakeholders to inform this work.

6.3 Study 4: Strengthening the delivery of palliative care in the Australian hospital setting: A co-design study to design actions for practice, policy, education and research

6.3.1 Publication reference

This manuscript was submitted to the Australian Health Review (AHR) on June 12, 2020. The AHR is the peer reviewed journal of the Australian Healthcare and Hospitals Association, with an impact factor of 1.228, focusing on health policy and management, healthcare systems and clinical programs. This journal was chosen because it will disseminate the work among a readership of policy makers and service managers with the jurisdiction to direct change. The following provides an edited version of this submitted work.

> **Virdun, C.,** Luckett, L., Davidson, P., and Phillips, J (2020). Strengthening palliative care in the hospital setting: a codesign study. BMJ Supportive & Palliative Care, *(In Press).*[30]

6.3.2 Overview

The majority of Australians living with advanced progressive illnesses die within the hospital setting.[31, 32] In addition, many people living with advanced illnesses are hospitalised during their last year of life,[33-36] with these needs projected to increase.[37, 38] Australians' experience of inpatient palliative care varies considerably[32, 39] with calls for improvements noted.[31, 40, 41] For the last 30 years, patients and families have consistently reported the elements required for optimal inpatient palliative care.[21, 22, 42, 43] However, delivering optimal, person-centred palliative care within acute, episodic care environments is challenging. Poor inter-disciplinary teamwork and poor communication, combined with a lack of early identification of patients with palliative care needs, all contribute to sub-optimal palliative care provision.[31, 44-48] Delivering best-evidence based palliative care across Australia's 1300 public and private hospitals,[37] located in metropolitan and rural areas, whilst managing different population, socio-economic and cultural diversity needs, poses significant challenges.

The OPAL Project has confirmed three categories of importance (Person-centred care, Expert care and Optimal environment for care) that contribute to a positive experience for inpatients with palliative care needs and their families, each with related domains and practice points to guide optimal care.[21, 22, 42, 43, 49] Translating these patient and family care priorities into actionable strategies is critical to driving the policy reforms required and enable clinicians and managers to implement best palliative care at the ward level.

Study 4 focused on informing next steps for achieving real and sustainable improvements in hospital-based palliative care practice through co-designing a comprehensive set of actions, to inform practice, policy, education and research. This co-design method was founded upon the outcomes from the OPAL Project's mid-point meta-inference (reported in Chapter 5) revealing the categories for optimal inpatient palliative care, inclusive of their related domains and key practice points.

6.3.3 Objective

To identify actions required to strengthen the delivery of palliative care in Australian hospitals so that it addressed the domains of care identified as important for inpatients with palliative care needs and their families.

6.3.4 Methods

The co-design study methods are provided in Chapter 3. Study 4 included a workshop based on the outcomes from the OPAL Project's mid-point meta-inference (reported in Chapter 5) involving palliative care and acute hospital policy, consumer and clinical representatives. A modified nominal group process generated a series of actions, which were subsequently thematically analysed and circulated to participants to gain consensus.

6.3.5 Findings

Participants

Key Australian and NSW palliative care and acute hospital policy, consumer, medicine, nursing or allied health representatives were identified and invited (n=52) to a four-hour co-design workshop, with 30 (58%) attending. Of those who were unable to attend (n=22) all contributed to the co-design process online. Details about the participant sample are provided in Table 6.3.

Table 6.3: Overview of the sample who attended the workshop and/or participated in targeted online feedback

Participant	Attended (n=30)	Apologies sent - included in online communications (n=22)
Senior medical palliative care clinicians	5	3
Senior nursing palliative care clinicians	6	2
Senior palliative care allied health representatives	2	4
NSW state level policy experts	6	6
National policy experts	3	7
Palliative care consumers	4	0
Research team members	4	0

Participants were allocated into four inter-professional working groups (7-9 participants per group), specifically arranged to be inclusive of a medical, nursing, allied health, state and national policy expert, palliative care consumer and research representative. Given attendee numbers on the day, and with only two allied health clinicians and three national policy experts available, full coverage of all participant 'types' was not possible. However, each group was as diverse in roles as was feasible. Each group had a predetermined group facilitator (a workshop participant) and scribe (member from the research team) to maintain consistent focus on the allocated group process, as well as the provided data packs based on optimal inpatient palliative care informed by the OPAL Project's mid-point meta-inference outcomes.

Results

Nine proposed actions, each with details of the steps required, were developed and approved via online email feedback. These actions included: 1) evidence-informed practice and national benchmarking; 2) funding reforms; 3) securing executive level support; 4) mandatory clinical and ancillary education; 5) fostering greater community awareness; 6) policy reviews of care of the dying; 7) better integration of advance care planning; 8) strengthen nursing leadership; and 9) develop communities of practice. The actions required at the macro (national), meso (organisation) and micro (ward) levels, are summarised below, with the full results detailed in Appendix 17.

Action 1: Evidence-informed practice and national benchmarking

- Macro (national level): Policy and infrastructure

Nationally, there is a need for the development of standardised patient and family-reported experience measures, based on what is important for inpatients with palliative care needs, that can inform national benchmarking, highlight gaps in care and identify areas for improvement. There is a potential opportunity to facilitate this through the Australian Palliative Care Outcomes Collaboration.[50] Patient and family experience measurement is needed at two levels: 1) a higher-level focus (10-15 questions); and 2) a tool providing the opportunity for a 'deeper dive' if specific issues are identified. In addition, a predesigned pack to measure clinician and ancillary staff experience, morale and happiness at work is required. Streamlining access to available data is also important, with recommendations made to: improve embedded coding for identification of patients coded as 'palliative' so that retrieval of data becomes possible from current sources (e.g. being able to access data from inpatient experience surveys limited to people with palliative care needs); a national minimum data set for palliative care; and facilitated access to state and national level datasets.

- Meso (hospital and health district level): Resourcing and infrastructure

Facilitating an organisational project to inform optimal inpatient palliative care based on national measurement tools and indicators is required. Supporting senior clinical leadership at the ward level (via the Nursing Unit Manager ('NUM') role) to redesign and innovate in response to such measurement is important. That is, organisational support, resourcing and infrastructure to enable clinicians to measure patient and family experience, receive timely feedback and innovate in response to this before measuring again, are required. Adding to this, ensuring the measurement of and response to clinician and ancillary staff experience, morale and happiness at work data is important. Finally, developing a process for reporting on and reviewing expected deaths in hospital within established Morbidity and Mortality meetings, including a mechanism for feeding this information back to the relevant NUM, will also support evidence-informed improvement work.

- Micro (ward level): Implementation and innovation

Strengthening inpatient palliative care based on the routine use of patient and family-reported measures relies on local implementation of data collection and use. Ward-level nursing leadership, supported by national measurement tools and benchmarks, will enable progression towards evidence-informed practice that is respectful of local approaches to care provision and innovations required.

Action 2: Funding reforms

- Macro (national level): Policy

A review of the funding linked to inpatients coded as being ‘palliative’ is required. This coding should facilitate access to services needed to maintain comfort and function. Given patients clearly describe their wish to maintain independence where possible, facilitating rehabilitation supports is important. Finally, the need to ensure consistency in relation to palliative care resourcing and to actively resource inpatient palliative care beds in line with the Palliative Care Australia guidance[51] is highlighted.

Action 3: Securing executive level support

- Macro (national level): Toolkit development

Development of a National Palliative Care Inpatient – Executive Engagement Toolkit (‘toolkit’) is required. It is suggested this work could be led by the Australian Commission on Safety and Quality in Health Care. The aims of this toolkit are to: highlight what patients and families describe as most important for quality inpatient palliative care; and embed that inpatient palliative care is ‘core business’ and therefore strengthening the quality of this care is of paramount importance.

- Meso (hospital and health district level): Resourcing

Explicit review and provision of resourcing levels to enable optimal inpatient palliative care is required. The foci of such resourcing includes: supporting NUMs with education and opportunities to lead collaborative improvement work across the sector; support for clinicians to spend time on reflective practices required to undertake this work; support for driving quality improvements through the identification and navigation of barriers; and developing a mechanism to reward excellence in care, both to acknowledge the importance of palliative care in the work of hospital clinicians and ancillary staff and to enable sharing of excellent practice.

Action 4: Mandatory clinical and ancillary education

- Macro (national level): Policy and resource development

Ensuring a defined competency level of communication skill nationally is required for clinicians and ancillary staff. Progressing from this, a national suite of learning resources for use both online and face-to-face is required and could be developed by a leading palliative care academic department. A national suite of resources ensures evidence-based approaches to inform local training provision. A national approach will also enable due consideration of population diversity and subsequent considerations for optimal communication at the end of life. In addition, the need to co-design, with palliative care consumers, a learning package for all levels of hospital clinicians and ancillary staff that focuses on the need for kindness, gentleness, acknowledgment of personhood and human interaction, vital to the wellbeing of both patients and families requiring inpatient palliative care, is highlighted.

- Meso (hospital and health district level): Policy and implementation

Organisational leadership to articulate and resource minimum requirements for effective communication and shared decision-making competence for all clinicians and ancillary staff is required. Implementing annual mandatory training on effective communication, supported by the suite of evidence-based national learning resources, is essential. It is recommended that this education be disseminated to clinicians and ancillary staff at orientation and other appropriate fora.

Action *5: Fostering greater community awareness*

- Macro (national level): Policy

Adopting the success of the advocacy campaign in paediatric health highlighting the importance of ‘the first 1000 days’ of life,[52] it is suggested to launch a campaign that promotes the last year of life as a further critical focus for healthcare. Co-designing this campaign with consumer representatives is critical. Avenues for promoting this campaign include: State and Federal government health ministers; national medical, nursing and allied health organisations; media outlets; and academic platforms.

Action 6: Policy reviews of care of the dying

- Meso (hospital and health district level): Policy

Policy guiding the appropriate and respectful care for the recently deceased patient is required. The practice of applying identification tags to people who have died and placing them into body bags on the ward itself, where this may cause distress to families, is questioned. It is suggested this procedure could be done after removing the person from the ward.

Action 7: Better integration of advance care planning

- Meso (hospital and health district level): Infrastructure and policy

The need for infrastructure to enable the timely capture and access to advance care planning documentation within Electronic Medical Record systems is essential to informing current care provision, inclusive of documented discussions, nominated substitute decision makers and agreed resuscitation status. Policy support to incorporate an advance care planning screening question on admission is required to assist in the identification of a person’s advance care planning preferences to guide care provision.

Action 8: Strengthen nursing leadership

Participants considered local hospital and ward level nursing leadership to be instrumental in enabling system level improvements in inpatient palliative care. They recommended using a co-design process to strengthen the NUM role to enhance palliative care provision. Equipping and supporting leadership and the operationalisation of person-centred care were seen to be critical.

Leadership

- Meso (hospital and health district level): Policy, resourcing and infrastructure

Nursing leaders require support from the organisational level to lead, drive and embed the profound cultural change required to ensure respectful and compassionate care is provided to every inpatient, including those with palliative care needs. Respecting local conditions is important, given each ward’s unique needs, but enabling through adequate resourcing and addressing noted barriers collaboratively is important. Enabling nursing leaders and colleagues to focus on Standard 5 from the Australian Commission on Safety and Quality in Health Care’s accreditation standards,[53] to embed systems and processes to enhance the safety and quality of care for inpatients with complex needs, is required. Facilitating this process through provision of time, enabling central functions and supportive policy, is important.

Micro (ward level): Implementation focus

Implementing changes led by the NUM, in line with local conditions, to enable care that aligns with patient and family identified areas of importance, is required. Supported by organisational policy, NUMs need to focus on driving evidence-informed change to ensure: all patients and families experience respectful and compassionate care; all clinicians and ancillary staff meet the stated minimal competence for effective communication and shared decision-making; and a process to enable a point of ‘linkage’ for information provision. Role modelling collaboration across teams, disciplines and departments is also required, including ensuring nursing representation on medical ward rounds, establishing effective handover processes, and enabling timely bed management for people who are dying. Ensuring expert practice where nursing leaders confirm adequate skill-mix and that each clinician is working to the top of their scope of practice and is focused on the ‘right’ work for their role is important. Finally, implementation of optimal inpatient palliative care requires NUMs to support and mentor clinicians to understand and value palliative care, working to assist every patient with palliative care needs to live as well as they can within the context of their illness.

Operationalising Person-centred care

- Macro (national level): Resource development

The national collation of evidence-based tools that: facilitate routine and regular identification of inpatients with palliative care needs; facilitate optimal assessment and care planning; and operationalise person-centred care is required.

- Micro (ward level): Implementation focus

The implementation of the nationally endorsed collation of tools to support identification and assessment of inpatients with palliative care needs to inform optimal care planning is required to be embedded into routine practice. Instituting a process of asking all patients and families about their individual needs and documenting this for interdisciplinary use is required to operationalise person-centred care. Ensuring that the ward nursing team have the skills to ask patients directly about how to best support their maintenance of role, identity and meaning, and then to act on this information, is important. Optimising the ward environment as much as is possible, in line with areas of noted importance for patients, such as a quiet area and next to a window where possible, is another focus for ward-level nurse leadership. Nurses need to provide family members with an opportunity to be involved in the care of inpatients with palliative care needs. Ensuring that medical ward rounds occur at a set time, which is publicly available would facilitate more timely family input into care discussions. Embedding processes to assess and support family needs and specifically consider information about parking supports, Wi-Fi, catering options and access to the hospital out of hours is required. Finally, implementing a process for supporting inpatients who are imminently dying and their families, proactively showing kindness, support, care and checking for any additional needs is important.

Action 9: Develop communities of practice

- Macro (national) and Meso (hospital and health district level): Policy and resourcing

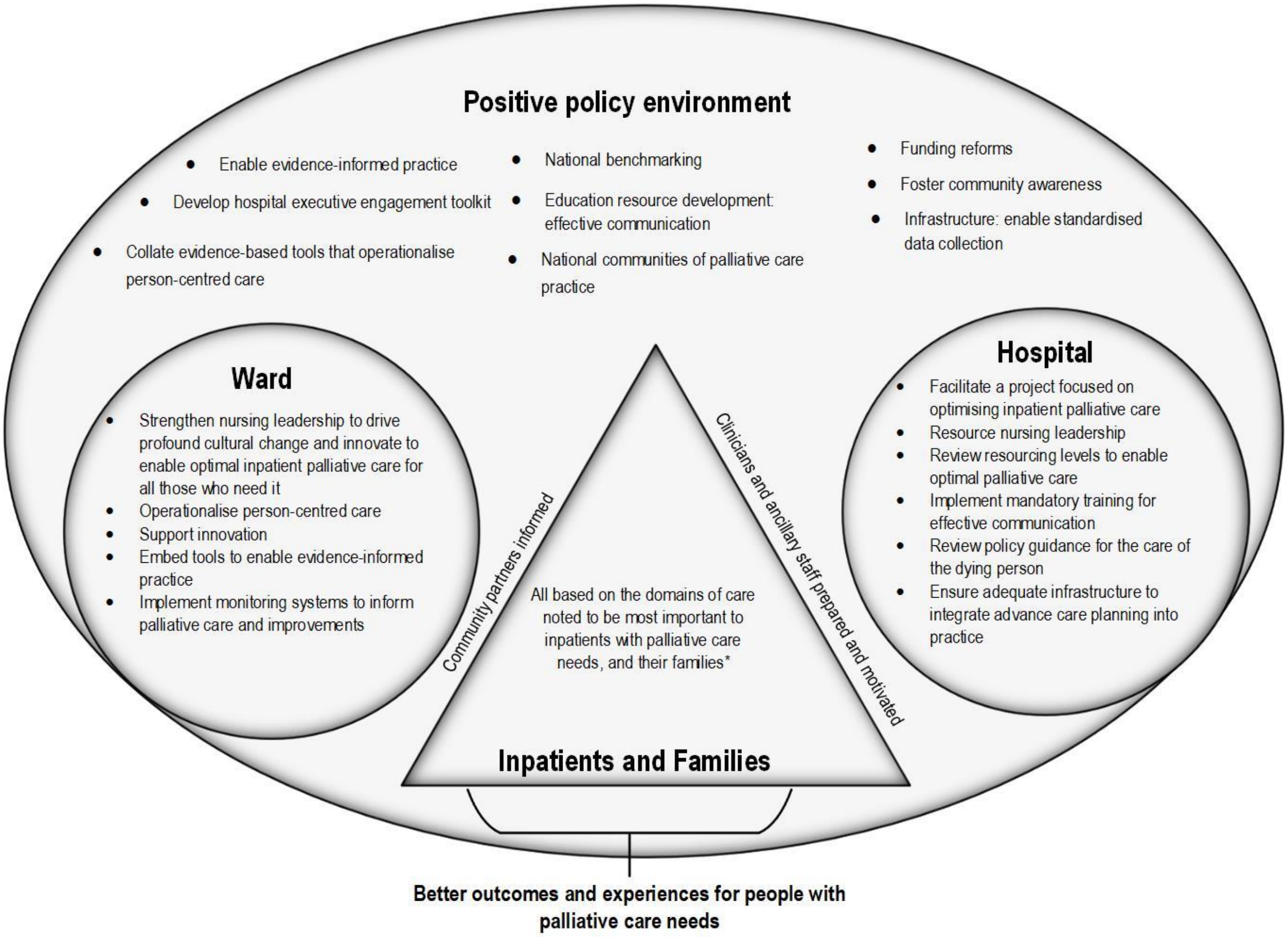
The development and implementation of local, regional and national inpatient palliative care communities of practice that engage ward-level clinicians and specialist palliative care clinicians is important. These communities of practice aim to support the implementation of palliative care improvements, learning from experiences and sharing excellence.

6.3.6 Discussion

Findings from this co-design process yielded nine discrete but related actions to enable Australian hospitals to provide optimal inpatient palliative care. Embedded within these actions is a series of policy, practice, education and research recommendations at the macro, meso and micro levels.

Given the complexity and diversity of palliative care needs and hospital environments (ranging from intensive, critical and high-dependency care units through to all ward areas and emergency departments), strengthening inpatient palliative care provision will benefit from: executive support declaring the importance of palliative care in hospitals;[54] support for each ward to deliver care in accordance with patient and family-identified areas of importance;[21, 22, 49] integrated use of evidence-based tools; and validated and standardised approaches to measure patient and family outcomes and experiences to inform quality improvement, national benchmarking and ongoing models of care provision.

Enabling sustained improvements in palliative care provision within a system focused on the bio-medical approach looking to cure or prolong life is complex.[45, 47, 48, 55] However, adapting key principles from the World Health Organization's Innovative Care for Chronic Conditions Framework[56] may provide useful insights to guide clinicians, hospital administrators and policy makers. While this framework has been used widely in community setting, its components resonate strongly with the actions emerging from this co-design study, including: a focus on placing patients and families at the centre of all care; framing reforms within the context of a positive policy environment; the importance of a strategic reorganisation of healthcare (in this case, the ward environment) to deliver the required changes, and ensuring a well-informed and engaged community. Addressing the changes required within each of these components would lead to improvements in line with this co-design Study's proposed actions (Refer Figure 6.4).



**Domains noted to be most important for optimal inpatient palliative care informed by previous research*[21, 22, 49]

Figure 6.4: Adaptation of the Innovative Care for Chronic Conditions Framework[56] to address the specific needs for the Australian inpatient palliative care population.

Innovative care for chronic conditions: building blocks for action: global report. Report no. 9241590173. Pruitt, S., & Epping-Jordan, J. Chapter 3, Innovations in Care: Meeting the Challenge of Chronic Conditions, p.72 (2002). Access date - 29/04/20: https://www.who.int/diabetes/publications/icccreport/en/ (permission noted in Appendix 5)

6.3.7 Strengths and limitations

The strength of this co-design study lies in its focus on patient and family-perceived areas of importance for optimal inpatient palliative care.[21, 22, 49] Working from this foundation ensures that the co-designed set of actions informs improvements in what matters most to those with palliative care needs. However, there are two important limitations: 1) The data used as the foundation for this study did not sufficiently reflect views of those from minority, culturally diverse and Indigenous communities and, therefore, it cannot be assumed that ensuing proposals would enable optimal inpatient palliative care experiences for all; and 2) The actions were co-designed with palliative care consumers, policy experts and specialists in palliative care, rather than representatives from other specialties relevant to the bulk of hospital palliative care. It was deemed important to first seek advice from those with special expertise in palliative care within hospital settings to understand their perspectives on leading change. However, it is essential to also include perspectives from the broader hospital community in co-designing the next steps to ensure that interventions are acceptable and feasible for implementation and testing within their contexts of work.

6.3.8 Summary

The set of actions generated from Study 4 provides explicit guidance to inform changes to practice and policy aimed at strengthening palliative care within the Australian hospital setting. Importantly, these actions were co-designed with senior clinicians specialised in palliative care, policy experts and palliative care consumers and focused exclusively on domains of care identified as important by inpatients with palliative care needs and their families. The next step is to co-design interventions with hospital clinicians and administrators more broadly, to enable implementation and testing of each action within clinical practice, so that improvements can become embedded and sustainable.[57, 58] This work is beyond the scope of the OPAL Project but will be important to enable progress in the efforts to enable optimal inpatient palliative care within Australian hospitals.

The next Chapter integrates the OPAL Projects four data sets to generate the end-point meta-inference which will inform Project conclusions and recommendations for optimising inpatient palliative care within the Australian context.

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Chapter 7: Conclusions and recommendations

7.1 Introduction

Chapter 1 established that inpatients with palliative care needs do not always receive optimal care. Chapter 2 described the domains of care that inpatients and their families have consistently reported to be important (Studies 1a and 1b).[1, 2] Two key evidence-gaps emerged from Study 1a and 1b's systematic review and meta-synthesis, namely the need for a greater depth of understanding of: 1) these domains of importance and how they impact on clinical care; and 2) key mechanisms likely to drive sustainable improvements within Australian hospitals, in alignment with these domains of importance. The rationale for adopting a fully mixed sequential dominant design[3] was detailed in Chapter 3. Chapter 4 reported results from a qualitative study on the perspectives of Australian inpatients and their families, on what is important for optimal palliative care (Study 2). The mid-point meta-inference (Study 1a, 1b and 2 data), reported in Chapter 5, confirmed three categories of care for optimal inpatient palliative care and distilled these into key domains and practice points for inpatient palliative care provision. The insights emerging from the mid-point meta-inference informed Studies 3 and 4 (Chapter 6), which sought to inform the practice, policy, education and research changes needed to ensure the domains of inpatient palliative care noted to be most important to patients and their families are addressed by Australian hospitals.

This final Chapter integrates data from the OPAL Project's four Studies to answer research questions 2 and 3, posed in Chapter 1. Research question 1, answered by the mid-point meta-inference, is reported in Chapter 5. Meta-inference of the data from all four Studies, supported by the World Health Organization's *Innovative Care for Chronic Conditions Framework,*[4] *The Person-centred Practice Framework*[5] and relevant policy documents, allows for a series of recommendations to strengthen the delivery of palliative care in the Australian hospital setting. Joint display tables for each research question are included as appendices (Appendices 11, 18 and 19).

7.2 Research Question 1: What are the domains of care that are most important to inpatients with palliative care needs and their families?

The mid-point meta-inference of Study 1a, 1b and 2 data, reported in Chapter 5, revealed 14 domains of care that are most important to inpatients with palliative care needs and their families. These 14 domains fall into three overarching categories: Person-centred care; Expert care; and Optimal environment for care, as shown in Figure 7.1:

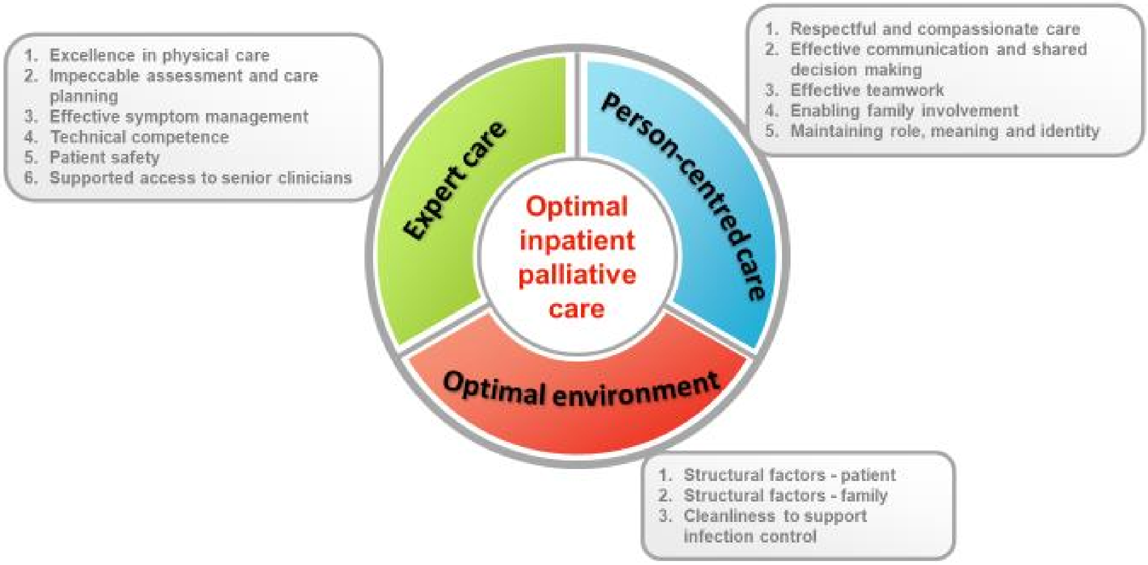


Figure 7.1: Key domains of importance for optimal inpatient palliative care

The meta-inference of data also facilitated the identification of key practice points (n=68) to inform clinical care provision, as detailed in Chapter 5. Many components within each domain cited as important are relevant to other inpatient populations. However, there are some unique requirements for inpatients with palliative care needs that warrant careful consideration, particularly in relation to someone who is imminently dying. Understanding how to drive change to enable this care within the clinical, geographical and population diversity evident within Australian hospitals, is an important next step.

7.3 Research Question 2 – Is there a suite of indicators to assist measurement of inpatient palliative care quality?

In order to answer this question, a review of nationally available quality indicators and how they align with areas of importance for optimal inpatient palliative care (research question 2a) and their implementation (research question 2b) was completed as outlined below.

7.3.1 2a: What national quality indicators are available to support measurement of quality palliative care and do these align with the domains of care that matter most to inpatients with palliative care needs and their families?

Five countries (Australia, Belgium, Netherlands, Sweden and the United States) in February 2017, had developed national quality indicators (n=128) to support services to measure the quality of their palliative care provision. Meta-inference of data from Studies 1a, 1b, 2 and 3 (Appendix 18) revealed that the majority (88%, n=113) of identified indicators report on areas noted to be important to inpatients with palliative care needs, and/or their families. However, few domains of importance are measured in their entirety.

The domain with the greatest number of available indicators for inpatient palliative care was effective symptom management, with 32 indicators overall. Of these, 15 specifically measure aspects aligned with consumer-noted areas of importance, namely: regular assessment and rapid management of symptoms (n=14), although most indicators currently are symptom specific rather than more general; and responsive attention to any forms of distress for an imminently dying person (n=1). As symptom management is core to clinical care and the indicators aligned to this have been tested in clinical practice, it would be sensible to continue to refine and optimise these for ongoing clinical application and focus specifically on patient and family (where proxy required) reported outcomes, aligned to noted areas of importance. Gaining consensus on the most robust indicators that are feasible for sustainable clinical implementation will assist with taking this indicator development forward, as well as using such measurement to inform optimal care practices.

There were 26 indicators that measured impeccable assessment and care planning, with most areas of noted importance being addressed. However, there are measurement gaps in relation to the assessing of social needs and there is no specific indicator to determine whether a clinician is knowledgeable about a person’s specific health needs within the context of their broader health concerns, with this aspect of care noted to be important to avoid a siloed approach to care provision. Given the large number (n=26) of available indicators within this domain and the importance of impeccable assessment and care planning, it would be useful to build upon this work through focusing on the areas that have not previously been addressed. Developing these additional indicators would ensure that there was a suite of comprehensive measurement options aligned with areas that matter most to inpatients requiring palliative care. The large number of indicators available across all domains suggests that the ideal next step would be to work with palliative care consumers and clinicians to prioritise indicators for future use that both measure areas of importance and maximise implementation efforts within busy clinical environments.

It is worth noting that for some of the domains for which indicators currently don’t exist, there may be scope to develop indicators that could be captured by the hospital system via a different mechanism. For example, in terms of measuring technical competence, patient safety and hospital cleanliness, an indicator captured at the local level could provide reliable data in line with consumer-noted areas of importance. Given the large crossover of areas of importance noted by inpatients with palliative care needs and the non-palliative inpatient population, it is important to comprehensively review existing data sources that could contribute to measurement and reporting practices. For example, many hospitals administer post discharge experience surveys with several questions within such tools being of relevance for people with palliative care needs. Understanding how such data could be accessed and analysed effectively for a specific population will be useful to avoid duplicated effort where new indicators being implemented could be answered from existing data.

Despite being noted as important by inpatients and/or families the domains of ‘enabling family involvement’ and ‘maintaining role, meaning and identity’ have very limited indicator availability. While patient safety; supported access to senior clinicians; structural factors – patient focused; and cleanliness to support infection control are not measured at all (Appendix 18). Developing indicators that measure these domains is an important area for future research.

7.3.2 2b: Where a country has national palliative care indicators available, have they been successfully implemented?

Across the globe, implementation of the available palliative care indicators has had varied success, with successful implementation noted in Sweden and for the majority of specialist palliative care services across Australia, where national policy supports this work (Appendix 18). Belgium, the Netherlands and the United States do not have national policy frameworks to implement their indicator sets, which supports the notion of the importance of positive public policy[4] as being an enabler of success. Successful implementation of national palliative care indicators also relies on the provision of data infrastructure for clinical services, including legal and regulatory support. Where this has occurred, there is evidence that patient outcomes have improved over time.[6, 7] While accreditation processes are useful, if they are mostly informed by local data systems and not discrete patient outcome measures, the opportunities to improve direct care delivery and outcomes are further limited.

7.4 Research Question 3: What are the key drivers for enabling improvement in palliative care provision within Australian hospitals?

Meta-inference of data across all four Studies within the OPAL Project (Appendix 19) revealed that there are five key drivers to enable improvement in palliative care provision, based on patient and family-identified priorities, within Australian hospitals, as described below:

1. Recognising and valuing palliative care as core business and a priority for inpatient care;
2. Leadership at macro (policy), meso (hospital executive) and micro levels (ward) to develop systems and processes to enable optimal palliative care provision in accordance with consumer need;
3. Measurement to inform quality assurance and identify targets for improvement;
4. Innovation to co-design, with clinicians, administrators, other relevant experts and palliative care consumers, structures and processes that align with required patient and family-identified needs for optimal care; and

5. Targeted skill development to support clinicians and ancillary staff in their delivery of palliative care.

Each of these drivers is described in detail in the next section.

7.4.1 Recognising and valuing palliative care as core business and a priority for inpatient care;

Recognising and valuing palliative care as core business and a priority for inpatient care is an essential element to enable success in all other work completed within the additional four stated drivers (leadership, measurement, innovation and skill development). The World Health Organization's (WHO) *Innovative Care for Chronic Conditions Framework*[4] refers to the need for a paradigm shift and this thinking is useful when considering palliative care within hospital settings. The role that hospitals have in relation to palliative care is misunderstood, with contemporary policy often noting they have little to offer.[8, 9] The Australian Commission on Safety and Quality in Health Care has commenced work in addressing this with the recent addition of palliative care specific items and related actions within the national hospital accreditation standards (2nd edition),[10] and preparatory work informing these changes published.[11, 12]

As noted in preceding Chapters, the majority of expected deaths in high income countries continue to occur within the hospital setting,[13-18] and a growing proportion of people with palliative care needs are hospitalised within the last year of life[19-22] as a result of increasingly complex illness and variable community supports.[8, 21, 23] Some patients also prefer to be cared for and/or die in hospital for a range of reasons, including a lack of clinical and/or social support in their home setting (community or residential aged care) and a wish not to burden their family.[8, 24-27] The acknowledgement of this reality is important in moving towards a recognition that clinicians and ancillary staff working in hospitals provide an important role in caring for people with palliative care needs, in many cases from diagnosis through to the time of death.[8, 16, 28] To enable improvements in care provision, this role needs to be both valued and prioritised. Explicit support from the hospital executive to underscore the importance of this work and to resource it accordingly is critical to enabling success. Such support needs to remove barriers and enhance enablers for clinicians, ancillary staff and palliative care consumers to work together to innovate and lead care that addresses key areas of importance for optimal care. Without such support translated into actual resourcing and other enabling strategies, system level improvements cannot be achieved.

7.4.2 Leadership at macro (policy), meso (hospital executive) and micro levels (ward) to develop systems and processes to enable optimal palliative care provision in accordance with consumer need;

Palliative care within the hospital setting is currently of variable quality,[1, 2, 18, 29-32] despite discrete areas noted as being important for optimal care from the perspectives of inpatients with palliative care needs and their families.[1, 2, 32]

Macro: Leadership through a positive policy environment[4] valuing palliative care provision, strengthening partnerships and collaboration and advocating for adequate human resources is fundamentally important to progressing better outcomes for people with palliative care needs.[4] Australia is fortunate to have significant policy support available at both national[10, 33, 34] and jurisdictional[35-42] levels. However, ensuring that all such policy frames and supports optimal inpatient palliative care provision is paramount.

Meso: Leadership at each healthcare organisation is critically important to enable system-wide improvements, with a particular focus on adequate resourcing, embedding support for clinicians involved in this work both in relation to their professional development and their self-care, and truly enabling innovation given the complex needs for this population of patients.[4, 5] For example, if one ward designed specific processes to better align with maintaining patients' independence and self-identity, it will be important for organisations to remove barriers that may exist and foster creativity within boundaries of patient safety (visitation of pets, opportunities for patients to leave the ward etc.). In addition, this executive leadership needs to be embedded in regular hospital administrative processes and informed by evidence, hence immune to changes in personnel or healthcare delivery structures. The *Innovative Care for Chronic Conditions*[4] *and Person-centred Care Frameworks*[5, 43] underscore and resonate strongly with OPAL Project conclusions, with particular emphasis placed on the need for adequate resourcing to equip health care teams[4, 5, 43] and creating a practice environment that promotes: appropriate skill mix, shared decision-making systems, effective staff relationships, supportive organisational systems, power sharing and the potential for innovation and risk taking.[5]

Micro: Finally, leadership at each ward level is critical and will need to be reflective of the full interdisciplinary team (medical, nursing and allied health). The domains within *The Person-centred Practice Framework*[5, 43] provide evidence-based guidance to support the development of person-centred processes and outcomes that resonate directly with outcomes from the OPAL Project, inclusive of the need for: shared decision making, authentic engagement, working holistically, being 'present' and working with the person's beliefs and values. The OPAL Project specifically identified the importance of leadership through the Nursing Unit Manager (NUM) role, to transform ward culture and realign care with the domains noted to be most important for optimal inpatient palliative care. Supporting NUMs to do this work at each ward level (micro) will account for local conditions and diversity. Given their availability 24 hours a day, seven days a week, nurses are vital in leading significant benefits for people with palliative care needs, supported by medical and allied health colleagues.[44] The role a NUM can play in reviewing current care structures, processes and outcomes and informing how each local area can consider changes to inform improvements is significant. In order to achieve success, executive support and adequate resourcing are critical. Partnering with palliative care consumers will ensure this reform remains focused on improvements that matter most to patients with palliative care needs, and their families.

7.4.3 Measurement to inform quality assurance and identify targets for improvement

Measuring care outcomes through clinically meaningful quality indicators is an essential driver for system level change, with the importance of this well documented within palliative care.[11, 45-51] However, the complexity of achieving this within Australian hospital settings is notable, given the diversity of work completed and the fact that hospitals are already measuring many areas of care provision in line with local policy and national accreditation requirements.[11] The need to consider a suite of indicators and data sources that align to the key practice points noted as important for optimal hospital-based palliative care provision is a good first step towards achieving this aim. Given that many areas noted to be important for inpatients with palliative care needs resonate with the non-palliative inpatient population, designing indicators specifically for palliative care is unlikely to be necessary or feasible for implementation. Rather, it would seem most helpful to look at existing data sources and consider, pragmatically, how these relate to noted areas of importance. Following this, gaps can be identified for palliative care, enabling clarity about new indicators and data that may be needed. Where gaps are identified, looking to existing indicators in use with some level of validation and psychometric testing is important.[50, 52] An exception to this approach is for the population of people who are imminently dying, for whom families have outlined optimal care that is unlikely to be measurable through more generalised processes (such as patient experience surveys). Consideration of feedback about such care from bereaved family members is important, with successful national implementation of such measurement evident in England.[18] Development and implementation of a strategy to measure palliative care quality will need to be informed on an ongoing basis by co-design work with palliative care consumers to ensure it remains grounded in that which matters most to those who need this care. Measurement is the first step to enabling evidence-based review of quality of care provision but must be complemented by processes of feedback, reporting and identification of key improvement areas to enable improvement over time.

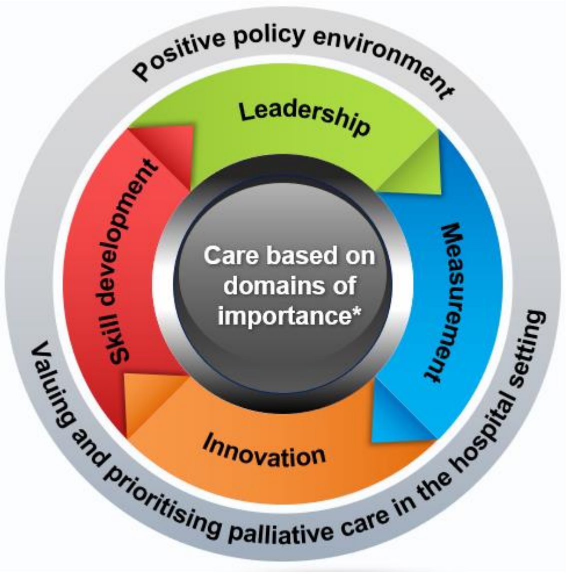
7.4.4 Innovation to co-design, with clinicians, administrators, other relevant experts and palliative care consumers, structures and processes that align with required patient and family-identified needs for optimal care;

A key driver to enabling successful change is through empowering local innovation at each ward level to review structures and processes that can contribute to optimal palliative care provision. This is supported by *The Person-centred Practice Framework*[5, 43] that articulates the need for learning cultures that enable innovation to enhance evidence-informed practice and create understanding of the interrelationships between system processes and outcome effectiveness.[43] Networks of support and collaboration are an essential component of this work in order to prevent duplicated effort and to maximise learnings over time. However, due to variance of staffing, resourcing, populations and policy supports, consideration of each proposed change within the specific requirements of each ward unit is important. For example, the implementation of a process for routine screening of patients with validated tools is important to enable identification of inpatients who have palliative care needs. Once a patient with such needs is identified, evidence-based assessment and care planning processes, valuing the uniqueness of the individual and their particular circumstances, ought to follow in alignment with the key practice points, enabling optimal care. Tools to support such work and indicators to measure outcomes can be consistent across regions, and indeed should be. However, exactly how one ward may implement such tools and ideas will change across wards to account for unique local conditions, as well as whether a ward may engage with this work regularly or infrequently.[53] Again, co-design with palliative care consumers will be an important pillar for this work. However, in addition to consumers, it will be important to think innovatively about who else may be able to contribute to the development of possible strategies for consideration. For example, data experts, designers, other key leaders working with chronic and complex illnesses and IT specialists can all contribute to different elements of optimal inpatient palliative care provision.

7.4.5 Targeted education and skills development to support clinicians and ancillary staff in their delivery of palliative care

Targeted education for clinicians and ancillary staff working within hospital environments[54] is required to enhance knowledge, skills and confidence in palliative care provision given to date they have not seen this as their core business. There are three foci for such education: core skills in palliative care for clinicians; core skills in palliative care for ancillary staff; and an education package for all levels of hospital staff focused on kindness, gentleness, acknowledgment of personhood and human interaction. There is a need for these education packages to have a face-to-face component, repeated at least annually, mandated for all staff to complete and founded within an improved understanding and confidence in communication skills. Evidence of improved palliative care knowledge and skill following education provision for those working in hospital settings is noted;[54-57] however, the majority of these programs were evaluated using self-assessment[54, 56] or satisfaction with education provided.[57] It would be useful to develop key education packages and implementation strategies linked to an understanding of improved clinical outcomes and experience both for patients and families as well as hospital staff (clinical and ancillary).

In summary, there are five drivers for enabling improvement in palliative care provision within Australian hospitals. Firstly, there is an overarching driver, being the recognition and valuing of palliative care as core business and a priority for hospital inpatient care. Embedded within this, the additional four drivers refer to leadership, measurement, innovation and education to enable optimal care. These five drivers are based upon the meta-inference of data informing what is most important for optimal inpatient palliative care from the perspectives of patients with palliative care needs and their families, an understanding of current system level drivers for change, and co-designed action proposals from clinicians, policy experts, researchers and palliative care consumers, as shown in Figure 7.2:



**Key domains of importance (n=14) for optimal inpatient palliative care from the perspectives of patients with palliative care needs and their families*

Figure 7.2: Key drivers for optimal palliative care in the Australian hospital setting

7.5 Discussion

The OPAL Project has developed two key packages of evidence that in combination inform how to optimise care for people with palliative care needs and their families in the Australian hospital setting.

Key areas of importance for optimal inpatient palliative care

Meta-inference of data across Studies 1a,[1] 1b[2] and 2[32] has led to a comprehensive understanding of what is important for optimal inpatient palliative care, from the perspectives of patients with palliative care needs and their families. Data globally has been very consistent over time with the need for excellence in person-centred care and clinical expertise fundamentally important.[1, 2, 25, 28, 30, 32] Understanding of the needs for supportive environmental factors within hospitals has been limited to more recent work[25, 32] but key features are now well described. Financial implications of illness differ across nations, perhaps unsurprisingly given some countries have universal healthcare and others do not. The exact features of financial implications as a domain of importance to inpatients and families require further exploration at national levels, rather than internationally, to guide practice and policy. The impact of nutrition on a person's experience of their inpatient care is a newer feature of importance and also requires further research to understand this in relation to both nutritional factors and comfort provided by diet personally and culturally. Given the demographics of participants across all of the OPAL Project's Studies tend to reflect White Europeans, Americans, Canadians and Australians, the aspect of culture requires greater attention. Nevertheless, the current package outlining three categories, 14 domains and 68 practice points to inform optimal inpatient palliative care is reflective of a large cohort of people with palliative care needs and is a robust contribution from which to move forward in informing practice evaluation and subsequent improvement.

Key drivers to strengthen optimal palliative care in the Australian hospital setting

The second package of evidence developed via the OPAL Project is the result of meta-inference of data from all four Studies to enable an understanding of the key drivers to strengthen optimal palliative care in the Australian hospital setting. Based on the first package of evidence (key areas of importance for optimal inpatient palliative care) these drivers are reflective of requirements at national (macro) levels, health care organisation (meso) levels and ward (micro) levels. These drivers are the first step in enabling optimal inpatient palliative care, based on what patients and families have stated is most important for their care. Both pieces of evidence (the key areas of importance and the drivers to enable optimal care) are crucial to informing system-wide improvements in Australian inpatient palliative care. To date, such evidence packaged for review and implementation has not been available. An examination of how these packages can be operationalised at the macro, meso and micro level will now be provided.

7.5.1 Considerations at the macro (national) level – policy, accreditation, clinical care standard and data infrastructure

Policy: The OPAL Project found that a key driver for strengthening inpatient palliative care is to recognise, value and prioritise the importance of this work in the hospital setting. Strengthening the policy environment is urgently required at both national and jurisdictional levels to enable excellence in inpatient palliative care centred around the expressed needs of patients and families. The need for this positive policy environment is also noted within *The Innovative Care for Chronic Conditions Framework,* accompanied by critical elements for consideration[4] that resonate directly with outcomes from the OPAL Project, inclusive of: partnership working, supportive legislation, policy integration, leadership and advocacy, promotion of consistent financing, and development of human resources.

To enable optimal inpatient palliative care, the policy environment ought to provide leadership and advocacy specifically for this population of people, to enable a focus on living well despite advanced illness, and care delivery in line with stated areas of importance. Policy needs to explicitly prioritise and value inpatient palliative care, supported by detail in relation to how it is resourced, operationalised and evaluated. Often, policy frameworks describe the need for palliative care across all care settings but principally discuss the need for community supports to limit hospitalisation.[34] Whilst not arguing against the optimal provision of care to limit hospitalisation where this is the preference for the patient, such policy statements do not in themselves provide explicit support, priority or value for those working in the acute care setting and therefore highlight an opportunity for review and improvement.

The policy environment with the greatest degree of influence within Australian hospitals is the national standards and accreditation system led and overseen by the Australian Commission on Safety and Quality in Health Care (‘the Commission’).[10] The second edition of the National Safety and Quality Health Service Standards (‘Standards’) was released in November 2017, with mandated assessment in line with these updated Standards from January 2019. These updated Standards[10] articulated a notable increase in quality items referring to optimal inpatient palliative care. Whilst this is a great step forward, such items do not comprehensively address all the noted aspects of importance for optimal inpatient palliative care and their particular focus on safety and quality neglects specific attention on patient and family experience of care, an area of such critical importance for palliative care provision. A comprehensive mapping of the noted areas of importance with the 2nd edition of the Standards will enable an understanding of how to move this work forward into coming years. Basing this mapping work on the key areas of importance noted by inpatients with palliative care needs and their families will ensure the progression of this work is reflective of areas of care that matter most to those who require it.

The development of Clinical Care Standards, co-designed by clinical experts and consumer representatives, on health conditions that would benefit from a nationally coordinated approach to care has been led by the Commission since 2013.[58] Palliative care is not currently included as a clinical care standard. Given the wide variation in illnesses and prognoses of people requiring palliative care within the hospital setting, a clinical care standard for the broader aspects of palliative care is difficult to achieve and arguably could not be captured in a singular pathway of optimal care. However, this is not the case for the care of someone who is imminently dying. This population of inpatients and their families has clear needs in relation to respectful and compassionate care, identification of their dying and accordingly explicit communication, responsiveness to any symptoms or related distress, allocation of a private room, supportive care and processes at the time of a person's death and follow-up care for the family. Such care needs are well articulated by bereaved family members.[1, 2] Therefore, there is a great opportunity to use this information to co-design a clinical care standard for the imminently dying patient in the hospital setting that brings together the aspects of optimal care from the bereaved carer perspective, alongside clinical evidence of best practice for common symptoms experienced by imminently dying patients. This would be highly supportive for clinicians supporting dying patients in the wards within Australian hospitals and ensures a focus on optimal care for dying patients.

Data infrastructure for measurement: Measurement of palliative care quality in Australia remains an area of challenge at local, state/territory and national levels.[34] In the hospital setting, national data are captured by the Australian Institute of Health and Welfare in relation to people seen by a specialist palliative care service, where they are appropriately coded as receiving such care.[59] There are two key concerns with this approach: firstly, many patients with palliative care needs may not have the opportunity to see, or indeed need to see, a specialist palliative care service provider and therefore are not captured by the current approach to data collection; and secondly, current data collected describes access and activity rather than quality of care and/or experience. Whilst not disputing that current data is helpful, this program of work would benefit from expansion to consider the full population of people with palliative care needs rather than rely solely on those referred to specialist palliative care services, and to consider data linkage to enable an understanding of clinical care outcomes and experiences.

Internationally to date, Sweden is the only nation to develop a coordinated data collection and reporting infrastructure for palliative care across all care providers irrespective of care setting.[52] They have successfully embedded a focus on processes and outcomes of care for people in their care immediately prior to death. However, their current data collection is heavily weighted on symptom management and physical care and therefore a focus on the broader elements of importance from patient and family perspectives is not provided. In addition, their data collection is triggered by a person's death and therefore does not enable collection of care outcomes or experience across the last year or so of life.

Australia's national palliative care data collection program (the Palliative Care Outcomes Collaboration - PCOC) enables data collection across a broader range of clinical care provision (not solely at the time of death) but is mostly focused on care provided by specialist palliative care providers at the time of writing.[52, 60] PCOC's outcome measures include measurement of symptom burden (i.e., symptom severity and subjective states of distress), performance status and functional dependency. predominantly focus on physical symptoms and function.[60] Importantly, PCOC embeds two key features within their data collection program: an assessment framework to guide clinical care; as well as data collection and a quality improvement process to enable services to reflect on their care, benchmark with other care providers and identify key areas for improvement. Recommendations from the OPAL Project are to enable a focus on all care providers within the hospital setting and also to measure care provision, outcomes and experiences across multiple timepoints for people with palliative care needs, not just at the time of their death. The complexity of achieving this is clearly stated.[11, 34, 52] However, Australia is well-positioned to take this work forward for the hospital setting with a focus on: all care providers, care provision and commissioning, development of data items and key definitions, data linkage from local, state/territory and national levels (particularly experience, outcome and accreditation data already collected), leveraging off work from the Palliative Care Outcomes Collaboration and investing in data infrastructure that enhances efficiency and feasibility of data collection and reporting to assist clinicians in their work. Work to achieve the collection and use of patient reported outcome and experience data has already started in some jurisdictions where linkage of data from electronic medical records, implementation of outcome and experience measurement tools and data linkage are in early stages of development. Aligning with such work will be important in progressing feasible strategies for people with palliative care needs. Measurement at this scale will inform both clinical care and service commissioning and in doing so enable targeted review of funding drivers and resource allocation for people with palliative care needs, across hospitals and related care services.

Lastly, the establishment and resourcing of networks of excellence to inform collaborative improvement at state/territory and national levels, based on data informing quality of care in line with patient and family identified areas of importance, is an important recommendation to inform system-wide improvements cogniscant of local variation and need. These networks provide a forum for clinicians from varied perspectives (rural, metropolitan, diverse populations, specific ward etc.) to disseminate innovative practice that made a positive impact on quality of care informed by explicit outcome data. The importance of this recommendation is twofold: firstly, the collaborative networks will drive improvement efforts without duplicated effort and secondly, such work will continue to underscore that inpatient palliative care is valued and prioritised within the Australian hospital setting.

7.5.2 Considerations at the meso (organisational) level – implementing policy, resourcing, equipping and use of data to inform sustained improvements

The OPAL Project identified the need for explicit support from the hospital executive to enable change and sustainable improvements in inpatient palliative care. Executive requirements were noted to include valuing, resourcing and supporting clinicians and ancillary staff in this work in an ongoing manner. Importantly, enabling change and improvement within the acute care setting is best achieved through articulated support at macro levels (national policy and mandates) that are implemented with executive support (meso) for those providing care (micro).[61-64] The OPAL Project highlights direct interrelations at the macro (national) level with the need for strong policy support and data infrastructure. At the meso (organisational) level, expressed needs correlated with components expressed within the macro and meso domains of the *Innovative Care for Chronic Conditions*[4] and *The Person-centred Practice*[5] *Frameworks,* inclusive of: promoting consistent financing; developing and allocating human resources; ensuring efficient information systems; organising and equipping health care teams for success; encouraging quality through data review, reporting and feedback; and strategic leadership. Specifically, the OPAL Project noted the need to inform, engage with and foster executive level champions for optimal inpatient palliative care. A strong policy environment valuing and prioritising inpatient palliative care is an important component to support this work. Informed by this, hospital executives can then review the methods to enable such care in relation to local resourcing, systems and processes.

Enabling change across an entire organisation is complex. Indeed, it is well documented that achieving sustainable change and improvement in inpatient palliative care provision has remained elusive for some time.[65-69] Furthermore, doing so across the more than 1300 public and private hospitals across Australia,[70] located across all geographical settings (metropolitan and rural) and representative of considerable population and socio-economic diversity, requires careful consideration. A one-size-fits-all approach is not likely to succeed. Rather, the provision of strong policy support, founded in evidence and linked to key resources to assist clinicians to implement within their own systems and processes, is the approach considered most helpful.[63]

The OPAL Project found that the role of the Nursing Unit Manager (NUM) in enabling profound improvement was critical. This aligns with recent work completed that found the NUM is an important and powerful gatekeeper in relation to implementation of evidence and policy within each ward.[63] However, the pressures of time constraints and adequate resourcing are real, and executive support to acknowledge this and assist in navigating such barriers is critical.[63] Furthermore, enabling NUMs to lead in this work requires a focus on their own educational requirements to prepare them for leading change that is based within clinical expertise and critical thinking, rather than implementing an enforced policy – enabling rather than enforcing is key.[63] When considering the diverse needs of people with palliative care needs in the hospital setting, this final point is critically important. A one-size-fits-all approach does not align with person-centred care where clinicians are required to think critically and be innovative in care planning and delivery to truly enable a person to live as well as they can, in the context of advanced illness. Executive support to invest in and adequately resource NUMs to engage with this work is fundamental to enabling successful improvements in inpatient palliative care provision.

7.5.3 Considerations at the micro (ward) level – leadership, innovation, measurement and skill development

The OPAL Project identified the Nursing Unit Manager (NUM) as the key enabler to design and lead improvements in inpatient palliative care. The NUM role can enact changes in line with local requirements connecting patient, clinician and ancillary staff experience with hospital process and policy. However, their need to be enabled (not enforced)[63] to do so through appropriate resourcing, explicit executive support articulated to national policy declaring the importance of this area of care,[8] integrated use of evidence-based tools appropriate for the local clinical area (reducing duplication and enhancing quality)[51, 63] and, importantly, validated approaches to measure patient and family outcomes and experience to inform ongoing models of care provision cannot be overstated. Strengthening inpatient palliative care provision within Australian hospitals cannot be done without all such aspects aligning and supporting such busy, complex and diverse clinical settings (ranging from intensive, critical and high-dependency care units through to all ward areas and emergency departments).

The OPAL Project has developed a robust and comprehensive understanding of what is important for optimal inpatient palliative care, from the perspectives of inpatients with palliative care needs and their families. This must form the foundation of work progressed at the ward (micro) level to ensure all improvement work is focused on that which matters most to those who need this care. In addition to this foundation, the OPAL Project has articulated five key drivers for how change can occur at scale within Australian hospitals, being: positive policy environment, leadership, measurement, innovation and skill development. At the ward (micro) level the focus will predominantly be on leadership (NUM role), measurement to understand how changes are impacting upon patient and family experience, skill development to assist clinicians and ancillary staff in their palliative care work, and innovation to drive improvements within the busy and varied clinical contexts of acute care settings.

There are many examples of excellent palliative care within the hospital setting.[18, 24, 28] The challenge is to enable this experience to be possible across all wards, irrespective of location or population. Innovation at local levels (micro), supported by executive levels (meso) and networked to others working in similar settings is critical to reduce duplicated effort and identify the incremental changes that can contribute to improvements over time.[61, 71] To enable success, the next step in this work must be to work closely with NUMs to understand their perspectives, to work together to identify key areas of concern (informed by data where possible) and then allow the NUMs to be supported whilst innovating to formulate solutions.[61, 62] The solutions to enabling optimal inpatient palliative care will be varied, albeit needing to be founded within available evidence. However, to enable successful commitment to change, NUMs will need to be drivers in both the discussion and implementation of changes.[62] For example, one key area for analysis and innovation is in relation to accurate identification of people who have palliative care needs in the hospital setting. This is the first step in ensuring subsequent care planning and provision informed by the domains of optimal palliative care. There are several validated tools to assist in this work but how they will be implemented in each ward will vary. Imposing this process is neither helpful nor likely to lead to critical thinking or sustainable change.[62, 63] Therefore, starting with a group of NUMs to carefully consider the outcomes from the OPAL Project is an important next step in progressing this work.

7.6 Recommendations

Meta-inference of data across all four Studies within the OPAL Project revealed an evidence-based understanding of what domains are most important for optimal inpatient palliative care, from the perspectives of patients and families, and what the key drivers are to strengthen delivery of care in line with such domains within all wards across Australian hospitals. The *Innovative Care for Chronic Conditions*[4] and *The Person-centred Practice Frameworks* provide useful concepts to draw together this work, with reference to critical elements at the national (macro), health organisational (meso) and ward level (micro) all being focused on enabling optimal inpatient palliative care. Recommendations are framed at these different levels, with relevant interrelations between levels identified as these relate to the identified needs of inpatients with palliative care needs and their families, as shown in Figure 7.3.

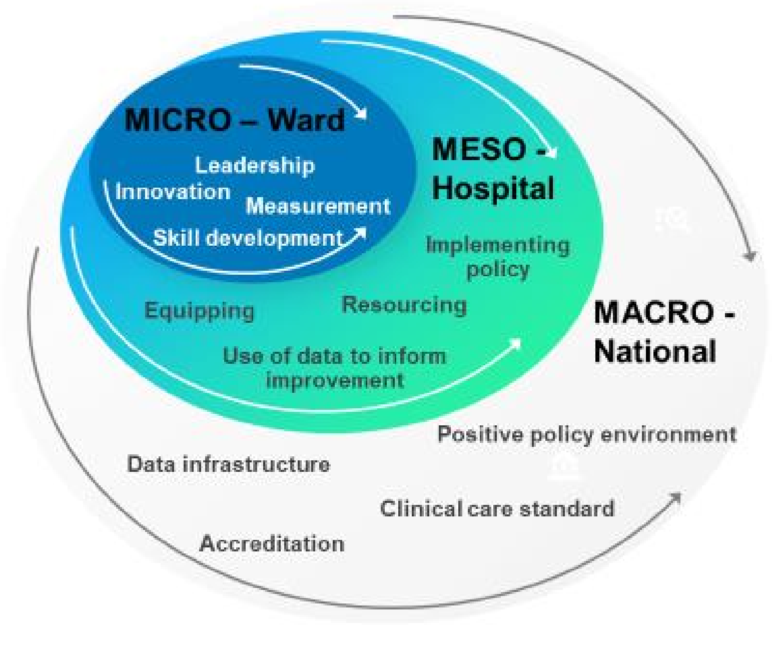


Figure 7.3: Key components of recommendations for systematic improvements in inpatient palliative care within Australian hospitals

7.6.1 Recommendations for Macro level - policy, accreditation, clinical care standard and data infrastructure

Macro level recommendations are centred around the key drivers of enabling a positive policy environment and measurement to inform practice and research, and include recommendations that:

1. national, state and territory palliative care policy acknowledges inpatient palliative care as valued core business for all hospitals and clinicians and articulates appropriate resourcing to enable optimal care;
2. the Australian Commission on Safety and Quality of Health Care's National Safety and Quality Health Service Standards (2nd Ed) are revised where appropriate to reflect the key domains for optimal inpatient palliative care;
3. the national accreditation process incorporates a focus on patient and family experiences of care in addition to their current safety and quality foci;
4. the Australian Commission on Safety and Quality of Health Care adopts a co-design (consumer representatives and clinicians) methodology to develop a clinical care standard for the imminently dying inpatient;
5. key data leaders (inclusive of the Australian Institute of Health and Welfare, the Palliative Care Outcomes Collaboration, national and jurisdictional policy and data experts) develop an efficient system to measure palliative care quality within Australian hospitals with a focus on: all care providers, care provision and commissioning, development of data items and key definitions, data linkage from local, state/territory and national levels (particularly experience, outcome and accreditation data already collected), leveraging from the Palliative Care Outcomes Collaboration and investing in data infrastructure that enhances efficiency and feasibility;
6. jurisdictions establish and resource networks of excellence to inform collaborative improvement at state/territory and national levels based on data informing quality of care in line with patient and family identified areas of importance; and
7. national and jurisdictional policy leaders challenge current funding drivers and resource allocation for people with palliative care needs across hospitals and related care services.

7.6.2 Recommendations for Meso level – implementing policy, resourcing, equipping and use of data to inform sustained improvements

Meso level recommendations are centred around the key drivers of implementing a positive policy environment, measurement to inform practice and local policy, leadership and skill development. Recommendations include that:

1. national project funding is awarded to develop and implement a ‘toolkit’ to provide practical guidance on the importance of optimal inpatient palliative care to hospital executives, informed by national policy, and highlighting the key practice points required to enable such care. This tool needs to outline:
    - the importance of inpatient palliative care and how to determine quality of care provision at each hospital level;
    - how to ensure quality data for palliative care provision is reviewed within a regular and sustained executive level process for review, feedback and improvement planning;
    - suggested resourcing levels for inpatient palliative care considering both the needs of people with palliative care needs and those imminently dying in hospital;
    - suggested educational resources to support clinicians and ancillary staff to provide optimal care including the need to implement mandatory education for all about the core components of palliative care and effective communication;
    - suggested mechanisms to support clinicians in their work considering supervision, de-briefing, reflective practices and self-care supports;
    - suggested mechanisms for executive support in driving improvement and enabling clinicians to navigate noted barriers;
2. national investment is provided for a project focused on equipping and supporting NUMs to lead collaborative improvement work across the sector, supported by local specialist palliative care clinicians;
3. jurisdictions and local health districts develop a mechanism to reward excellence in care, both within an organisation and connecting to regional / state / territory and national networks of excellence, to acknowledge the hard work of clinicians involved and to enable sharing of excellent practice;
4. local health districts review all policies relevant to palliative care provision and ensure alignment with the domains of importance for optimal inpatient palliative care (e.g. policies related to care of a person at the time of death).

7.6.3 Recommendations for Micro level – leadership, innovation, measurement and skill development

Micro level recommendations are founded upon the key drivers of leadership centred around the role of the NUM, innovation to drive meaningful and sustainable change, measurement to inform practice and ongoing focus for improvements and education to enable skill development. Recommendations include that:

1. NUMs, hospital executives, quality experts, specialist palliative care clinicians and palliative care consumers co-design a targeted project, to be led by NUMs, focused on how to optimise inpatient palliative care, based on the domains revealed as most important for patients and families, via the OPAL Project. This project must incorporate planning in relation to how to enable such care at each local site, how wards would know if care experience was occurring in line with these domains and required tools to support optimal care provision;
2. specialist palliative care clinicians, NUMs and palliative care consumers co-design two education programs (one for clinicians and one for ancillary staff) focused on core principles of palliative care and effective communication (tailored from the nationally provided resources), to be delivered to all clinicians and ancillary staff annually.

7.7 Significance of the OPAL Project

The OPAL Project is the first body of work to comprehensively synthesise data to inform domains of importance for optimal inpatient palliative care exclusively from the perspectives of patients with palliative care needs, and their families. Taking this work further, the OPAL Project has also informed how to enable such care within the Australian hospital setting. This is important work that aligns with national standards,[10, 72] strategies and policies[34-42] targeting quality palliative care and provides a robust foundation from which to move forward.

7.8 Strengths and Limitations

The strength of the OPAL Project is the meta-inference of data from different Studies identifying the key domains of importance for optimal inpatient palliative care from the perspectives of patients with palliative care needs and their families. These data have been collected in a systematic and rigorous way (representing thousands of perspectives) and were mixed using joint display tables informing a robust base to work from when designing changes to enable improvements. The key limitation in relation to this is the lack of cultural diversity reflected in the outcomes from this work. Taking these domains to diverse populations and Australia's Indigenous population is important as this work progresses to ensure their views and needs are represented in future improvement initiatives.

The work completed to inform the key drivers for enabling optimal care in the Australian hospital setting is based on the domains of optimal care integrated with data from Studies 3 and 4. Study 3 involved key experts to ensure a realistic and far-reaching view of practice and policy globally. However, this was a cross-sectional snapshot at a point of time (November 2017 – February 2017). Experts were sourced via a Global Quality of Death Index[73] (and snowballing) and it is possible that not all the professionals with expertise in this field were consulted and/or progress and changes in such work through to current day may not be comprehensively recorded. Also, the decision was made to limit the review of available quality indicators to those available for national implementation in order to inform wide scale system level change. However, there will be indicator work underway at local levels and by research teams that can provide useful considerations as this work progresses.

7.9 Conclusions

Inpatient palliative care requires a concerted effort to enable improvements aligned with the care that matters most to patients with palliative care needs and their families.[1, 2, 18, 29-31] The OPAL Project provides a robust platform for clinicians, health administrators and policy experts to work from in relation to their design of policy, measurement to drive improvement and skill development. System-level improvement will only occur with interrelated work across the macro (national), meso (hospital) and micro (ward) levels. It is fundamentally important that all such work remains grounded in what patients and families state is important. Ongoing consumer input into the design of changes remains critical to ensure their voice does not become diluted as translation into clinical structures and processes occurs.

Implications for practice

A consistent message about what inpatients with palliative care needs and their families require for optimal care has been provided for three decades now.[1, 2, 32] It is time for practice to align with these needs, supported by positive policy frameworks and adequate resourcing. The opportunity for nurses to innovate and lead this change is clear, centred upon the NUM role, whilst networked with specialist palliative care clinicians, quality experts and nurses delivering ward-based care, who will be ideally positioned to articulate current barriers and frustrations to optimal care provision. Embedding feasible measurement options for clinicians to use in both their care delivery and improvement work is a vital component of this work that is currently absent in generalist inpatient palliative care.

Implications for future research

The question of what is needed for patients in relation to inpatient palliative care is well answered from White Northern Hemisphere and Australian perspectives. Future research to understand the articulated domains of importance from the perspectives of people from culturally diverse and

Indigenous backgrounds is required. Given representative recruitment for such varied populations and perspectives is difficult to achieve for this vulnerable population, the suggested next step is to take this work to appropriate representative bodies and discuss their views about how to co-design research studies to address this knowledge gap.

The question of how to drive change in line with noted areas of importance is reliant on understanding how to measure such care to understand and evaluate change. How to do this in relation to which tools, datasets and indicators are feasible and acceptable requires attention.[51] Better understanding data linkage opportunities at jurisdictional and national levels is important both to inform clinical practice improvements as well as benchmarking and collaboration opportunities.

Driving improvements for inpatients with palliative care needs will rely on innovative approaches to change implemented at local levels (micro). There is opportunity to frame this work in two ways: quality improvement initiatives or research. It will be important to support clinicians to frame their innovations appropriately in order to build evidence and understanding about optimal inpatient palliative care provision, thereby contributing to wide-scale and sustainable improvements across the acute care sector nationally and indeed, internationally.

7.10 References

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Appendix 1: Copyright permissions pertaining to published work contained within this thesis

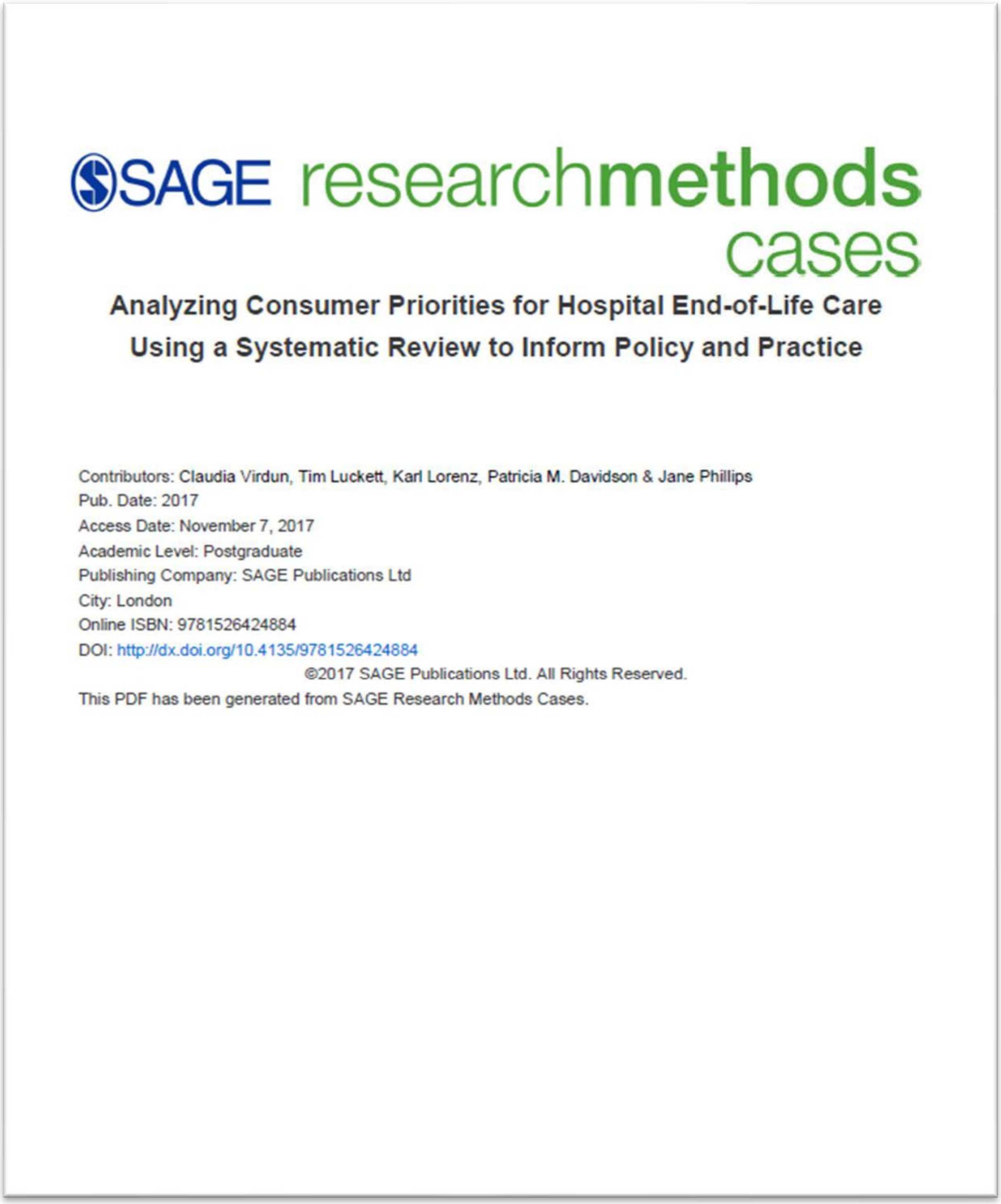
The OPAL Project has published five manuscripts and has another two under peer review (edited version reported in Chapters 4 and 6). This appendix details the copyright permissions in relation to the five published manuscripts detailed below. Three of these publications are presented as lightly edited versions of the final post-referee article. Two publications are provided as PDF copies of the published versions.

Publication reference	**Copyright permissions**
Virdun, C., Luckett, T., Davidson, P. M., & Phillips, J. (2015). Dying in the hospital setting: A systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. *Palliative Medicine*, 29(9), 774-796.	Via a search on Sherpa/Romeo 25/04/20: Author's cannot publish the PDF of the published version of this article. However, archiving of the final draft post-refereeing is permitted. Therefore, not attached in this appendix – edited version reported in Chapter 2.
Virdun, C., Luckett, T., Lorenz, K., Davidson, P. M., & Phillips, J. (2016). Dying in the hospital setting: A meta-synthesis identifying the elements of end-of-life care that patients and their families describe as being important. *Palliative Medicine*, 31 (7), 587–601.	Via a search on Sherpa/Romeo 25/04/20: http://sherpa.ac.uk/romeo/search.php Author's cannot publish the PDF of the published version of this article. However, archiving of the final draft post-refereeing is permitted. Therefore, not attached in this appendix – edited version reported in Chapter 2.
Virdun, C., Luckett, T., Lorenz, K., Davidson, P. M., & Phillips, J. (2017). Analyzing Consumer Priorities for Hospital End-of-Life Care Using a Systematic Review to Inform Policy and	Email from Michael Gill, Commissioning editor on 27/02/20: "Reuse Rights / Permitted Rights: SAGE grants to Contributor a non-exclusive license to use and reproduce, after the initial publication of the Contribution in the Work, excerpts from the Contribution in any literary work written by a Contributor; and the entire Work in any literary work where a Contributor is the primary (main) contributor or editor and in

Practice. *SAGE Research Methods Cases.*	photocopies for use by a Contributor in classroom teaching, provided that appropriate attribution and full bibliographic citation to the Work is given in each instance." The PDF of this published article is contained within this appendix.
Virdun, C., Luckett, T., Lorenz, K. A., & Phillips, J. (2018). National quality indicators and policies from 15 countries leading in adult end-of-life care: a systematic environmental scan. *BMJ Supportive & Palliative Care*, 8(2), 145-154.	Via a search on Sherpa/Romeo 25/04/20: http://sherpa.ac.uk/romeo/search.php Author's cannot publish the PDF of the published version of this article. However, archiving of the final draft post-refereeing is permitted. Therefore, not attached in this appendix – edited version reported in Chapter 6.
Virdun, C., Luckett, T., Gilmore, I., Brassil, M., Lilian, R., Lorenz, K., & Phillips, J. (2019). Involving consumers with palliative care needs and their families in research: A case study. *Collegian*, 26(6), 645-650.	Email from Niranjana Sathyamoorthy, Journal Manager on 28/02/20: "you can include a PDF of the article in thesis and post that thesis on University's repository, however the PDF must be embedded in your thesis and the article not made available via the repository as a standalone piece of content." The PDF of this published article is contained within this appendix.

With respect to relevant permissions obtained as recorded above, the following two PDFs are provided:

- Virdun, C., Luckett, T., Lorenz, K., Davidson, P. M., & Phillips, J. (2017). Analyzing Consumer Priorities for Hospital End-of-Life Care Using a Systematic Review to Inform Policy and Practice. *SAGE Research Methods Cases.*
- Virdun, C., Luckett, T., Gilmore, I., Brassil, M., Lilian, R., Lorenz, K., & Phillips, J. (2019). Involving consumers with palliative care needs and their families in research: A case study. *Collegian*, 26(6), 645-650.



SAGE researchmethods cases

Analyzing Consumer Priorities for Hospital End-of-Life Care Using a Systematic Review to Inform Policy and Practice

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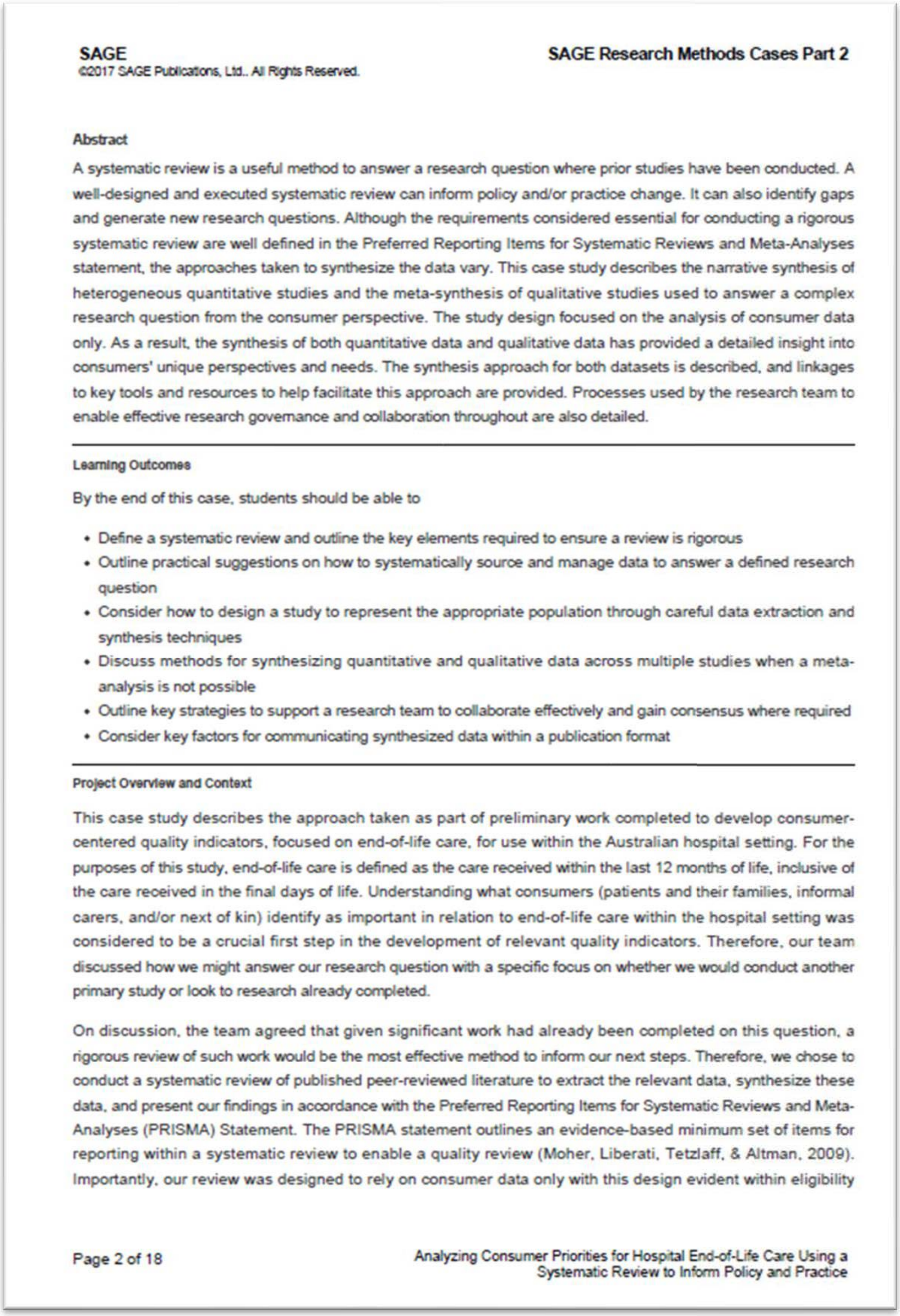

Abstract

A systematic review is a useful method to answer a research question where prior studies have been conducted. A well-designed and executed systematic review can inform policy and/or practice change. It can also identify gaps and generate new research questions. Although the requirements considered essential for conducting a rigorous systematic review are well defined in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement, the approaches taken to synthesize the data vary. This case study describes the narrative synthesis of heterogeneous quantitative studies and the meta-synthesis of qualitative studies used to answer a complex research question from the consumer perspective. The study design focused on the analysis of consumer data only. As a result, the synthesis of both quantitative data and qualitative data has provided a detailed insight into consumers' unique perspectives and needs. The synthesis approach for both datasets is described, and linkages to key tools and resources to help facilitate this approach are provided. Processes used by the research team to enable effective research governance and collaboration throughout are also detailed.

Learning Outcomes

By the end of this case, students should be able to

- Define a systematic review and outline the key elements required to ensure a review is rigorous
- Outline practical suggestions on how to systematically source and manage data to answer a defined research question
- Consider how to design a study to represent the appropriate population through careful data extraction and synthesis techniques
- Discuss methods for synthesizing quantitative and qualitative data across multiple studies when a meta-analysis is not possible
- Outline key strategies to support a research team to collaborate effectively and gain consensus where required
- Consider key factors for communicating synthesized data within a publication format

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Project Overview and Context

This case study describes the approach taken as part of preliminary work completed to develop consumer-centered quality indicators, focused on end-of-life care, for use within the Australian hospital setting. For the purposes of this study, end-of-life care is defined as the care received within the last 12 months of life, inclusive of the care received in the final days of life. Understanding what consumers (patients and their families, informal carers, and/or next of kin) identify as important in relation to end-of-life care within the hospital setting was considered to be a crucial first step in the development of relevant quality indicators. Therefore, our team discussed how we might answer our research question with a specific focus on whether we would conduct another primary study or look to research already completed.

On discussion, the team agreed that given significant work had already been completed on this question, a rigorous review of such work would be the most effective method to inform our next steps. Therefore, we chose to conduct a systematic review of published peer-reviewed literature to extract the relevant data, synthesize these data, and present our findings in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Statement. The PRISMA statement outlines an evidence-based minimum set of items for reporting within a systematic review to enable a quality review (Moher, Liberati, Tetzlaff, & Altman, 2009). Importantly, our review was designed to rely on consumer data only with this design evident within eligibility

criteria, data extraction, and synthesis:

> A systematic review is a review of a clearly formulated question that uses systematic and explicit methods to identify, select, and critically appraise relevant research, and to collect and analyze data from the studies that are included in the review. (Moher et al., 2009, p. 334)

In the era of evidence-based medicine, systematic reviews are required to adhere to the same rigorous methodological standards as primary studies. The subjective nature of a non-systematic literature review, whereby the evidence or included studies are chosen selectively (not systematically) based on what appear to be most suited to the research question, increases the likelihood of generating biased results and reducing confidence in the review findings. The emergence of checklists for reporting such as the PRISMA statement has greatly enhanced transparency and reproducibility of methods, and most journals now require manuscripts reporting reviews to adhere to this guidance. Furthermore, explicit guidance about review design and conduct is available from the Cochrane Collaboration and ought to inform planning (Higgins, 2008).

Ensuring that systematic reviews are conducted and reported using the highest standards is essential because, given the plethora of reviews, the methodologic rigor is rated using various rating systems, and the extent to which reviews contribute to the evidence synthesis process is ultimately determined by the level of quality their conduct and reporting adhere to (Shea et al., 2007). Although quality of conduct and quality of reporting are two different aspects to a review, the reader can only make an informed judgment about quality of conduct if a review has reported all the necessary details.

Each stage of a systematic review requires careful thought and consensus discussion within the research team. That is, agreement on the research aim, eligibility criteria, search terms, and databases to be searched along with other information sources is required prior to commencing the search itself. Following this, detailed data extraction occurs to inform both a quality assessment and the synthesis itself. In relation to quality, agreement is required on the purpose and means of assessing the quality of included work and how this affects inclusion/exclusion. Finally, clarity about data and the approach for data synthesis are fundamental to ensuring a quality review occurs and contributes to development of new knowledge.

Completing this planning work within a research team requires meetings for planning, discussion, and debate. Importantly, the governance structures for our work were discussed and agreed upon at the commencement of the study and included the following: a schedule for regular meetings (inclusive of face-to-face and teleconference options to enable international collaboration); planning for recording of meetings, outcomes, and key actions (this was the role of the PhD student to maintain); and a shared repository for working documents and the valuing of debate to ensure mutual agreement. Our meetings often highlighted additional questions for further consideration, and these were often managed by group email until a final protocol for the research was available. Careful attention to each team member's thoughts and ideas was managed through record keeping and updating documents accordingly. As newer versions of work became available, earlier iterations were archived for future review if needed.

This approach valued the iterative nature of unfolding research through ongoing reflection and refinement as required. Although published reviews seem quite straightforward, our experience of getting to this stage was one of needing ongoing reflection, discussion, and debate with an explicit focus on our research aim to guide thinking and avoid project creep. In addition, it is vital to establish clear governance procedures for the research team to value all contributions and ensure collegiality, consensus, and confidence in publishing results collectively. Our experience reflects one of rigorous debate throughout different stages of the study, which led to improved critical analysis of our work and an improved outcome. We did not experience any discord given the team remained respectful of all views and considered how these did or did not align to our research aim and, therefore, in what ways they affected study planning, conduct, or reporting.

Research aims underpin work completed and in relation to reviews inform either comprehensively synthesizing all results from included primary studies or focusing on specific outcomes or other measures. Our review of qualitative studies chose to prioritize patient and family views over the views of the authors of the primary studies, and therefore, our search design, data extraction, and synthesis methods continued to focus on the voice of the consumer through extraction and use of their raw data rather than "Results" sections in their entirety as is more commonly the case. Indeed, this approach also occurred within our quantitative review (Virdun, Luckett, Davidson, & Phillips, 2015) where any data from health professionals were excluded from analysis.

This case study describes the first stage of our program of research. The point of difference in relation to our work was the design of our review to focus purely on consumer data. It is important to think about and design to enable review results to represent a particular population, and this case study explains one approach to achieve this.

Research Practicalities

This review had two key areas of consideration in relation to research practicalities, namely,

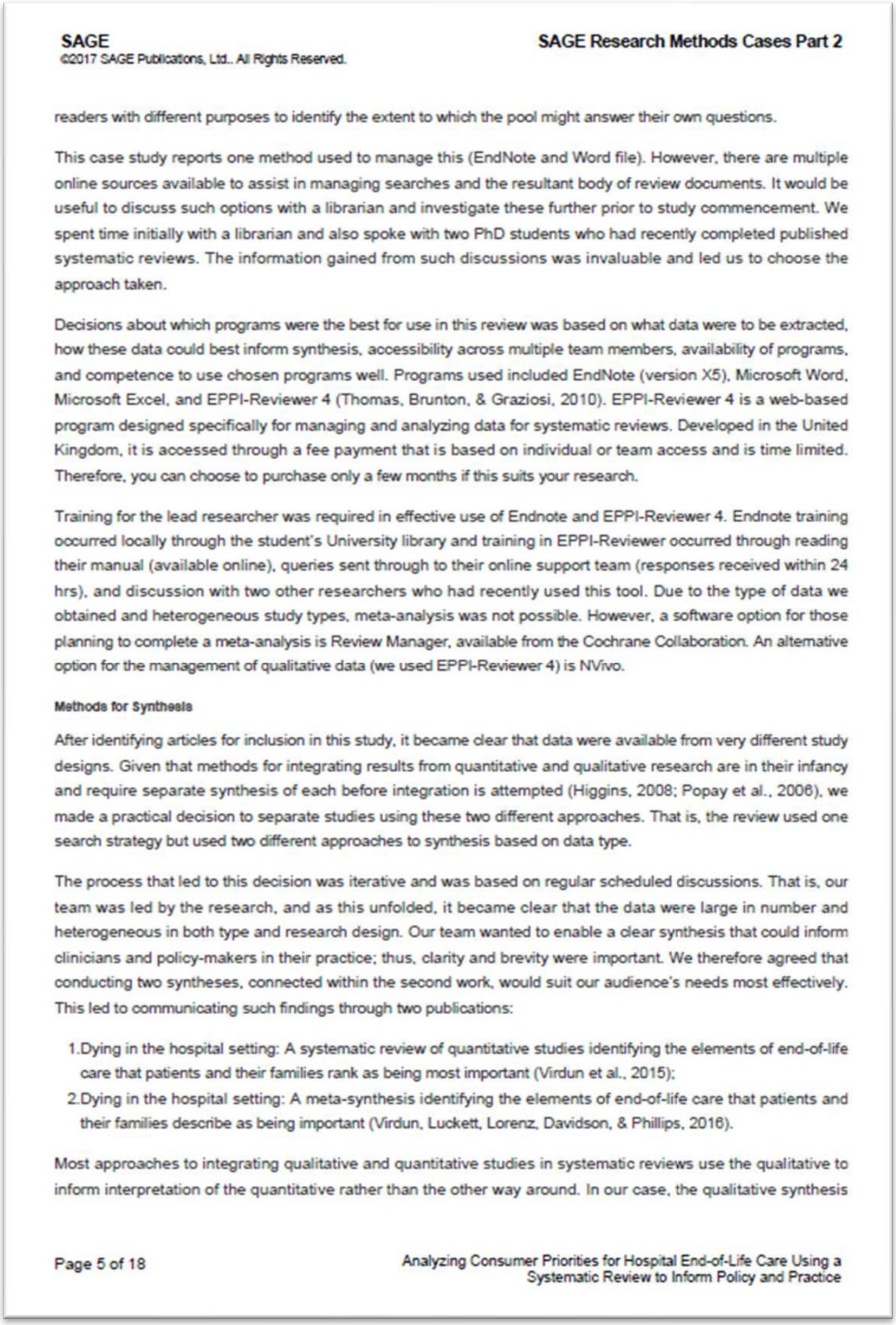
1. How to manage the large number of articles retrieved by the original search and determine which programs would be the best ones to use to support data extraction, analysis, and synthesis (article and data management);
2. How to synthesize data from heterogeneous study designs, including both quantitative and qualitative research (methods for synthesis).

Article and Data Management

We retrieved close to 2,000 articles from a search across nine electronic literature databases (Virdun et al., 2015). In addition to this, further articles were found via desktop searching of the Internet and through handsearching the reference lists of included articles. Consideration about how to best manage articles retrieved from each search was important to ensure accurate conduct and reporting in accordance with the PRISMA method. A decision was made to import all search results into EndNote (version X5), consolidate this list via the "remove duplicates" function, and then manage the title and abstract review through the use of smart groups.

EndNote is a software package that supports referencing, managing a library, and organizing such material. This was freely available to the team, appeared to enable the key functions we required, and our institution provided librarian support to assist with learning and troubleshooting. All potential articles for inclusion were managed within one smart group for ease of review by the whole team. Smart groups within EndNote are created by the author and correspond with key topic areas. For example, you can create a smart group for "included" and within this group; all articles to be included in the synthesis are available. This practical approach had both positive and negative aspects when implemented, as described later.

In addition to the use of EndNote for managing imported searches, a detailed document that outlines search strategies used and results obtained is also fundamentally important. The use of both EndNote with this additional search overview document (Microsoft Word file) ensures the search used could be reproduced, building confidence that the pool of studies was likely to be comprehensive, given the research aims stated, and enabling



readers with different purposes to identify the extent to which the pool might answer their own questions.

This case study reports one method used to manage this (EndNote and Word file). However, there are multiple online sources available to assist in managing searches and the resultant body of review documents. It would be useful to discuss such options with a librarian and investigate these further prior to study commencement. We spent time initially with a librarian and also spoke with two PhD students who had recently completed published systematic reviews. The information gained from such discussions was invaluable and led us to choose the approach taken.

Decisions about which programs were the best for use in this review was based on what data were to be extracted, how these data could best inform synthesis, accessibility across multiple team members, availability of programs, and competence to use chosen programs well. Programs used included EndNote (version X5), Microsoft Word, Microsoft Excel, and EPPI-Reviewer 4 (Thomas, Brunton, & Graziosi, 2010). EPPI-Reviewer 4 is a web-based program designed specifically for managing and analyzing data for systematic reviews. Developed in the United Kingdom, it is accessed through a fee payment that is based on individual or team access and is time limited. Therefore, you can choose to purchase only a few months if this suits your research.

Training for the lead researcher was required in effective use of Endnote and EPPI-Reviewer 4. Endnote training occurred locally through the student's University library and training in EPPI-Reviewer occurred through reading their manual (available online), queries sent through to their online support team (responses received within 24 hrs), and discussion with two other researchers who had recently used this tool. Due to the type of data we obtained and heterogeneous study types, meta-analysis was not possible. However, a software option for those planning to complete a meta-analysis is Review Manager, available from the Cochrane Collaboration. An alternative option for the management of qualitative data (we used EPPI-Reviewer 4) is NVivo.

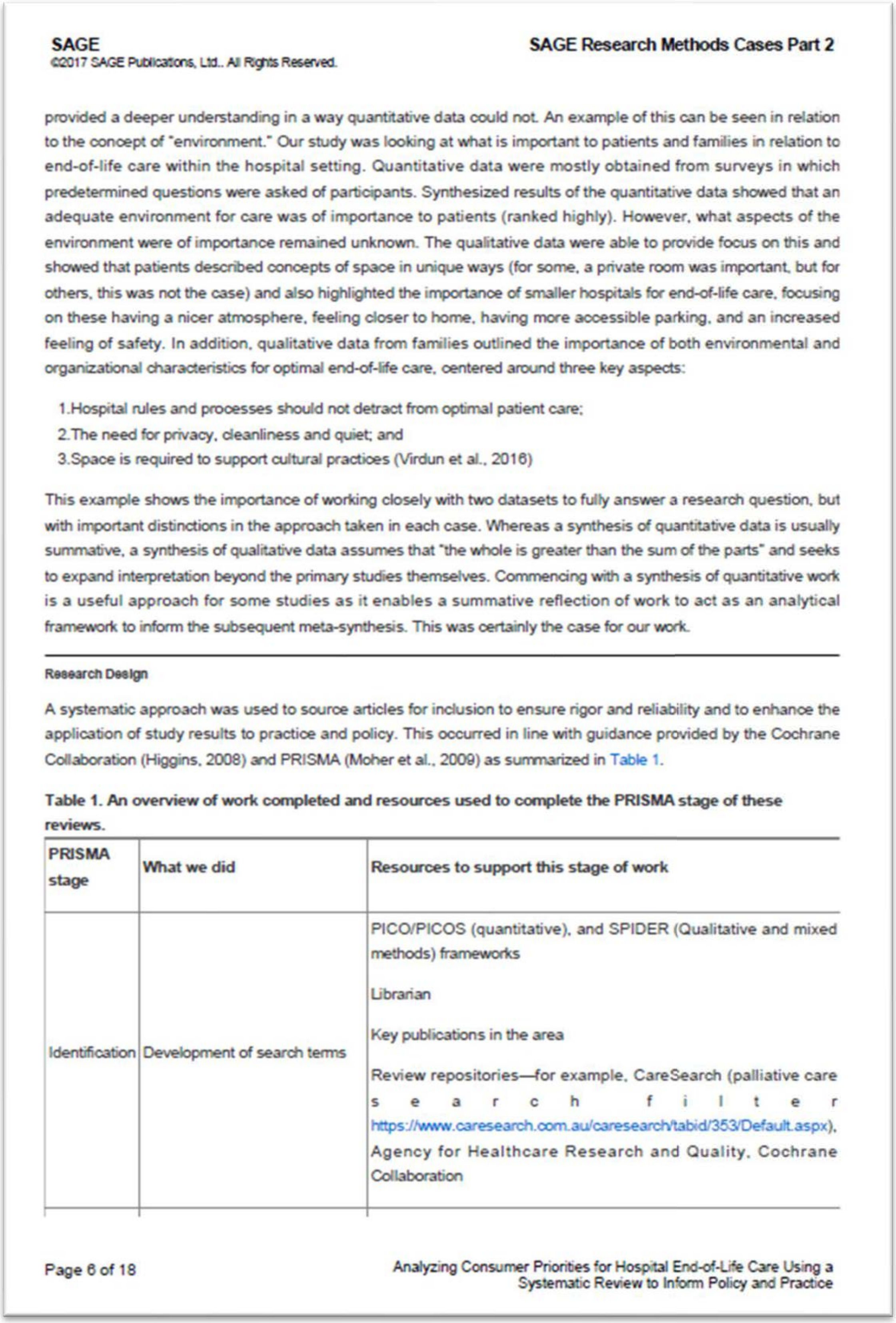
Methods for Synthesis

After identifying articles for inclusion in this study, it became clear that data were available from very different study designs. Given that methods for integrating results from quantitative and qualitative research are in their infancy and require separate synthesis of each before integration is attempted (Higgins, 2008; Popay et al., 2006), we made a practical decision to separate studies using these two different approaches. That is, the review used one search strategy but used two different approaches to synthesis based on data type.

The process that led to this decision was iterative and was based on regular scheduled discussions. That is, our team was led by the research, and as this unfolded, it became clear that the data were large in number and heterogeneous in both type and research design. Our team wanted to enable a clear synthesis that could inform clinicians and policy-makers in their practice; thus, clarity and brevity were important. We therefore agreed that conducting two syntheses, connected within the second work, would suit our audience's needs most effectively. This led to communicating such findings through two publications:

1. Dying in the hospital setting: A systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important (Virdun et al., 2015);
2. Dying in the hospital setting: A meta-synthesis identifying the elements of end-of-life care that patients and their families describe as being important (Virdun, Luckett, Lorenz, Davidson, & Phillips, 2016).

Most approaches to integrating qualitative and quantitative studies in systematic reviews use the qualitative to inform interpretation of the quantitative rather than the other way around. In our case, the qualitative synthesis



provided a deeper understanding in a way quantitative data could not. An example of this can be seen in relation to the concept of "environment." Our study was looking at what is important to patients and families in relation to end-of-life care within the hospital setting. Quantitative data were mostly obtained from surveys in which predetermined questions were asked of participants. Synthesized results of the quantitative data showed that an adequate environment for care was of importance to patients (ranked highly). However, what aspects of the environment were of importance remained unknown. The qualitative data were able to provide focus on this and showed that patients described concepts of space in unique ways (for some, a private room was important, but for others, this was not the case) and also highlighted the importance of smaller hospitals for end-of-life care, focusing on these having a nicer atmosphere, feeling closer to home, having more accessible parking, and an increased feeling of safety. In addition, qualitative data from families outlined the importance of both environmental and organizational characteristics for optimal end-of-life care, centered around three key aspects:

1. Hospital rules and processes should not detract from optimal patient care;
2. The need for privacy, cleanliness and quiet; and
3. Space is required to support cultural practices (Virdun et al., 2016)

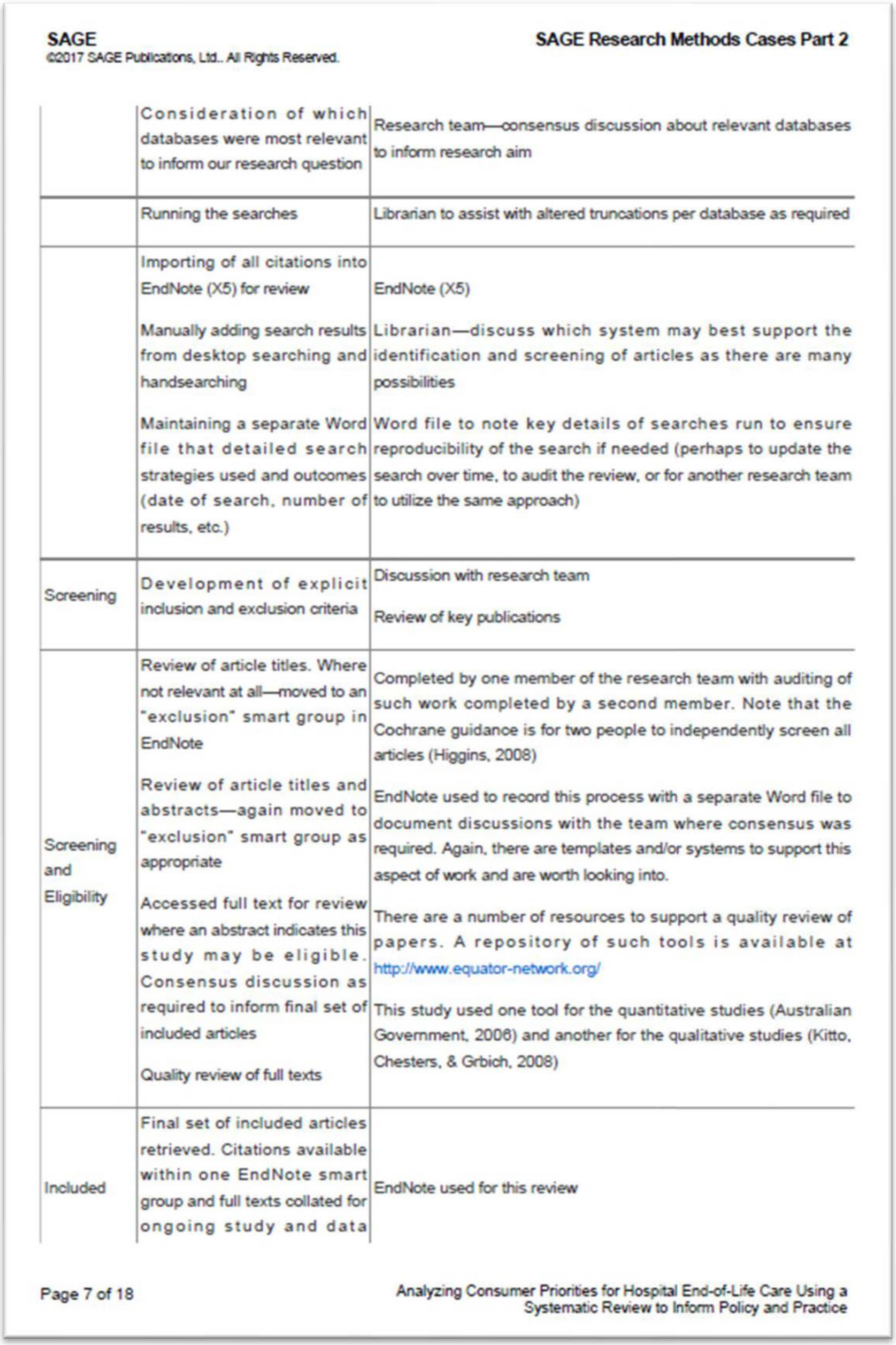
This example shows the importance of working closely with two datasets to fully answer a research question, but with important distinctions in the approach taken in each case. Whereas a synthesis of quantitative data is usually summative, a synthesis of qualitative data assumes that "the whole is greater than the sum of the parts" and seeks to expand interpretation beyond the primary studies themselves. Commencing with a synthesis of quantitative work is a useful approach for some studies as it enables a summative reflection of work to act as an analytical framework to inform the subsequent meta-synthesis. This was certainly the case for our work.

Research Design

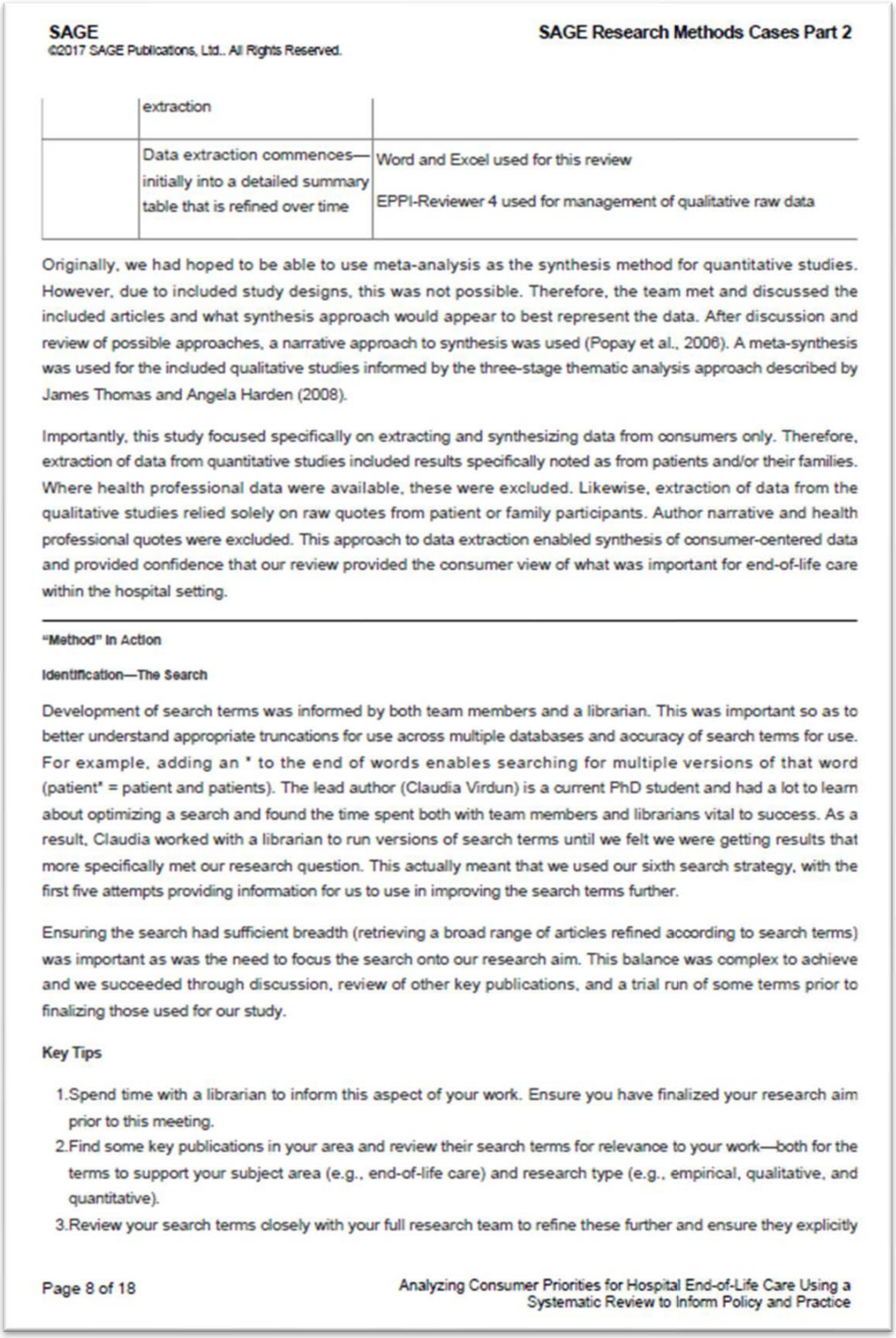
A systematic approach was used to source articles for inclusion to ensure rigor and reliability and to enhance the application of study results to practice and policy. This occurred in line with guidance provided by the Cochrane Collaboration (Higgins, 2008) and PRISMA (Moher et al., 2009) as summarized in Table 1.

Table 1. An overview of work completed and resources used to complete the PRISMA stage of these reviews.

PRISMA stage	What we did	Resources to support this stage of work
Identification	Development of search terms	PICO/PICOS (quantitative), and SPIDER (Qualitative and mixed methods) frameworks Librarian Key publications in the area Review repositories—for example, CareSearch (palliative care search filter https://www.caresearch.com.au/caresearch/tabid/353/Default.aspx), Agency for Healthcare Research and Quality, Cochrane Collaboration



	Consideration of which databases were most relevant to inform our research question	Research team—consensus discussion about relevant databases to inform research aim
	Running the searches	Librarian to assist with altered truncations per database as required
	Importing of all citations into EndNote (X5) for review Manually adding search results from desktop searching and handsearching Maintaining a separate Word file that detailed search strategies used and outcomes (date of search, number of results, etc.)	EndNote (X5) Librarian—discuss which system may best support the identification and screening of articles as there are many possibilities Word file to note key details of searches run to ensure reproducibility of the search if needed (perhaps to update the search over time, to audit the review, or for another research team to utilize the same approach)
Screening	Development of explicit inclusion and exclusion criteria	Discussion with research team Review of key publications
Screening and Eligibility	Review of article titles. Where not relevant at all—moved to an "exclusion" smart group in EndNote Review of article titles and abstracts—again moved to "exclusion" smart group as appropriate Accessed full text for review where an abstract indicates this study may be eligible. Consensus discussion as required to inform final set of included articles Quality review of full texts	Completed by one member of the research team with auditing of such work completed by a second member. Note that the Cochrane guidance is for two people to independently screen all articles (Higgins, 2008) EndNote used to record this process with a separate Word file to document discussions with the team where consensus was required. Again, there are templates and/or systems to support this aspect of work and are worth looking into. There are a number of resources to support a quality review of papers. A repository of such tools is available at http://www.equator-network.org/ This study used one tool for the quantitative studies (Australian Government, 2006) and another for the qualitative studies (Kitto, Chesters, & Grbich, 2008)
Included	Final set of included articles retrieved. Citations available within one EndNote smart group and full texts collated for ongoing study and data	EndNote used for this review



	extraction	
	Data extraction commences—initially into a detailed summary table that is refined over time	Word and Excel used for this review EPPI-Reviewer 4 used for management of qualitative raw data

Originally, we had hoped to be able to use meta-analysis as the synthesis method for quantitative studies. However, due to included study designs, this was not possible. Therefore, the team met and discussed the included articles and what synthesis approach would appear to best represent the data. After discussion and review of possible approaches, a narrative approach to synthesis was used (Popay et al., 2006). A meta-synthesis was used for the included qualitative studies informed by the three-stage thematic analysis approach described by James Thomas and Angela Harden (2008).

Importantly, this study focused specifically on extracting and synthesizing data from consumers only. Therefore, extraction of data from quantitative studies included results specifically noted as from patients and/or their families. Where health professional data were available, these were excluded. Likewise, extraction of data from the qualitative studies relied solely on raw quotes from patient or family participants. Author narrative and health professional quotes were excluded. This approach to data extraction enabled synthesis of consumer-centered data and provided confidence that our review provided the consumer view of what was important for end-of-life care within the hospital setting.

"Method" In Action

Identification—The Search

Development of search terms was informed by both team members and a librarian. This was important so as to better understand appropriate truncations for use across multiple databases and accuracy of search terms for use. For example, adding an * to the end of words enables searching for multiple versions of that word (patient* = patient and patients). The lead author (Claudia Virdun) is a current PhD student and had a lot to learn about optimizing a search and found the time spent both with team members and librarians vital to success. As a result, Claudia worked with a librarian to run versions of search terms until we felt we were getting results that more specifically met our research question. This actually meant that we used our sixth search strategy, with the first five attempts providing information for us to use in improving the search terms further.

Ensuring the search had sufficient breadth (retrieving a broad range of articles refined according to search terms) was important as was the need to focus the search onto our research aim. This balance was complex to achieve and we succeeded through discussion, review of other key publications, and a trial run of some terms prior to finalizing those used for our study.

Key Tips

1. Spend time with a librarian to inform this aspect of your work. Ensure you have finalized your research aim prior to this meeting.
2. Find some key publications in your area and review their search terms for relevance to your work—both for the terms to support your subject area (e.g., end-of-life care) and research type (e.g., empirical, qualitative, and quantitative).
3. Review your search terms closely with your full research team to refine these further and ensure they explicitly

relate to your research question and will draw the data type (e.g., qualitative, quantitative, and empirical) you are seeking.

4. Run some "trial searches" so as to review the accuracy of your chosen search terms and refine as necessary. It is very helpful to do this with a librarian if possible.

Screening and Eligibility

Taking the time to discuss screening methods and inclusion criteria in detail at the commencement of our study was very important and indeed fundamental to the success of both systematic reviews. That is, you need to be clear from the outset (prior to the search itself) about what you are seeking to find and understand why such factors are important to the quality of your work. We held focused meetings to enable this development with email feedback for further refinements as needed. Being new to this work, Claudia underestimated the importance of this step (she was keen to jump into the search and get going!) and in hindsight can see how important this stage of planning and preparation is.

Once the eligibility criteria were clear, reviewing articles for inclusion and exclusion was mostly straightforward. Where there was any ambiguity or disagreement, several members of the team reviewed these for discussion and consensus agreement. Disagreements occurred around two aspects of article screening: quality review and inclusion for some articles that perhaps had some aspects of importance but predominantly did not answer the research question. Claudia kept a record of such articles or quality screening disparities (screened by two team members independently) and discussed these at scheduled meetings for team consensus. Careful listening to all team members and collegial working enabled this to be an easy process to engage in.

It is important to keep a record of agreement consistency and predefine approaches to rating of articles. If possible, dual review at all steps is the ideal approach to decrease the effects of bias from one author's perspectives and also to draw focus to areas where differences have occurred and discussion is therefore warranted.

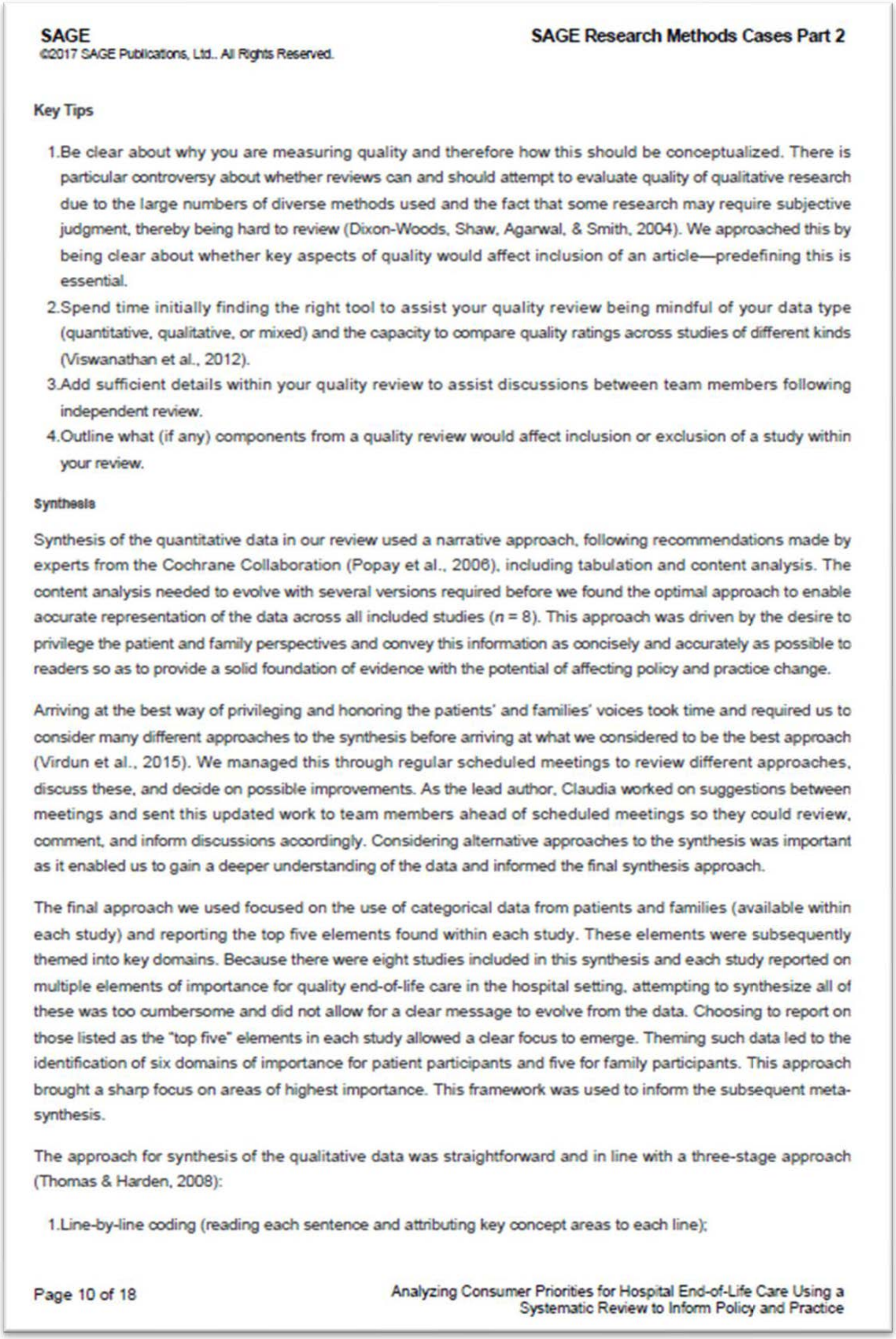
Key Tips

1. Define the inclusion and exclusion criteria carefully—be specific and take time to get this right. Ensure you are led by your research question for this.
2. Develop a document to record agreement consistency and consensus discussions.
3. Create smart groups within EndNote to match your exclusion categories to inform your PRISMA reporting.

Eligibility—Quality Review of Included Articles

To ensure a rigorous quality review, it was important for our team to use different appraisal tools for the two different datasets we worked with. That is, we used tools specifically designed for either quantitative studies or qualitative studies. For our quantitative review, we used a tool that had been designed for use within some recently published palliative care guidelines (Australian Government, 2006), and for our qualitative review, we used a tool designed specifically for qualitative studies (Kitto et al., 2008). This work was completed independently by two members of the team using an Excel template.

This was a great approach as it allowed the lead author, Claudia, to review the completed screens, highlight any differences in ratings, and bring this to a meeting for full team discussion prior to finalization. This supported full team engagement in this process, supported learning for Claudia as a PhD student, and provided confidence in the rigor of this screening process.



Key Tips

1. Be clear about why you are measuring quality and therefore how this should be conceptualized. There is particular controversy about whether reviews can and should attempt to evaluate quality of qualitative research due to the large numbers of diverse methods used and the fact that some research may require subjective judgment, thereby being hard to review (Dixon-Woods, Shaw, Agarwal, & Smith, 2004). We approached this by being clear about whether key aspects of quality would affect inclusion of an article—predefining this is essential.
2. Spend time initially finding the right tool to assist your quality review being mindful of your data type (quantitative, qualitative, or mixed) and the capacity to compare quality ratings across studies of different kinds (Viswanathan et al., 2012).
3. Add sufficient details within your quality review to assist discussions between team members following independent review.
4. Outline what (if any) components from a quality review would affect inclusion or exclusion of a study within your review.

Synthesis

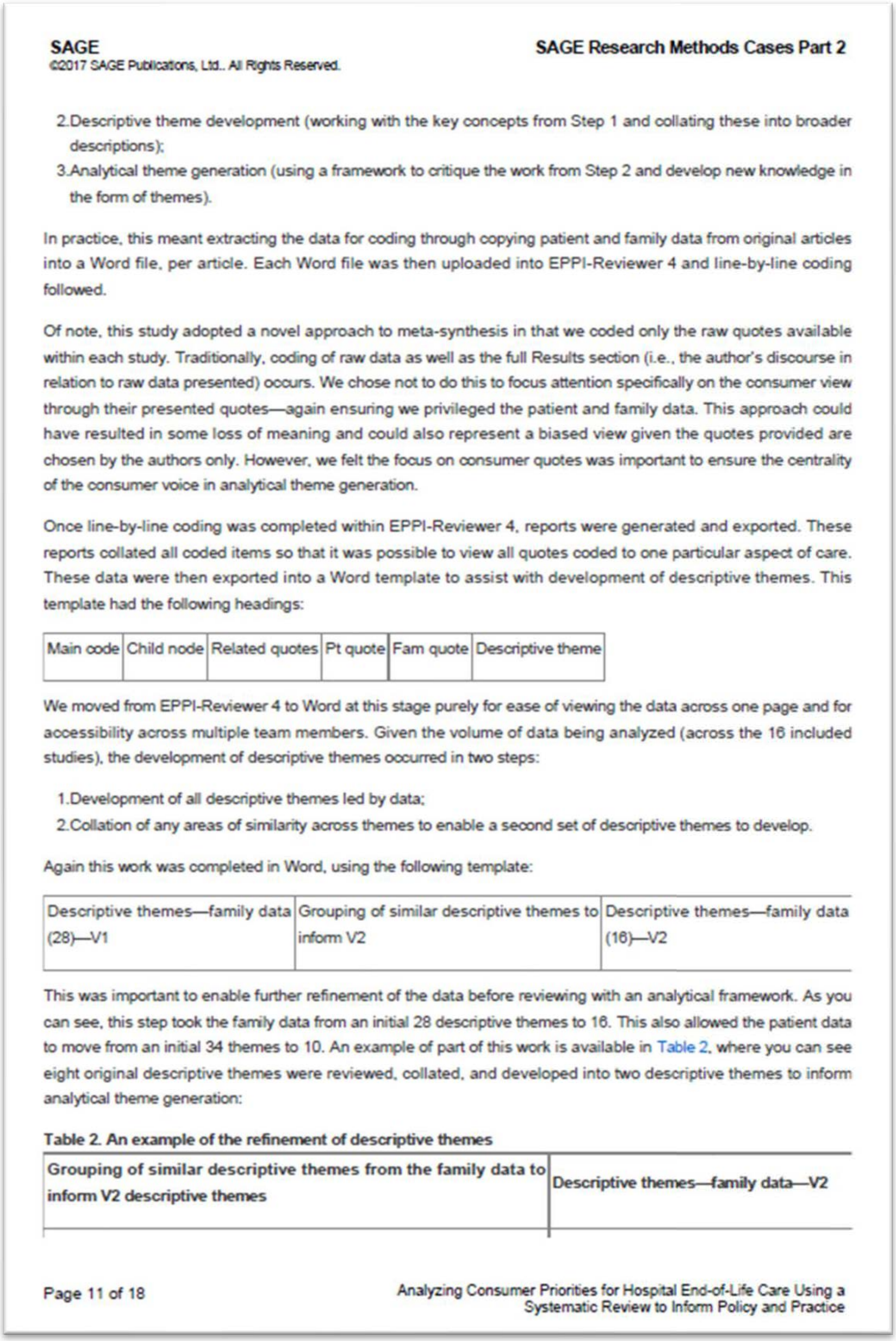
Synthesis of the quantitative data in our review used a narrative approach, following recommendations made by experts from the Cochrane Collaboration (Popay et al., 2006), including tabulation and content analysis. The content analysis needed to evolve with several versions required before we found the optimal approach to enable accurate representation of the data across all included studies (*n* = 8). This approach was driven by the desire to privilege the patient and family perspectives and convey this information as concisely and accurately as possible to readers so as to provide a solid foundation of evidence with the potential of affecting policy and practice change.

Arriving at the best way of privileging and honoring the patients' and families' voices took time and required us to consider many different approaches to the synthesis before arriving at what we considered to be the best approach (Virdun et al., 2015). We managed this through regular scheduled meetings to review different approaches, discuss these, and decide on possible improvements. As the lead author, Claudia worked on suggestions between meetings and sent this updated work to team members ahead of scheduled meetings so they could review, comment, and inform discussions accordingly. Considering alternative approaches to the synthesis was important as it enabled us to gain a deeper understanding of the data and informed the final synthesis approach.

The final approach we used focused on the use of categorical data from patients and families (available within each study) and reporting the top five elements found within each study. These elements were subsequently themed into key domains. Because there were eight studies included in this synthesis and each study reported on multiple elements of importance for quality end-of-life care in the hospital setting, attempting to synthesize all of these was too cumbersome and did not allow for a clear message to evolve from the data. Choosing to report on those listed as the "top five" elements in each study allowed a clear focus to emerge. Theming such data led to the identification of six domains of importance for patient participants and five for family participants. This approach brought a sharp focus on areas of highest importance. This framework was used to inform the subsequent meta-synthesis.

The approach for synthesis of the qualitative data was straightforward and in line with a three-stage approach (Thomas & Harden, 2008):

1. Line-by-line coding (reading each sentence and attributing key concept areas to each line);



2. Descriptive theme development (working with the key concepts from Step 1 and collating these into broader descriptions);
3. Analytical theme generation (using a framework to critique the work from Step 2 and develop new knowledge in the form of themes).

In practice, this meant extracting the data for coding through copying patient and family data from original articles into a Word file, per article. Each Word file was then uploaded into EPPI-Reviewer 4 and line-by-line coding followed.

Of note, this study adopted a novel approach to meta-synthesis in that we coded only the raw quotes available within each study. Traditionally, coding of raw data as well as the full Results section (i.e., the author's discourse in relation to raw data presented) occurs. We chose not to do this to focus attention specifically on the consumer view through their presented quotes—again ensuring we privileged the patient and family data. This approach could have resulted in some loss of meaning and could also represent a biased view given the quotes provided are chosen by the authors only. However, we felt the focus on consumer quotes was important to ensure the centrality of the consumer voice in analytical theme generation.

Once line-by-line coding was completed within EPPI-Reviewer 4, reports were generated and exported. These reports collated all coded items so that it was possible to view all quotes coded to one particular aspect of care. These data were then exported into a Word template to assist with development of descriptive themes. This template had the following headings:

Main code	Child node	Related quotes	Pt quote	Fam quote	Descriptive theme

We moved from EPPI-Reviewer 4 to Word at this stage purely for ease of viewing the data across one page and for accessibility across multiple team members. Given the volume of data being analyzed (across the 16 included studies), the development of descriptive themes occurred in two steps:

1. Development of all descriptive themes led by data;
2. Collation of any areas of similarity across themes to enable a second set of descriptive themes to develop.

Again this work was completed in Word, using the following template:

Descriptive themes—family data (28)—V1	Grouping of similar descriptive themes to inform V2	Descriptive themes—family data (16)—V2

This was important to enable further refinement of the data before reviewing with an analytical framework. As you can see, this step took the family data from an initial 28 descriptive themes to 16. This also allowed the patient data to move from an initial 34 themes to 10. An example of part of this work is available in Table 2, where you can see eight original descriptive themes were reviewed, collated, and developed into two descriptive themes to inform analytical theme generation:

Table 2. An example of the refinement of descriptive themes

Grouping of similar descriptive themes from the family data to inform V2 descriptive themes	**Descriptive themes—family data—V2**

Determining the best approach in relation to treatments is complex and ambiguous being influenced by medical possibilities, emotion, finances, considering futility, doing all that is possible, and enabling a peaceful death	
Importance of family members feeling sufficiently informed in a timely manner: "Nothing, nothing was important to me as much as just being able to talk to the doctor and to get the information there." (Nelson et al., 2010)	
Importance of staff proactively talking with family members—providing information, updates, and support	Regular effective communication is fundamental to optimal end-of-life care in relation to shared decision making and overall support
The importance of medical staff nominating a time for families to meet/speak with them on a regular basis	
Navigating communication across staff and families—the need for family meetings	The need for scheduled updates from the medical team and regular family meetings is essential
Effective communication enabling shared understanding about the current situation and expectations for the future—"please, tell me in English." (Nelson et al., 2010)	
The importance of timely information and support to access appropriate financial assistance to enhance overall comfort for patients and families	
The complexity involved within end-of-life decision making	

The framework used to further analyze the final versions of descriptive themes was the domains found in the earlier quantitative synthesis (Virdun et al., 2015). Again, this was done within Word using the following template:

Related quotes	Descriptive theme V1	Descriptive theme V2	Analytical theme	Additional areas of focus from qualitative literature

This approach to meta-synthesis was systematic and it remains easy to track how each included article and indeed each included quote contributed to final themes.

Key Tips

1. Allow your initial data extraction to contain sufficient detail (e.g., demographics of participants, specifics about research methodology, and details about findings). This can be refined into more of a high-level summary for publication. However, the detailed extraction is useful to keep going back to as the study unfolds.
2. In addition to your data summary table (Word or Excel), keep a demographics overview (in Excel) to inform aspects such as mean age, overall cultural representation, and male/female inclusion. Using some of the formula options within Excel is useful for this aspect of reporting.
3. Allow flexibility in data synthesis approaches. Keep trying different approaches until a method is found that

allows the data from multiple studies to accurately speak for itself and succinctly inform a readership. Ensure auditing and consensus discussions by the research team continue to occur throughout this process.

4. Carefully record all stages of data synthesis to enable auditing of work completed.
5. Consider the audience for this work from the outset as this will inform the most appropriate methods for data presentation.

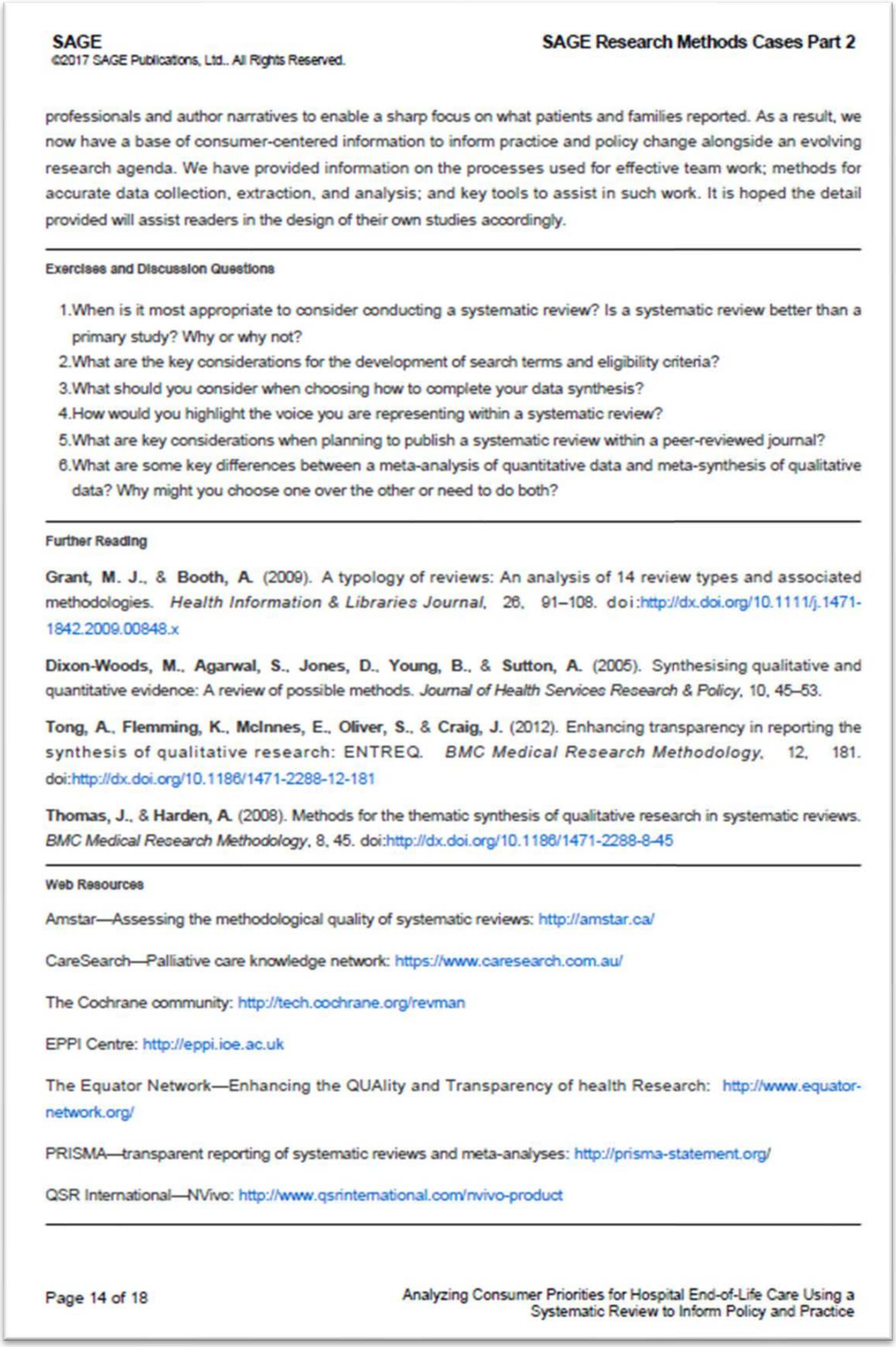
Practical Lessons Learned

There were five key practical lessons learnt throughout this study:

1. The use of EndNote for managing the sourcing and inclusion/exclusion of articles through their smart group function is an excellent method. However, completing this approach within an existing EndNote library is not advised. Due to the fact that multiple databases are used, duplicate references are expected. This leads to a huge reference library with many of these references not relevant or, indeed, duplicates. On this occasion, this led to a corrupted library that was not usable. We were able to recover the library but did not use this again for any other purpose other than tracking inclusion/exclusion. A key tip in relation to this would be to create an EndNote library specifically for a systematic review and use it for this function only. Then, once you have established your "included" articles, these citations can be imported into your working library for use when publishing this work. Furthermore, in addition to the use of EndNote, it is necessary to track other information for ongoing reference. We did this within Word and recorded details such as the database searched, date of the search, search strategy used, and results found.
2. Work with software that is simple and specifically meets your needs. Most of the work completed was in fact done within Word and Excel. EPPI-Reviewer 4 was an easy-to-use tool to enable line-by-line coding for the meta-synthesis. NVivo is another tool that would enable such data analysis.
3. Keep the initial data extraction as detailed as possible to prevent having to continue reverting to the original articles. Once there is a detailed overview, it can be refined for other purposes such as publication. Think carefully about the categories of data extraction as these need to inform study overview (aim, design, method, participants, setting, and results), data for synthesis, demographic information, and data to inform a quality analysis. This can be done within Word or Excel, depending on your preference.
4. Presenting findings in such a way that busy clinicians and policy-makers can grasp an overview of available literature with confidence is vital. Considering the main audience for the work is the first step. Second, writing up the work succinctly is important and will be informed by publisher guidelines. Finally, drawing explicit links to policy and practice within a discussion section of a publication paves the way forward for readers.
5. Establishing clear working procedures for the research team from the commencement of the study is important. You need to consider aspects such as methods of communication, processes for consensus, documentation of discussions held/email communications, delegation of work roles, frequency of contacts, and a method for managing any urgent concerns to enable work to progress as required. We also established a shared work folder online (we used DropBox) for the team to have access to as needed. Having a discussion about these components of team work at the outset should enable effective collegiality and collaboration.

Conclusion

Completing a systematic review of published literature to answer a well-researched question is an excellent method of informing policy, practice, and future research. There is significant published guidance about how to design, conduct, and report a quality systematic review. This case study reports on the specific approaches this team used to privilege the consumer voice in relation to our study aim. We actively excluded data from health



professionals and author narratives to enable a sharp focus on what patients and families reported. As a result, we now have a base of consumer-centered information to inform practice and policy change alongside an evolving research agenda. We have provided information on the processes used for effective team work; methods for accurate data collection, extraction, and analysis; and key tools to assist in such work. It is hoped the detail provided will assist readers in the design of their own studies accordingly.

Exercises and Discussion Questions

1. When is it most appropriate to consider conducting a systematic review? Is a systematic review better than a primary study? Why or why not?
2. What are the key considerations for the development of search terms and eligibility criteria?
3. What should you consider when choosing how to complete your data synthesis?
4. How would you highlight the voice you are representing within a systematic review?
5. What are key considerations when planning to publish a systematic review within a peer-reviewed journal?
6. What are some key differences between a meta-analysis of quantitative data and meta-synthesis of qualitative data? Why might you choose one over the other or need to do both?

Further Reading

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Web Resources

Amstar—Assessing the methodological quality of systematic reviews: http://amstar.ca/

CareSearch—Palliative care knowledge network: https://www.caresearch.com.au/

The Cochrane community: http://tech.cochrane.org/revman

EPPI Centre: http://eppi.ioe.ac.uk

The Equator Network—Enhancing the QUAlity and Transparency of health Research: http://www.equator-network.org/

PRISMA—transparent reporting of systematic reviews and meta-analyses: http://prisma-statement.org/

QSR International—NVivo: http://www.qsrinternational.com/nvivo-product

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Involving consumers with palliative care needs and their families in research: A case study

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ABSTRACT

Background: There are significant policy imperatives to involve consumers at the outset of and throughout research. How best to achieve this in an authentic and meaningful way is elusive, particularly within the palliative care population.
Aim: To determine how best to engage people with palliative care needs and their families in co-designing a qualitative study to better understand how to improve care of the dying in the acute care setting.
Methods: A case study design informed this work, informed by pre-determined research questions that focused on consumers advising on participant experience within the research, rather than research methodology *per se*.
Findings: Eleven consumers contributed across five panel meetings. Analysis of documented feedback led to four key areas of protocol change: *Getting the language in the recruitment materials and information and consent forms right; Developing a feasible and acceptable recruitment strategy; Opportunities to more clearly articulate the explicit value of this research for patients and families; Support strategies for participants.*
Discussion: Authentic consumer engagement requires time and effort; however, the outcomes are well worth the invested time and energy. Key foci outlined within this case study to enhance authenticity included: collaboration; preferencing the consumer voice; adequate preparation to support consumer engagement; and openness to all feedback provided.
Conclusion: Co-designing research with consumers enabled the outcome to be feasible for implementation, without any modifications required. Ensuring relevance and consumer-centredness for the expanding palliative care evidence base is essential and can only be achieved through meaningful partnerships with consumer representatives.

Summary of Relevance
Problem or Issue

- Policy imperatives call for consumer engagement in the design and implementation of research;
- Achieving meaningful and authentic engagement across palliative care populations is unclear.

What is Already Known

- People with palliative care needs, and their families/carers are keen to contribute to research;
- The need for early engagement with consumers, clarity of role at the outset, the valuing of consumer contributions and supporting flexible methods for participation is outlined.

What this Paper Adds

- This short report outlines one approach to meaningful consumer engagement in co-designing a research protocol that sought to understand the experiences of patients with palliative care needs, and their families/carers, of hospital care.

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1. Introduction

There is a growing international policy imperative for involving consumers at the outset of new research and implementation projects in order to improve their quality, relevance and impact (Canadian Institutes of Health Research, 2011; Cancer Australia & Cancer Voices Australia, 2011; National Health & Medical Research Council, 2016; NHS Health Research Authority, Health & Care Research Wales, & NHS Research Scotland, 2017; Scholz, Bevan, Georgousopoulou, Collier, & Mitchell, 2019; The National Institute for Health & Care Excellence, 2014). The United Kingdom has led significant work in this area, with additional policy and study work evident from Canada, the United States and more recently, Australia (Brett et al., 2014). However, achieving authentic consumer ('patient, carer and/or family') engagement continues to be challenging in many contexts (Ball, Harshfield, Carpenter, Bertscher, & Marjanovic, 2019; Brett et al., 2014; Daveson et al., 2015; Hubbard, Kidd, Donaghy, McDonald, & Kearney, 2007; Oliver, Kothari, & Mays, 2019). A recent review found that integrating consumers' perspectives into projects designed to reform the Australian health system and/or care delivery has evolved significantly over the past 20 years in relation to their work in developing, implementing and evaluating such work (Consumer Health Forum of Australia, 2015). However, the need to develop evidence to inform methods for effective consumer representation is noted as a priority (Consumer Health Forum of Australia, 2015). National Health and Medical Research Council policy recommends that health and medical researchers consider and plan for how they involve consumer representatives in the development, conduct and communication of their studies (National Health & Medical Research Council, 2016). The uniqueness of every new research project demands targeted consumer involvement from the outset (National Health & Medical Research Council, 2016).

Engaging consumers focused on palliative care in the conceptualisation and development of research protocols has been noted as important for over a decade (Bradburn & Maher, 2005; Scholz et al., 2019). Involving such consumers in new research initiatives increases the person with palliative care needs' sense of empowerment, of legacy and of meaning to their days whilst living with a terminal illness (Bloomer, Hutchinson, Brooks, & Botti, 2018; Bradburn & Maher, 2005). Recent consumer focused research has added to our understanding of the perspectives and experiences of people with palliative care needs, their family and/or carers, in relation to research participation (Aoun, Slatyer, Deas, & Nekolaichuk, 2017; Bloomer et al., 2018; Harrop et al., 2016; Pessin et al., 2008; Scholz et al., 2019; Terry, Olson, Ravenscroft, Wilss, & Boulton-Lewis, 2006; White & Hardy, 2010).

A 2010 systematic review found positive outcomes from research participation for people with palliative care needs and their families particularly in relation to altruism and personal gain (White & Hardy, 2010). However, this same review notes the importance of participant autonomy and the need for trial design to be as simple as possible (to enable participant understanding), data collection processes to be minimal to prevent burden on the participant and no noted financial burden (White & Hardy, 2010). One large study of family carers identified that participants described positive experiences both from an inward-directed perspective (sharing of experience, ability for reflection, validation of role) and an outward-directed perspective (connection with others) (Aoun et al., 2017). A more recent integrative review published in 2018, examining the perspectives and experiences of dying people in relation to research participation outlines four themes: (1) the value of research, (2) desire to help, (3) expression of self and (4) participation preferences (Bloomer et al., 2018). Beneficial aspects to participation including validation of self-worth, altruism and social interaction are well described for both people with palliative care needs and their family carers (Aoun et al., 2017; Harrop et al., 2016; Pessin et al., 2008; Scholz et al., 2019; Terry et al., 2006). Participation preferences were noted to include the desire to be approached by a clinician familiar to the patient or family, for involvement within comparator trials and to be involved in research that is not too burdensome for the person both in relation to time investment and/or invasiveness of proposed interventions (Bloomer et al., 2018).

Despite this guidance, there is little evidence to guide clinical researchers as to how best to involve consumers in palliative care clinical research (Daveson et al., 2015; Scholz et al., 2019; White & Hardy, 2010). A consultation workshop (incorporating expert presentations, discussion and nominal group work to develop recommendations) focused on this particular issue, suggests that optimal engagement with consumers focused on palliative care in meaningful research participation, depends on the following attributes:

1) Researchers being clear at the outset about a consumer's role and valuing the contribution and difference consumers make to the research outcomes;
2) Early engagement to aid productivity, quality and relevance;
3) Flexibility is essential, incorporating multiple methods for participation (virtual and face to face) to account for health fluctuations, alternate priorities and responsibilities; and
4) Assisting consumers to focus on improved productivity, quality and relevance in line with a researcher's agenda is important (Daveson et al., 2015).

This short report outlines one approach to engaging consumers focused on palliative care in co-designing a research protocol that sought to understand their experiences of hospital care including [for some] stays where a family member died. This case study informed a broader program of sequential mixed methods research (Andrew & Halcomb, 2009) focused on how to support system level improvements in care for people with palliative care needs in the hospital setting, and their families/carers.

Aim: To determine how best to engage people with palliative care needs and their families in co-designing a qualitative study to better understand how to improve care of the dying in the acute care setting.

2. Methods

An exploratory case study design informed this work (Baxter & Jack, 2008; Yin, 2003) and involved people with palliative care needs, bereaved carers and cancer survivors. Pre-determined research questions were articulated, clear boundaries in relation to the case outlined and varied data sources used to enhance understanding (Baxter & Jack, 2008). Of note, the two predetermined research questions provided clarity about the purpose for consumer input with their focus maintained on participant experience within the research, rather than research methodology *per se*. The research questions for this case study were:

1 What do consumers perceive to be the best strategies for identifying, approaching and recruiting people with palliative care needs, and their families, and supporting participation within research focused on optimal hospital-based palliative care?
2 Do consumers perceive this program of research to be important, and if so, how can we best promote this work to a non-clinical audience?

Ethical approval was not required in the development of this research protocol. Regular presentations to and feedback from

consumer panels (n = 5) occurred throughout protocol design with adaptations in response to consumer feedback (Goodyear-Smith, Jackson, & Greenhalgh, 2015) made until consensus was achieved. Consumer panels were drawn from two organisations, one being from a tertiary academic environment's consumer advisory group and the other from a translational cancer research network's consumer panel. Members of both organisations' consumer groups included: people living with cancer, cancer survivors, people with palliative care needs and bereaved carers. Ensuring adequate preparation for meaningful consumer engagement occurred through sending draft documentation for review prior to panel meetings and using organisational templates for standardised information provision. These templates allowed unique study information to be presented in a manner that provided consumer representatives with some consistency of format and data type.

Descriptive analysis of data from field notes taken within each panel informed research team discussions and case study outcomes. Ensuring openness to feedback, even when a difference between lay and clinical perspectives occurred, was prioritised throughout all discussions. That is, decisions were led by consumer perspectives in relation to the research questions set out (consumer participation strategies and communication options). Steps taken to ensure prioritisation of the consumer voice included noting and reviewing every individual's feedback; accepting all feedback given in relation to language used to describe our population – that is valuing all concerns voiced; openly reviewing all protocol-related changes needed to address noted areas of consumer concern and ensuring consensus prior to document finalisation. Difficulties in instituting these approaches included the fact that not all consumer representatives were present across all panel discussions and the need to truly embrace feedback given, even when it did not align with clinical thinking, was challenging. However, the lessons learned from such an approach were profound, with the consumer perspective echoing the perspective of screening clinicians and potential participants.

3. Results

Eleven consumers (inclusive of bereaved carers (n = 7), people with palliative care needs (n = 2) and cancer survivors (n = 2)) contributed, with six attending more than one panel. Five panel meetings were conducted and detailed field notes documented at each one. Each panel meeting included a 20 min discussion about this particular piece of work. Analysis of documented feedback led to four key areas of change centering upon improving the participant's experience from recruitment through to participation. Specifically, feedback focused on the following:

3.1. Getting the language in the recruitment materials and information and consent forms right

Consumers were asked for advice about appropriate terminology to describe the study population in written study materials. As the study aimed to recruit patients with palliative care needs, with a likely prognosis of 12 months of less, this needed to be clearly and sensitively articulated in the protocol, ethics application and the participant information sheet. Consumers were adamant that terms such as "advanced, progressive illness; advanced and non-curable health conditions; people approaching the end of their lives" would be too confronting for many patients with palliative care needs and their family members. After several panel discussions, and iterations of the participant information sheet, consumers suggested that using the term 'serious chronic illness', was the preferred terminology as it was most likely to be acceptable to potential participants and unlikely to cause unnecessary distress.

Table 1
Inclusion and exclusion criteria for the study.

Inclusion criteria	Exclusion criteria
• Clinical indicators of one or multiple life-limiting conditions in accordance with the Supportive and Palliative Care Indicators Tool (SPICT™ (The University of Edinburgh)) • Australia-modified Karnofsky Performance Status (AKPS) (Abernethy et al., 2005) score between 30 and 70 • 1 or more admissions to hospital within the previous 12 months • Patient aware they have a serious chronic illness • Patient is comfortable talking about their serious chronic illness and related care needs • Willingness to give verbal informed consent and willingness to participate in and comply with the study • Family member/carer of someone with advanced dementia who has had at least 1 hospital admission within the previous 12 months • Bereaved family member or carer whose loved one had at least 1 admission to hospital in their last 12 months of life and their bereavement is within 2 years	• Patients less than 18 years of age • Patients and/or family members/carers who cannot converse in English • Patients with cognitive impairment that impairs their ability to describe prior hospitalisations and care experiences

However, this broader term presented challenges for the research team as it did not sufficiently describe people admitted to hospital who were likely to have a prognosis of 12 months or less. However, keeping with co-design principles the team acknowledged that it was important to honour and privilege this consumer feedback and to include the preferred term 'serious chronic illness' in all paperwork seen by potential participants. The screening strategy was devised to enable identification of people with a prognosis of 12 months of less (and their families) by senior clinicians in accordance with predetermined prognostic screening tools, including the Supportive and Palliative Care Indicators Tool (SPICT™ (The University of Edinburgh)) and Australia-modified Karnofsky Performance Status (AKPS) (Abernethy, Shelby-James, Fazekas, Woods, & Currow, 2005). As a result, the inclusion criteria became clearly defined (Table 1) and used language that was specific to the target population. This eligibility criteria provides clear guidance to the clinicians screening patients for this study, as well as providing them with a conversation script to honestly discuss the study with potential participants without causing distress. The wording focuses on the fact that participants are living with a serious chronic illness but does not refer to it as an advanced illness, prognosis or whether the illness is curable or not. This consumer guided advice enabled the team to navigate the complexity of not needing to detail prognostic information within the recruitment paperwork.

3.2. Developing a feasible and acceptable recruitment strategy

Initial recruitment strategies discussed with consumer representatives included the use of databases to identify people with palliative care needs, and their families. However, the consumer representatives advised that recruitment should be completed by people who knew a patient's care well and were actively involved in their care provision. The reasons for this were two-fold: 1) To ensure people approached were comfortable with talking about their illness and aware of their diagnosis; 2) Consumers felt it would

be most appropriate for the first contact to be made by someone whom potential participants knew rather than a stranger. This consumer advice was also prioritised and an approach using chronic care coordinators, nurse consultants, nurse practitioners or medical physicians, working with people who met the screening criteria, was developed. This presented the challenge of possible 'gatekeeping' in relation to study participation. However, the benefits of limiting potential distress for this vulnerable population were felt to outweigh the risk of missing eligible people who would have welcomed participation but were not given the opportunity to do so by their care coordinator. We also tried to offset this risk by providing support and education for the screening clinicians in relation to the importance of providing people with opportunities to participate.

3.3. Opportunities to more clearly articulate the explicit value of this research for patients and families

Consumers provided feedback in relation to the difference they perceived between the way this study was discussed during face-to-face panels and how they felt when reading the initial written study protocol, participant information sheets and consent forms and invitation letters. The face-to-face discussions allowed an element of the study to emerge that was not as obvious in the written materials, with feedback provided that the passion and energy to drive improvements in palliative care provision within the hospital setting, as a result of this study, were not evident within the paperwork presented. They suggested ensuring that all written study information be very patient- and family-centred and to remain focused on the reasons for undertaking this research. Suggestions also included clearly articulating how the research provides important insights into what is most important to patients with palliative care needs, and their families, to enable optimal care and how to measure this, and why the team is so passionate about answering these questions. The consumers cautioned against using too much jargonistic language, such as 'system level improvements' and to avoid dry, policy language. They encouraged the development of a lay research summary, which has been crafted and refined based on their subsequent feedback.

3.4. Support strategies for participants

Initial support strategies articulated within our study protocol included linking the patient and/or their family member back to their local general practitioner for support as required. However, the consumer advice was to also list the supports that their specialist teams could provide, given the patients we would be talking with are likely to have complex illnesses and be known to at least one specialist clinical team. Consumers felt such people often had closer ties with their specialist treating teams at this time than their general practitioners. This was useful feedback and easily integrated into the study protocol and the patient information sheet.

The Human Research Ethics Committee reviewed the research protocol detailing the proposed screening, recruitment, consent and participation strategies in relation to the identified vulnerable population, being those with palliative care needs and their families, in October 2018. This ethics submission was accepted without changes, despite the vulnerability of the population and sensitivity of topics to be explored in interviews, and screening and recruitment for this study is now underway. The language changes made at the suggestion of consumers, have resonated well with screening clinicians who noted that without such changes, their ability to recruit effectively would have been significantly impacted. Furthermore, our initial ideas of recruiting via databases and providing paperwork naming advanced illness and palliative care needs has been noted by screening clinicians as an approach they would have been unhappy to be involved with, as so many of their patients have varied perspectives on their illness, prognosis and the meaning of palliative care. Therefore, the consumer perspectives resonated with the perspectives of clinicians working closely with patients with palliative care needs, and their families.

4. Discussion

This case study outlines how one research team worked with consumer representatives to co-design a research protocol focused on palliative care. There is substantial literature outlining the value of integrating the consumer perspective into research design and implementation centering around impacts on quality (Brett et al., 2014; Daveson et al., 2015; Scholz et al., 2019; Woolf, Zimmerman, Haley, & Krist, 2016), appropriateness (Brett et al., 2014; Canadian Institutes of Health Research, 2011; Cancer Australia & Cancer Voices Australia, 2011; Scholz et al., 2019), relevance (Daveson et al., 2015; National Health & Medical Research Council, 2016; Scholz et al., 2019; Woolf et al., 2016), impact (Canadian Institutes of Health Research, 2011; National Health & Medical Research Council, 2016; Scholz et al., 2019; Woolf et al., 2016), improved outcomes and experiences for patients and families (Cancer Australia & Cancer Voices Australia, 2011; National Health & Medical Research Council, 2016), ethical respect for vulnerable populations (Woolf et al., 2016) and developing a research active nation (Daveson et al., 2015; National Health & Medical Research Council, 2016). However, barriers to such participation have also been noted, including a lack of clarity about the purpose and role of a consumer representative (Ball et al., 2019; Nathan, Johnston, & Braithwaite, 2011; National Health & Medical Research Council, 2016), inadequate preparation for consumer representatives (Ball et al., 2019; Consumer Health Forum of Australia, 2015; National Health & Medical Research Council, 2016; Woolf et al., 2016), tokenism (Ball et al., 2019; National Health & Medical Research Council, 2016), and tension in relation to the balance between lay and clinical perspectives (Ball et al., 2019; Beckett, Farr, Kothari, Wye, & le May, 2018; Martin & Finn, 2011; National Health & Medical Research Council, 2016; Scholz et al., 2019). Planning participation and role definition carefully and in view of each unique study's requirements is essential to enable such barriers to be overcome (Ball et al., 2019; Cancer Australia & Cancer Voices Australia, 2011; National Health & Medical Research Council, 2016). This case study addressed such concerns through: collaborating to co-design a research protocol with clarity about the purpose for consumer engagement focusing on participant experience within the research, rather than research methodology *per se*; carefully considering how to value the consumer voice; ensuring adequate preparation for meaningful consumer engagement through sending draft documentation for review prior to meetings; ensuring openness to feedback even when a difference between lay and clinical perspectives was noted and felt challenging. This process was time consuming and required work; however, the outcomes of a feasible and acceptable screening and recruitment strategy for a vulnerable population (being those with palliative care needs) were well worth the invested time and energy. Discussions with screening clinicians continue to underscore the importance of the change in our early thinking in relation to language and planned approaches to access our defined population; that was fully precipitated by consumer co-design. Although some of the feedback provided at the commencement of the protocol co-design was difficult to hear and accommodate, the principles of committing to meaningful consumer engagement and prioritising their feedback in relation to the pre-designed feedback questions enabled successful discussions, consensus building and eventual protocol finalisation.

Significant progress in relation to meaningful engagement with consumer representatives within research design, conduct and

reporting has occurred over the past decade (Ball et al., 2019; Woolf et al., 2016), with some of this progress credited to the work led by the Patient-Centered Outcomes Research Institute (PCORI) (Frank, Basch, & Selby, 2014; Selby, Forsythe, & Sox, 2015). PCORI is a non-governmental organisation, established in 2010 in the United States, with a noted mandate to *'improve the quality and relevance of evidence available to help patients, caregivers, clinicians, employers, insurers, and policy makers make better-informed health decisions'* (Patient-Centered Outcomes Research Institute, 2017) and they do so in a variety of ways, one being to ensure engagement of patients and family members across all stages of the research cycle. However, the need to continue to look at each unique study and how co-design can enhance question generation, protocol design, implementation and dissemination is vital, with some areas of research perhaps benefitting more than others (Oliver et al., 2019). Consumer participation is widely recognised as important within cancer services and cancer research (Cancer Australia & Cancer Voices Australia, 2011); however, the progression of this within palliative care remains emerging (Bloomer et al., 2018) and therefore careful consideration about how to achieve this is important. This case study provides evidence of one such approach which worked well for this particular study. Like so many areas of healthcare, a personalised approach to meaningful consumer participation is essential to ensure this work can reach its potential (Oliver et al., 2019). This can be challenging and requires significant effort; however, when successfully achieved, it can vitalise work, enhance its relevance and increase its application into practice (Woolf et al., 2016).

4.1. *Strengths and limitations*

The strength of this work lies within the clear establishment of aims for consumer participation, informed by the predesigned research questions. This enabled clarity about the purpose of the consumer role which helped the team to provide the consumers with the necessary content to make an informed contribution. This step, in turn helped to focus the consumer panel discussion to optimise the consumers input in a timely way. Furthermore, the upfront clarification of consumer role enabled the research team to privilege the consumer's feedback in relation to the set research questions and this informed discussions and consequently outcomes. The limitation of the approach taken was that the team did not seek consumer feedback about the engagement process and actual experience of contributing to co-designing the research protocol. Although all consumer representatives appeared to interact comfortably and consensus on the preferred wording and framing of the research protocol was achieved, it would have been useful to have sought consumer feedback about the processes used and outcomes gained.

4.2. *Recommendations for future research*

This short report highlights the importance and value of meaningful consumer engagement at all stages of the research process, from the initial idea, through to the development of the concept through to implementation into practice. However, this report demonstrates the importance of clearly articulating the consumer representative's role and for this role to be understood by both the consumers and the research team. This short report describes one method for establishing research questions specifically for the consumer roles focused on appropriateness of the study question through to accessibility and experience for potential participants within the proposed study. It would be helpful to research such approaches more systematically through establishing mechanisms for consumer feedback in relation to approach taken and ability for meaningful engagement for all involved.

5. Conclusion

Significant policy work outlines the importance of engaging with consumers throughout the development and implementation of research. Preferencing consumer data and engaging meaningfully with consumer representatives has enabled this case study to remain focused on that which is of most importance to people with palliative care needs, and their families. Co-designing a research protocol with consumers focused on palliative care enabled the outcome to be feasible for implementation within a clinical setting, without any modifications required. Ensuring relevance and consumer-centredness for the expanding palliative care evidence base is essential and can only be achieved through meaningful partnerships with consumer representatives.

Author contributions

All authors (CV, TL, IG, MB, RL, KL, and JP) contributed to manuscript preparation, editing and finalisation. The initial research design was developed by CV, TL, KL and JP. The co-design process outlined involved all authors, as did related consensus discussions.

Ethical statement

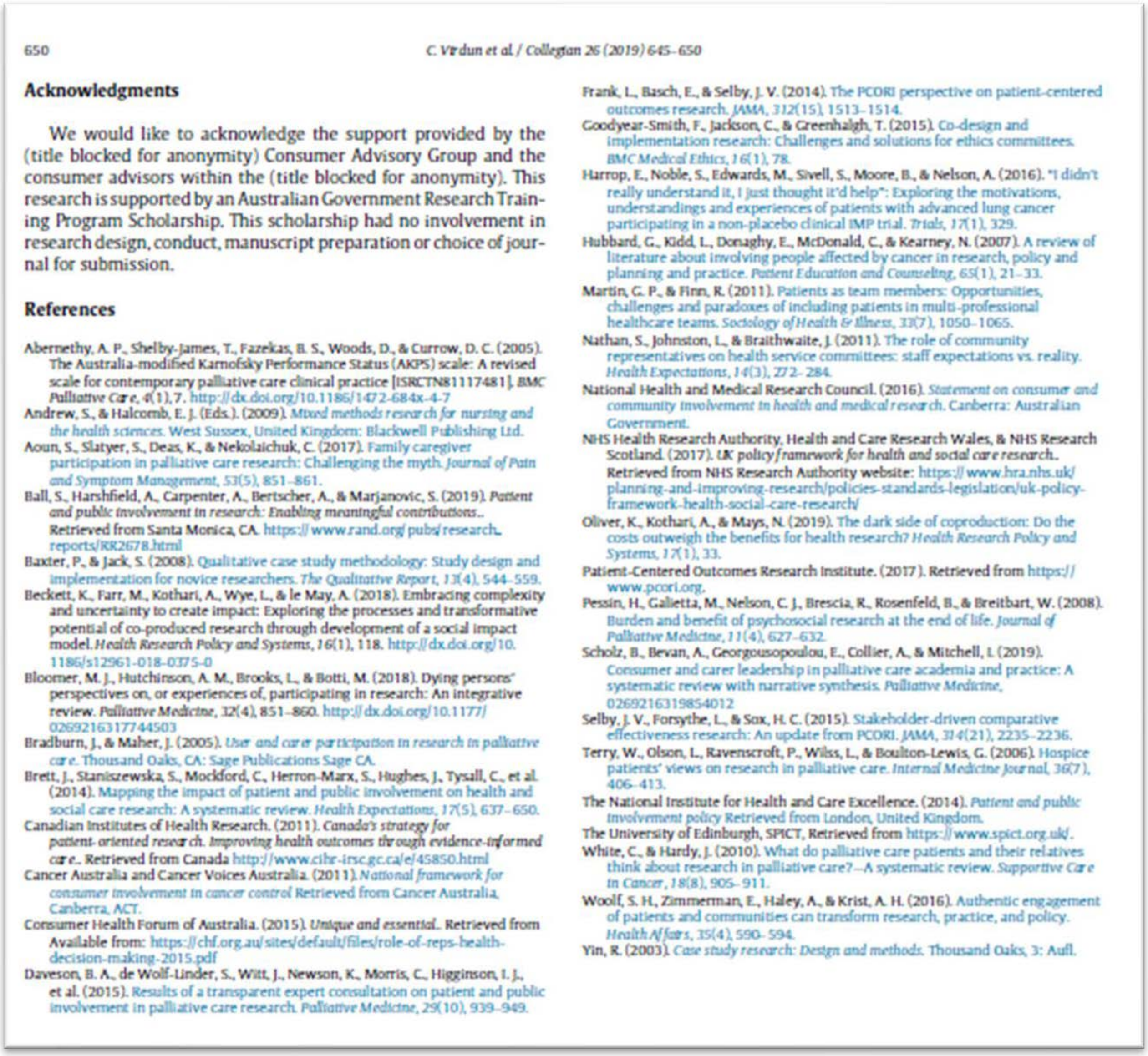
All listed authors have made a significant contribution to the manuscript – as outlined more specifically within the uploaded author statement document, in the form of a CRediT statement. We can also declare that this work is both original and without plagiarism, with various references who have informed our thinking noted accordingly. This work has not been published in any other form nor submitted for review by any other journal. Ethics review was not sought in relation to this noted co-design work (of which the case study reports). However, the co-design work let to the completion of a protocol that was then presented for review by a Human Research Ethics Committee prior to enabling commencement of the study. This manuscript outlines working with consumer advocates to co-design the research protocol, rather than data pertaining to the study that is currently underway and therefore the latter ethics approval details have not been provided.

CRediT authorship contribution statement

Claudia Virdun: Conceptualization, Methodology, Validation, Formal analysis, Writing - original draft, Writing - review & editing. **Tim Luckett:** Conceptualization, Methodology, Validation, Writing - review & editing, Supervision. **Imelda Gilmore:** Conceptualization, Writing - review & editing. **Meg Brassil:** Conceptualization, Writing - review & editing. **Ruth Lilian:** Conceptualization, Writing - review & editing. **Karl Lorenz:** Conceptualization, Methodology, Validation, Writing - review & editing, Supervision. **Jane Phillips:** Conceptualization, Methodology, Validation, Writing - review & editing, Supervision.

Conflict of interest

There are no known direct or indirect potential competing interests relating to this work from any of the listed authors. This case report describes work that has been completed to inform a larger mixed methods study and this is noted within the paper itself.



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Appendix 2: Overview of quality rating of included manuscripts (Study 1a and 1b) following dual assessment (C.V and supervisor)

Quality rating of included quantitative articles (Study 1a)

Article	Osborn et al., 2012 [1]	Gelfman et al., 2008 [2]	Moyano et al., 2007 [3]	Heyland et al., 2006 [4]	Heyland et al., 2005 [5] **	Baker et al., 2000 [6]	Kristjanson, 1989 [7]	Young et al., 2009 [8]	Rocker et al., 2008 [9]	Heyland et al., 2010 [10]	Steinhauser et al., 2000 [11]
Aim	To inform areas for quality improvement interventions in the ICU in relation to end-of-life care	To assess quality of medical care at the end-of-life in hospital	To evaluate satisfaction levels of caregivers in relation to information provision at the end-of-life in hospital	To describe key elements of end-of-life care and the relative importance of these from a patient and caregiver perspective	To increase understanding about what high quality end-of-life care in a hospital setting means from a patient and family perspective and how satisfied with these elements of care they are	Examine factors affecting family satisfaction with end-of-life care	To identify health care professional behaviours that are important to patients and families to identify whether care settings influence these perceptions	To explore the determinants of satisfaction with care at the end-of-life for people dying following a stroke in hospital	Describe elements of end-of-life care and the importance of these from the perspective of people with advanced COPD as compared to people with cancer	To identify key areas of end-of-life care requiring improvement from the perspectives of patients and families	To determine the factors considered important at the end-of-life by patients, their families, physicians, and other care providers
Design	Descriptive	Descriptive	Descriptive	Descriptive	Descriptive	Descriptive	Descriptive	Descriptive	Descriptive	Descriptive	Descriptive
Level	IV	IV	IV	IV	IV	IV	IV	IV	IV	IV	IV
Quality of methods	3	4	1	2	3	3	2	4	3	3	4
Relevance to question*	4	2	2	4	4	4	4	3	4	4	4

*Any studies rated as ≤2 for this measure, were excluded; ** Excluded due to the fact this study reported on the same dataset as Heyland [4] without new perspectives provided

Quality rating of included qualitative articles (Study 1b)

	Clear aim	Clear research question	Appropriate method choice	Outline of why research design chosen	Clear data collection techniques	Transparent data analysis	Clear sampling techniques	Sampling techniques support conceptual generalisability	Conceptual discussion of results and linkage to new or existing theory to explain relevance of findings to targeted audience	Negative case inclusion	Clear statement of effect on the data of researcher's views	Clear evaluation of the relationship between researcher and those under research, addressing any ethical issues	Ethics approval obtained from an appropriate institution	Critical evaluation of application of findings to other similar contexts	Relevance of findings to policy and practice discussed	Include?
1	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	No	Yes	Yes
2	Yes	No	Yes	No	Yes	Yes	Yes	No	Yes	No	No	No	No	Yes	Yes	Yes
3	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	No	No	Yes	Yes	Yes	Yes
4	Yes	No	Yes	Yes	Yes	Yes	Yes	No	Yes	No	No	No	Yes	Yes	Yes	Yes
5	Yes	No	No	No	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	Yes	Yes
6	Yes	No	Yes	No	Yes	Yes	Yes	No	Yes	No	No	No	Yes	Yes	Yes	Yes
7	Yes	No	No	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	No	Yes
8	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes
9	Yes	No	No	No	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	Yes	Yes	Yes
10	Yes	No	No	No	Yes	No	No	No	No	No	No	No	No	Yes	Yes	Yes
11	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	Yes	Yes
12	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	No	Yes	Yes
13	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	No	Yes	Yes
14	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	Yes
15	Yes	No	Yes	No	Yes	Yes	Yes	No	No	No	No	No	No	No	Yes	Yes
16	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	No	No	No	No	Yes	Yes	Yes
17	Yes	No	No	No	No	No	Yes	Yes	No	No	No	No	No	No	No	No

Key:

	Reference		Reference		Reference
1.	Bussman et al. 2015	7.	Spichiger. 2008	13.	Rogers et al. 2000
2.	Steinhauser et al. 2014	8.	Payne et al. 2007	14.	Dunne and Sullivan. 2000
3.	Kongsuwan et al. 2012	9.	Hawker et al. 2006	15.	Tanaka et al. 1999
4.	Mossin and Landmark. 2011	10.	Ogasawara et al. 2003	16.	Pierce. 1999
5.	Nelson et al. 2010	11.	Kirchhoff et al. 2002	17.	Czerwiec. 1996
6.	Dzul-Church et al. 2010	12.	McGrath. 2001		

Percentage of articles which met the criteria as outlined by Kitto, Chesters [12] (qualitative rating – Study 1b)

Quality element as described by Kitto et al. (2008)	% of papers (n=17) which had evidence of this
Clear aim	100%
Clear research question	12%
Appropriate method choice	65%
Outline of why research design chosen	24%
Clear data collection techniques	94%
Transparent data analysis	88%
Clear sampling techniques	88%
Sampling techniques support conceptual generalisability	65%
Conceptual discussion of results and linkage to new or existing theory to explain relevance of findings to targeted audience	76%
Negative case inclusion	0%
Clear statement of effect on the data of researcher's views	24%
Clear evaluation of the relationship between researcher and those under research, addressing any ethical issues	18%
Ethics approval obtained from an appropriate institution	71%
Critical evaluation of application of findings to other similar contexts	65%
Relevance of findings to policy and practice discussed	88%

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Appendix 3: Study 1b: Patient data themed into domains of importance (red font denotes quotes also used in-text)

Domain	**Expert Care**
Example quotes from included papers	Good physical care • *I'm thankful for my hair being shampooed* [1] • *I can eat at a table when I wear a corset* [1] Symptom management • *How can they expect the doctors and the nurses to know what your pain is? They do not know, unless you tell them . . . and it will change . . . Every time they come in the room they should ask, 'How is your pain today, how is your pain tonight, what can we do to help you with it?* [2] • *And the one thing I used to hate, when it's coming on and you're pressing the button, and they do not come, and you're in a lot of pain* [2] • *[Relief of pain] is very important to your recovery. You do not feel good, you just do not care* [2] • *I am most delighted when the pain is gone* [1] • *At home I kept vomiting, but in the emergency department this was remedied within half an hour, an hour. They probably gave me morphine. And the restless legs didn't bother me any longer, I didn't vomit anymore, I wasn't nauseated. I felt like I was in heaven that afternoon, because I had improved so much* [3] • *They almost suffered themselves. One told me that the whole unit was preoccupied with me. That's good. And it is good that one realizes it* [3] • *I don't see any reason why I should be in pain. They ain't got it under control. They keep thinking because I'm a heroin addict I'm trying to get more pills* [4] Integrated care • *There's good work to be done. It's like a team effort. If you're a team and they're all together working with the patient itself, it's going to work out really good* [4] • *The communication between doctors and nurses, that's paramount . . . You want to make sure that the chain of communication between doctors, nurses, and patients is not broken, because if it is broken, the patient is gonna get lost* [2]
Domain	**Effective communication and shared decision making**
Example quotes from included papers	• *Put this in layman's terms for my family to understand. Why are you doing these tests and things that are painful and intrusive? Is there really reason enough to do it?* [2] • *Using terms that a person that's not a doctor could understand . . . You did not need to go get a dictionary to look it up . . . they explained themselves well* [2] • *The lack of communication was so severe that my wife could not even make informed decisions as to my care. She could not find out enough . . . Nobody told her anything, and this went on for eight days. Nothing. The doctors wouldn't come by. If they did, they wouldn't tell her anything. She had no idea what was going on* [2] • *The family's stress level is so high to begin with, and this just adds more stress, not knowing what my condition is* [2] • *Be honest, so, if you do not come out alive, [the family members] are not surprised, they expected that, they are going to be disappointed, but they realized that you might not make it* [2] • *Knowledge is power, and if my family is informed, then they could have comfort knowing what my status is and how I am progressing or not progressing, day to day, what to expect in the near future* [2] • *Communication, with compassion . . . because, being in the dark is like being in oil* [2] • *I think there are a lot of patients who are either not well enough to do anything about [their care], or not smart enough to do anything about [their care], don't voice their opinions and they just take it. But I'm not one to take it* [4]

	• *One patient thought it was crucial for the ICU to “know what I prefer” so that her family “would never feel guilty about having to make a decision.”* [2] • *Another, whose preeminent concern was to avoid “being a burden to my family,” stressed that she “would want the ICU to know that . . . at the beginning, absolutely,” and when asked if investigation of patient preferences should occur on admission to ICU, replied, “they should know before you even get into ICU.”* [2]
Domain	**Respectful and compassionate care**
Example quotes from included papers	• *I can see where the wheels are turning and people are thinking should he be here? Is he costing us too much? Is he an outpatient? Or is he a hospice patient? Don’t make him too comfortable. If he wants to be bathed, cleaned, he’s not supposed to be in a hospital. That’s not what we do—I can feel it from the staff.* [4] • *I think every patient deserves to be treated with love and respect . . . think of them not that they’re just kind of specimens, but they’re human beings . . . ask the patient what they feel . . . I want to talk to somebody maybe about what I’m feeling that day, just to have a conversation with them.* [4] • *[The nurse did]…just the absolute minimum that she had to do. There was the medications at night. She entered, didn’t say “Good evening”, did something with the equipment and, “Good night”, and out and gone. Didn’t ask, “How are you”, didn’t say, as the others did, “Call me, ring the bell, if you don’t feel well or whatever* [3] • *What really made it different was she treated me with respect and dignity, and the dignity was what made it above and beyond. . . And that really contributed to my healing, and getting better* [2] • *. . . they could bring the father here more often so you get communion. Because they want people going downstairs [for mass] . . . if you go in a wheelchair, usually you don’t have underwear on—when you get up to get communion . . . everybody’s looking at your rear end* [4] • *So I can only speak good really, you know, I’ve got no complaints whatsoever. They are so attentive, they’re so cheerful, they don’t mind how many times you ring your buzzer and whether it’s in the middle of the night or whatever.* [5] • *One could say that 90% of all who are here anticipate one’s every wish. And are concerned.* [3]
Domain	**An adequate environment for care**
Example quotes from included papers	• *Patient: It’s not so peaceful as the other room. I like it [being in a single room]. I like being on my own. Because they [nurses] all giggle, you know a lot, and I’m glad they do, but it gets on my nerves, that’s me, I mean nothing against the girls laughing, they like a good laugh, ... I’d sooner be quiet ...* [5] • *No, I wouldn’t want a room on my own ... I couldn’t be better cared for if I was in a private place with a room of my own, I couldn’t. It’s more fun with other people there to talk to ...* [5] • *It’s [community hospital] such a nice atmosphere, you feel so safe. I can see now how necessary they [DGH] are, but it’s a different atmosphere in here.* [5] • *I like it because it is near home and my son can get to me conveniently, which is a main plus, I feel nearer home, I feel safer.* [5] • *Well, the nursing is quite different and there is hardly any nursing, there are only two or three of them on duty, so the nursing is quite different and you’ve got to tune yourself to that to accept that things that you used to get done at the hospital [DGH] they don’t do here.* [5] • *As long as I am in hospital, I feel safe* [1] • *It would be more convenient for my family if I was to pass away here [the hospital], because then they could start my funeral arrangements going . . .No [I haven’t talked about these things with them]*[4]
Domain	**Family involvement in care provision**
Example quotes from included papers	• *I’m sitting here by myself. And just like everybody else, I need the company of somebody and to have the family. I need my family, too* [4] • *With my family I have always overcome difficult times. My family is the very source of my support* [1] • *The presence of my spouse has been indispensable to me. We have lived together through times of difficulties with the disease* [1] • *My friends and, more importantly, my family played a very, very big part in my, in my comfort level, and my emotional healing. And for me, the emotional healing is high, right there with physical*

	healing. It's all one. I would stare at the clock, and wait for visiting hours to come, and that was just very, very crucial for my personal healing, to get better and get out of here [2] • *The mind of the patient is not on himself only; his mind is also toward the family that is beside him, that is caring for him. Most times, most of the patients do not care much about themselves. But they care for the family that has been giving them support.* [2]
Domain	**Financial affairs**
Example quotes from included papers	• *I'm concerned about my hospital and living expenses for my family as I have been in hospital for a long time. I wouldn't care about the expenses if my stay were shorter.* [1]
Domain	**Maintenance of sense of self / identity**
Example quotes from included papers	• *'It is always there, it is never again not there.'* [3]. • *'I feel like I'm in prison.'* [3] • *'I will make an effort to maintain this improved condition.' …. 'I'm not going to look backwards; I want to live with this disease with all my strength and maintain my quality of life as a human being* [1] • *I'm concerned if the important documents are kept in order at home* [1] • *I wish I could go back to work even for a short while* [1]

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Appendix 4: Study 1b: Family data themed into domains of importance (red font denotes quotes also used in-text)

Domain	**Expert care (good physical care, symptom management and integrated care)**
Example quotes from included papers	Good physical care • *I'm not sure how well trained they were for when he needed his bag changing. There was mess made then, and stuff like that* [1] • *They really were fantastically caring and you know, the process of turning and mouth care, all that was done in an exemplary fashion* [1] Symptom management • *Symptom management is the highest priority* [2] • *My husband went into hospital because he was in severe pain but I don't think he was any better off. The pain never went away, he was always uncomfortable. I felt annoyed about that because if I had known I wouldn't have let him go to hospital* [3] • *Critically ill people should be free of pain in the terminal phase* [4] • *My husband had secondaries in his spine and he was paralysed. He suffered very severe pain and although he had drugs given for the pain, it never seemed to go away. He had pain right up until he died. The staff tried to do their best. Nobody seemed to be able to get to the bottom of it. It was very distressing for us as a family* [3] • *Want the patient to be free from pain* [2] • *It was important for him to have immediate care because he was very sick, and it hurt to have to wait and see him suffer. And there wasn't anything I could do to relieve that* [5] • *He was in obvious pain and they paged the doctor . . . then we just waited and waited and waited and waited and it was getting worse* [6] • *I don't agree with allowing the patient to have shortness of breath before death. This is because when we say anything to them, the mind will not receive it. The mind can only receive these ideas when the body is not suffering* [7] Integrated care • *The specification of professions involves that everyone treats only one aspect. Man as a whole is falling by the wayside* [4] • *More psychological support for the ill as well as the families* [4] • *The mentally and emotionally part of a dying person receive too little support* [4] • *If anybody has the story down and the plot and how it is going to turn out, the social worker does. They know what they need to bring to the table and what you are going to need help with . . . especially when you have a family member that is critically ill . . . They say the right things, know what to do . . . It should be an integral part of the care* [8] • *I want to start by giving praises, because I cannot praise the chaplain enough. I can't say enough about Paul Jones. He was just great . . . a great service* [9] • *The power of prayer cannot be outdone, especially in times of crisis, that is when people are looking for some place to go, for help. . . . Having someone that is going to come by and offer you prayers, it should not be forced upon anybody but it should be looked upon as a part of treatment that can help people* [8] • *A lot of times, we did not know who was in charge . . . Do they ever sit down and have somebody leading the discussion that's the patient's main doctor? You had all kinds of specialists* [8] • *If you gotta talk to two or three specialists, they come in with conflicting information* [8] • *So many different teams of doctors and nurses were involved . . . but those people were all communicating . . . were all on the same page* [8]
Domain	**Effective communication and shared decision making**

Example quotes from included papers	Effective communication leading to a shared understanding • *‘We were all generally happy enough with the information we got. It was understandable and we knew what to expect. The staff seemed concerned about us and were keen to do their best for us. I found this particularly in the last day or so.’* [3] • *‘The doctor did come in and tried to explain to us what it was, but I really wasn’t understanding it. It was kind of over my head because we’re not doctors’* [5] • *“I do not have a medical background,” said a family member, “so . . . I would be saying, please, tell me in English.”* [8] • *Physicians beat around the bush instead of talking in plain language. What a pity.* [4] • *“She’s going to tell you, she’s not going to give you a line, but she’s still sensitive. That’s the key.”* [8] Complexity involved in decision making at the end-of-life both in relation to medical complexity but also the fact such decisions also have significant emotional and financial implications • *"Here you are, you are so medically untrained, you have to put your faith and trust in people you have never seen and you don’t know….If they said ‘Should we do this or do that?’ I didn’t know what to tell them to do."* [10] • *‘The doctor would tell you, you can do this or this or this or this. And, it’s a medical decision, but it’s also an emotional decision and a financial decision, and . . . I did not know what was best.’* [8] • *The doctor would say, ‘well, I cannot advise you, but these are your options.’ But if I asked, ‘what would you do?’, then he could answer that question. And then I had more information to make my decision on, whereas he was, ‘you’ve got these choices.’* [8] Need for sufficient and timely information provision with a particular focus on being informed ahead of time, being included in the day to day care plan outlines and the importance of regular planned discussions with the healthcare team, specifically valuing discussions with medical physicians. • *Family members should be informed ‘early enough’ to support him (. . .).* [4] • *Why are they so afraid to talk with you about what they think might be happening? I wish they had told me sooner that they thought my son was dying . . . the sooner the better.* [9] • *She was there 45 days. . . . On Friday, the doctors and nurses knew she would die-she probably knew, too- but she wasn't told. . . . If they had just come out and said it, then we could have all said our goodbyes; we didn't.* [9] • *Doctors need to tell you more about what to expect, though-like how close to the end and what might happen next. You don't think to ask-they need to say what is likely to happen next . . . like, with her congestive failure, she got very short of breath-but I don't think she suffered; they gave her morphine on the last day.* [9] • *‘When I approached the nurses to say or ask anything I got the impression they were busy. Nobody explained how things were progressing. I mean we weren’t kept informed about daily events. It came as quite a shock to me when I became aware that my wife had only about 2 days to live. I knew this would happen of course but I didn’t realize she was as near to dying as she was at that time.’* [3] • *Even if it is also hard to know, I think it is better than not knowing, just wondering. Yes, it is positive, even if it is hard. To be present and to know what is going on.* [11] • *“that would be the very best thing that I can say all day today. If they would just say, okay, we’re real busy, but we can be there at 10:20, then the family member can make it there. We’ll go along with their schedule. We know they’re busy, but man, would that be helpful.”* [8] • *“ICU has rounds at a certain time in the morning. And after that time, when everybody that works there has met and talked, that would be a good time to arrange a family meeting, so we could find out what are they all thinking, what are their plans, just for today, to know what’s going on, instead of day after day, not being sure, not being able to get a hold of the doctor.”* [8] • *" You sit around waiting for the doctor to come in and tell you something….They say, ‘I will talk to you later,’ and….you don’t know when later is….so you don’t dare leave.”* [10] • *“Nothing, nothing was important to me as much as just being able to talk to the doctor and to get the information there.”* [8] • *I follow his routine, so I see him when he is here. To see him outside those hours is difficult, he is a busy man, but I thought there would be somebody here who would have a file, some information, so that I wouldn’t need to chase after the doctor ...* [12]

	• *She [sister] felt like I didn't give him a chance to get better. If they [the medical team] had called a family meeting, then everybody would have gotten the same information at the same time.*[5] • *...we were never invited to discuss his condition...I felt that we were gathering information from several people, squirreling it out of them.*[13]
Domain	**Respectful and compassionate care**
Example quotes from included papers	Provision of respectful and compassionate care noting this to include the preservation of dignity • *Everything matters-what people say, how they touch the patient-and you-how they look at you-whether or not you matter*[9] • *They once discharged her back to nursing home at midnight in her nightdress, with no coat — wouldn't even give us a blanket. Didn't inform nursing home*[13] • *To my mind even a dying man deserves dignity and Henry was not given this during his stay in hospital*[13] • *That was my mother. They need to realize that that's somebody's loved one in there . . . It's not like they need to have an emotional bond with each and every one of our relatives, but they need to have some compassion for these people*[8] • *Better humane care – affectionate care of patients!!!*[4] • *I did have the sense-sort of a bad experience----of people being cold, inattentive, like all routine stuff to them*[9] • *My brother came to get me and we went over to get my Dad's body released. Everyone was so nonchalant and really cool-like they couldn't care less*[9] • *They came in and stretched him out and put one pillow under his head and wiped his face. They had already come in a little bit earlier and changed him because he was very particular about his hygiene. (. . .) They had shaved him, bathed him, put him in clean pajamas before he died. After he died, the kind of propped him, and told me I could stay with him as long as I wanted to*[5] • *No diagnosis like 'You have metastases in the brain, there is nothing that can be done about that' and then leaving the patient without any help*[4] • *To still treat the deceased with dignity*[4] Care was provided by capable staff with key attributes principally centred on approaches to care provision rather than purely skilled task completion. • *First and foremost employment of capable nursing staff characterized by the qualities: helpful, empathic, affectionate, appreciative, comforting*[4] • *More sympathy of hospital staff and physicians, which know what families have to expect*[4] • *speaking gently to the patient*[2] • *approaches with a smile*[2] • *gentle touching*[2] • *want nurses to be constantly considerate of the patient's feelings*[2] • *Henry couldn't hear and the nurse just stood at the bottom of the bed and asked if he wanted anything, when he didn't answer she just left him, if we hadn't asked for drinks he would have died of dehydration*[13] • *The nurses were very nice and worked very hard, but I think they have become technicians rather than providing what we used to consider 'nursing care'*[13] • *but no, he was just left in his pyjamas and if he was out sat by his bed or lounging on his bed, he had no help to feed himself and he had no use of his right hand, so he needed all his food cut up and they weren't doing that for him. I'm not sure how well trained they were for when he needed his bag changing. There was mess made then, and stuff like that*[1] • *Better training for the caregivers attending the dying during the last hours*[4] Individualised care provision valuing the patient and their family – 'the little things are the important things'[1] • *[That] they don't become a 'number' but stay a human being and person. [That they are] treated humanely and [are] not used as a guinea pig*[4] • *That was my mother. They need to realize that that's somebody's loved one in there . . . It's not like they need to have an emotional bond with each and every one of our relatives, but they need to have some compassion for these people*[8]

	• *I think that while their focus is medical and saving lives and, you know, the science, I think also, along with that comes the responsibility of some kind of support to a relative or a family, that patient's loved one or caregiver. Yeah, and they actually did that, and that is part of high-quality care* [8] • *Some were good, and I thought some had a blank face, looking at my mother as just a number, number 35. So what I did, I said, my mother is not just an old lady, my mother had a life, of course now she's hooked up to a million cables. I brought in pictures of my mother when she was born, and when she got married to my father in 1936, and how she looked later on. And they saw her differently. It's not just a piece of meat that is sitting in that hospital bed. It's a life. That is 100% important* [8] • *He sat with us, listened to us, cared about Frank as a person-who he was, what he liked doing, what he meant to us* [9] • *One of the hardest things-that is burned indelibly right in my brain [drawing a line across her fore head]-is what a nurse said to me when I questioned why Ben had a feeding tube. She said: "These patients do better when they are fed early" -these patients!-these patients!-not "Ben" -not "your husband" -but "these patients!"-like he were a number, or one of a herd or something-that hurt a lot-I'll never forget it- I wanted to scream: "He's not a 'these patients!'"- he's Ben-he's my husband* [9] • *The whole atmosphere is very different from the General . . . they ignore you there, you know nobody comes and says "he's done this, he's done that, he's done anything" in the General, whereas when I went to [community hospital] they all recognised me and at least would say "hullo" or "he's such and such today" or make a comment about my husband, you know, even in the corridor for example, so I was connecting with them _ and I mean that helped ever such a lot. It was very homely, if that's the right word, and if he was sitting in the sitting room everyone immediately told you where he was, and where he was sitting, and take you to him and things like that _ which was very, which was nice. And I know they were all little things, but the little things are the important things* [1] • *One time, one of the nurses was clearly doing things her own way; her own routine. I wanted to suggest some things that I knew made Ed more comfortable; but . . . she clearly was moving to her own ways* [9] • *it was very important to my mother to tell her life story . . . it was important to my father to, to relate that, to others-who she was and what she spent her life doing* [9]
Domain	**Adequate environmental and organisational characteristics**
Example quotes from included papers	<u>Hospital rules and processes – these need to make sense and ought not to detract from optimal patient care</u> • *Admittance procedure was dreadful and distressing. Charles was in great pain — had eaten nothing since breakfast and was vomiting. He was taken up to a ward at 12 00 and made to sit in a chair for two hours until a doctor could see him and officially admit him* [13] • *By the time I got to the hospital, he had been moved from the Emergency Room to the ICU, but I didn't know that. I went to the Emergency Room and the person at the desk told me that I couldn't go to the ICU to see him until I moved my car from emergency parking because he was no longer a patient in the Emergency Department. I couldn't believe it! I started crying-I only wanted to go see Carl- finally, another person saw me and said: 'For Pete's sake, let her leave her car there!' but that shouldn't happen to people. Rules need to make sense* [9] • *Visiting hours for the families of dying patients should not be* restricted [4] • *Ease up on hospital rules depending on the patient's situation* [2] • *More assistance concerning questions about care, [and] the options one has. Quicker aid, less bureaucracy; you need certifications and forms for everything!* [4] • *He had esophageal cancer, so we know it's got a very, very low survival rate, so, as soon as he was diagnosed, he got [an advance directive] in place . . . One of the nurses came out and said, 'it's getting to the time where we need to decide' . . . and I said, we're not going to prolong this, and she said, 'do you have paperwork?' I said, yes, I've got paperwork, it's on file here. She called downstairs to medical records, they could not find it, and so I am just panicking, because I'm thinking he's going to code, and they're going to try, and he only weighs 80 pounds, so I sent my husband immediately to get it, and we live in another city. An hour and a half of anguish, and it wasn't necessary* [8]

- *Allowing more time for nursing staff and hospital nurses so that they can care for the patients wholeheartedly* [4]
- *. . . with a lack of personnel, documentation has high priority instead of treatment or care of the patient* [4]

Environmental characteristics contribute to quality end-of-life care with a particular noting of the need for privacy, cleanliness and quiet

- *Dying in a separate room with the possibility of a personal farewell – that would have been important for me* [4]
- *And he had a lovely, lovely room, a little doorway out on to a little patio. Yes, gorgeous, as I say he was really happy there* [12]
- *One big thing: There needs to be a more private space for family to be when death is imminent. Frank was moved out of ICU on the 24th-when they were sure that he would not recover from that second stroke. I spent the night with him. That next morning-there was a beautiful view out his window-the sun rose right over his bed-it was the most beautiful sunrise I had ever seen. He died that morning-the whole family had come in to be with him. I had wondered what was the purpose of moving him out of the ICU-then, I knew. It was beautiful* [9]
- *One should not put up critically ill persons in three- or four-bed rooms without shower and WC* [4]
- *In the ward where my husband was there really was no privacy. There didn't seem to be any place in the ward where you could talk in private to the staff or indeed to my husband. I never felt at ease when we were talking because I always thought there was somebody who could hear you* [3]
- *I never felt there was any privacy in the ward, there was only a curtain between the beds. I felt I couldn't talk about things that I wanted to because I was aware that others could hear me. We were disappointed that there wasn't a bit more privacy* [3]
- *I just wanted to be alone with him-that seemed so hard in the ICU. They let us come in and all, but it wasn't like being with him-it was watching* [9]
- *You hear so much about dirty beds, dirty pillows, things not being changed, my mum's linen was changed every day and she wasn't incontinent, um, I mean I'd go there when they didn't expect me, so it wasn't sort of, oh, she's coming, we'll do it, I remember going there one lunchtime, and they said, you'll have to hang on a minute, we're in the middle of doing your mum's bed, you know, so I was most impressed with the cleanliness I must admit* [1]
- *The hospital ward was not up to standard in hygiene (cleaning). I clean a locker and a bath before allowing him to use it* [13]
- *I do not think the standards of hygiene are good in hospital compared to the past. Odd rubbish seems to lie about* [13]
- *I appreciate the staff are working and that, but they do make a clatter sometimes, most of the time there is something going on. Yes, well those last few days we were in a ward directly opposite the nurses' station, and it was a tiny bit on the noisy side I mean you can't expect them to walk around whispering, but there were times when it was noisy. And the bell seemed to ring an awful lot, but I mean, they are patients, they need help. The casualty bell is a very strident bell, you know . . . I'm not complaining about it at all, its just they are constantly busy, it's not a quiet place. It's not a peaceful place* [1]
- *They shout from one end to the other. Yes, if they want somebody, they don't go and look for them, they shout for them* [12]

Space for cultural practices whether this be congregating multiple family members, chanting or other important rituals to support optimal end-of-life care. This information came from one article only [7].

- *At the end, all relatives and cousins have to be there. . .this will help the dying person to leave with happiness and in peace. . .not feeling alone. . .* [7]
- *I came to be with him and did some short chanting. I whispered that he should not worry, I will take care of mom. After that my younger brother came in to speak into his ear. Then my mom said to him to have a comfortable sleep, our sons were already grown, not to worry about her and to go to sleep in comfort* [7]
- *I knew that my dad was dying soon. . . in the moment of being informed of the impending death by the doctor. He said to me that dad would not survive. Then, I asked the nurse to turn on the taperecording of the monk's chanting. When dad heard the chanting voice, he grasped my hand*

	and closed his eyes. He wanted to hold every person's hand. I said to him that please pass peacefully, and prayed for his spirit to depart peacefully, not worrying about anything [7]
Domain	**Recognising and supporting the family role in care including valuing their expert knowledge of the patient and advocating for patient needs**
Example quotes from included papers	Wanting to be involved, to advocate and for their expertise as 'carer' to be recognised and valued • *From the time my mother went into the hospital and us knowing that she was going to die was an extremely trying time for all of us. I had looked after my mother at home and I still wanted to do that in hospital. I felt I didn't have a lot of contact with the staff. I felt helpless* [3] • *One nurse, one time, asked me to help turn Barbara, while she made the bed. . . . I got to hold her, and touch her. It was the only time-the only time that I felt like I was able to do something for her. I wanted to do so much to help her-there seemed to be nothing I could do. They let me help to turn him and hold him-that was important to me-I was helping keep him comfortable* [9] • *To me it felt safe to be there, but for him you might say it was a need. And to be able to help I felt was a good thing. Yes, I thought it was very good!* (Spouse 2) [11] • *I went to the doctor and I said that there is something wrong and I know (the patient) . . . and they found fifteen blood clots blocking the urethra . . . all the water was coming in and nothing was going out! I just said 'Sorry, but I know (the patient) better and he is in pain* [6] • *I probably made a nuisance of myself, but I really feel that my sister got much better care because I was there every day. I was a decision-maker, and I was a prodder, and I was a nagger, and I was an everything else* [8] • *Right from the word go, (the patient) never went anywhere without me. From the time (the patient) got sick and they put in the central line, I stuck by (the patient)* [6] • *The case seemed to be 'Just shut up. We are the experts; we will do what we think is right. We don't want to hear from you'* [6] • *There was no attempt to say, 'Are you concerned about it? Do you think things are going OK?' That sort of thing* [6] The importance of feeling welcomed as a partner in care so the carer is certain of their role • *It almost feels like it wasn't your place there. It was the patients', and they deal with the patient* [6] • *As caregiver, quite often, they didn't talk to me. So you felt like you were the third person watching the events . . . I found that difficult* [6] • *I will never forget that time in the hospital with my husband. I had cared for him at home. It was very hard knowing that he was going to die. I wasn't sure how to cope with it. I seemed to be in a panic all the time and when I went to the hospital I wasn't sure what I should do for my husband. I don't think we were helped much. I felt ill at ease and never seemed to be able to settle* [3] It is not necessarily beneficial to remove carers from distressing situations – involvement remains key for some and therefore should be supported • *And she just said "Would you like to sit in the lounge?" and I said, "No, I don't want to sit in the lounge; I will stand at the door, thank you." When they came out it was only a matter of a few minutes, I believe, and she said "Sorry (the patient) has gone," and I said "I want to be with (the patient)." I wanted to be with (the patient) all along and they tend to try to shoo you out. I did not see him when he was dying. (The patient) had wires all over his head and everything and that may not look good . . . but I could deal with all that. I would have preferred to be with (the patient) holding hands, even though it might only have been a small time* [6] • *They tried to get me out of the room saying this is not beautiful for your eyes . . . let's get you out of the room. And I said, "No, I am not going . . . this is someone I care about." And this other nurse said to me (later) that I held (your loved one's) hand and (the patient) breathed four times after everything was turned off and I held (the patients hand) and tried to comfort (the patient). (Crying) That really hurt me because that is my role. It was my role, and I just believe from hearing from people who were unconscious or had those near-death experiences that they know who is with them and know what is going on. I believe (the patient) would have known that I left the room and that hurts me to this day* [6]
Domain	**Financial affairs**
Example quotes	• *I am an 83-year-old pensioner not in the best of health...had we been told of attendance allowance before Graham died his last few months may have been a bit more comfortable* [13]

from included papers	- *The advice in completing social security forms and finding out about benefits he was entitled to claim was very poor. Because of this, he lost benefits in the first 8 weeks of illness. It was only through pulling their finances together and by financial assistance from 'Help the Aged' that eased our situation. This initial failure led Dad to worrying about bills being paid. He did not need this sort of additional stress in the last few months of his life* [13]
Domain	**Maintenance of patient safety and prevention of harm**
Example quotes from included papers	Families feeling hospitalisation did not provide any improved level of care compared with care at home – hospitalisation is not always the answer - *My husband went into hospital because he was in severe pain but I don't think he was any better off. The pain never went away, he was always uncomfortable. I felt annoyed about that because if I had known I wouldn't have let him go to hospital* [3] - *I will never forget that time in the hospital with my husband. I had cared for him at home. It was very hard knowing that he was going to die. I wasn't sure how to cope with it. I seemed to be in a panic all the time and when I went to the hospital I wasn't sure what I should do for my husband. I don't think we were helped much. I felt ill at ease and never seemed to be able to settle* [3] - *I think the 'care' he received made him worse not better* [13] - *From the time my mother went into the hospital and us knowing that she was going to die was an extremely trying time for all of us. I had looked after my mother at home and I still wanted to do that in hospital. I felt I didn't have a lot of contact with the staff. I felt helpless* [3] Poor care leads to a lack of patient safety with the following key areas particularly noted: poor communication; not considering a palliative approach as needed; not considering a patient's unique care needs; ensuring families feel aware of how to best support their loved ones; poor levels of core nursing care; lack of timely attention *Poor communication* - *One night I arrived and (the patient) was panicking after a doctor's visit and there was a total misunderstanding and basically what the doctor said was that (the patient) would die. I had to find the doctor and identify what was said. I told the doctors that in the future I want to be there for future meetings. My instructions were ignored by them* [6] - *Edward never wanted to be told he was going to die. It was clear on his hospital notes that he did not want to be told. The doctor at the hospital told him while he was alone. This upset everyone for a long time* [13] - *(she) understood enough about her illness to know the prognosis was poor. It was clearly not necessary to spell it out and it undermined my morale at a time when it was important to give Elizabeth encouragement* [13] *Not considering a palliative approach* - *My Dad was alert. He could squeeze my hand- but he had a breathing tube in. He seemed like he wanted to talk-I am regretful that I didn't ask to have that tube removed . . . . When it's happening, you do the best that you can . . . it's not a good situation for thinking straight* [9] *Not considering a patient's unique care needs* - One time, one of the nurses was clearly doing things her own way; her own routine. I wanted to suggest some things that I knew made Ed more comfortable; but . . . she clearly was moving to her own ways. [9] *Ensuring families feel aware of how to best support the patient* - *One of the things that is helpful for the family is to know that they have done as much as they can. . . It's not knowing, necessarily, that they have had as much medical treatment as they could, but maybe as much caring as they could-touching, music, listening . . .* [9] - *I would never want to experience that again, such a New Year. That was the most brutal; New Year's Eve at midnight, that was absolutely unbearable* [14] *Poor nursing care* - *Admittance procedure was dreadful and distressing. Charles was in great pain — had eaten nothing since breakfast and was vomiting. He was taken up to a ward at 12 00 and made to sit in a chair for two hours until a doctor could see him and officially admit him* [13] - *They once discharged her back to nursing home at midnight in her nightdress, with no coat — wouldn't even give us a blanket. Didn't inform nursing home.* [13]

	• *Nobody would take responsibility for him, nobody seemed to care. He was discharged before Christmas when they should never have sent him out. Never checked there was anyone there to look after him, they didn't arrange any support for him* [13] • *To my mind even a dying man deserves dignity and Henry was not given this during his stay in hospital* [13] • *Henry couldn't hear and the nurse just stood at the bottom of the bed and asked if he wanted anything, when he didn't answer she just left him, if we hadn't asked for drinks he would have died of dehydration* [13] • *On visiting Henry one evening we found his breakfast tray on his bed* [13] • *…but no, he was just left in his pyjamas and if he was out sat by his bed or lounging on his bed, he had no help to feed himself and he had no use of his right hand, so he needed all his food cut up and they weren't doing that for him. I'm not sure how well trained they were for when he needed his bag changing. There was mess made then, and stuff like that* [1] *Lack of timely attention* • *He was in obvious pain and they paged the doctor . . . then we just waited and waited and waited and waited and it was getting worse* [6] There is a need to support families and patients to 'speak up' about their care to ensure patient safety • *I thought that you weren't supposed to do that- but I was afraid to say anything* [9] • *You just don't want to complain about anything. You are at their mercy; your loved one is at their mercy . . . what would happen if they got mad at you?* [9] • *I'm so glad for this opportunity to say something- and not have it tied to me or my husband in any way. These things need to be said; but you can't when you so desperately need their help* [9]
Domain	**Preparation for death**
Example quotes from included papers	• *[We] needed this, our grandchildren especially needed that moment* [10] • *It would have been advantageous for me and my family if, at a point, of the better than 2 weeks that he was in ICU, we could have had some kind of counselling on end of life issues* [8] • *And, I believe I would have benefited greatly, if previous to this, I had been told by the doctor that this is the possibility, you need to start thinking about this. I just wasn't ready for it . . . We got a call at 5 AM and my brother was gone. And I never had the chance, you know* [8] • *She was there 45 days. . . . On Friday, the doctors and nurses knew she would die-she probably knew, too-but she wasn't told. . . . If they had just come out and said it, then we could have all said our goodbyes; we didn't* [9] • *The whole thing about the experience with me was I didn't know he was dying, so it was very hard* [5]
Domain	**Duty of care extending to the family after patient death**
Example quotes from included papers	• *I think that I did get very good attention and my father had the best of care, but . . . they just came and closed his eyes, started doing whatever they do when somebody dies, and basically just said to move. And, I just left. I did not know what else to do. . . . I would've liked a piece of follow-up, somehow. A call: 'Ms.___, I know your father just recently died, how are you doing? Did you know there's a group? Would you be interested in talking to someone? . . . It's important for people who have recently lost their loved ones,' or something like that* [8] • *At 8:00 PM, I went out there and felt like I was going into a war zone. I was put out like, out on the street. No one told me anything. They knew several days beforehand that I had arranged the date [for ventilator withdrawal], but nobody approached me . . . Nothing was addressed at all . . . Nobody asked, 'Are you able to take care of yourself; are you able to find a place to go to, as far as for grief, for death of your mother?' Where do you go, what do you do? . . . Prepare one for it a little bit. Not to walk out into the cold night* [8] • *After he died, they just came in there and pronounced him dead, and started covering him up and moving him, and pulling out all these things. And, I thought, do they need the room right now? They do not give me a minute to just kind of get up and grab my stuff and get out? So, I just left. I would have appreciated some follow-up or grief support or social work or anything. Because I did not cry over my father. . . . I did not cry at all, until 2 months ago, I finally had myself a good little fit. I did not know that I was so messed up. I wished that I had spoken with someone. Or someone had reached out to me. In some way* [8]

Domain	**Enabling patient choice at the end-of-life**
Example quotes from included papers	The importance of following established Advance Care Directives and for processes to be in place to facilitate this - *Physicians: should comply with existing patient advance directive and not prolong the suffering and dying for a few months* [4] - *My mother had made a decision against a nourishing probe in advance but everyone (paramedical and nursing staff, some physicians) made me a bad conscience: 'Do you want to let your mother starve?'* [4] - *For patients who had previously expressed preferences in an advance directive, there was agreement among participants that "the ICU needs to know immediately" before major decisions were actually at hand, if possible, "before something tragic happens." "What's the point of making one out if the information's not passed on?" in a timely way, a family member asked, rhetorically* [8] - *He had esophageal cancer, so we know it's got a very, very low survival rate, so, as soon as he was diagnosed, he got [an advance directive] in place . . . One of the nurses came out and said, 'it's getting to the time where we need to decide' . . . and I said, we're not going to prolong this, and she said, 'do you have paperwork?' I said, yes, I've got paperwork, it's on file here. She called downstairs to medical records, they could not find it, and so I am just panicking, because I'm thinking he's going to code, and they're going to try, and he only weighs 80 pounds, so I sent my husband immediately to get it, and we live in another city. An hour and a half of anguish, and it wasn't necessary* [8] - *One man had told his wife, " . . . [I]f I am physically able, but I have lost my mental facilities, . . . I would choose not to live, . . . [but] I would like to live to see these little kids (grandchildren] grow up* (Kirchhoff, 2002 #130) The fact decision making at the end-of-life is complex, even when in the context of being guided by an Advance Care Directive - *I knew [he] did not want to be on life support systems. . . . I made us up a living will every year, . . . but when you're actually faced with the reality, [that is] something! You have to go with the decision. . . . [but] I would have taken [him] under any circumstances* [10] The need for legalised euthanasia for critically ill patients - *Critically ill patients should get the legal option to end their lives painlessly and without complications if they wish (. . .)* [4]

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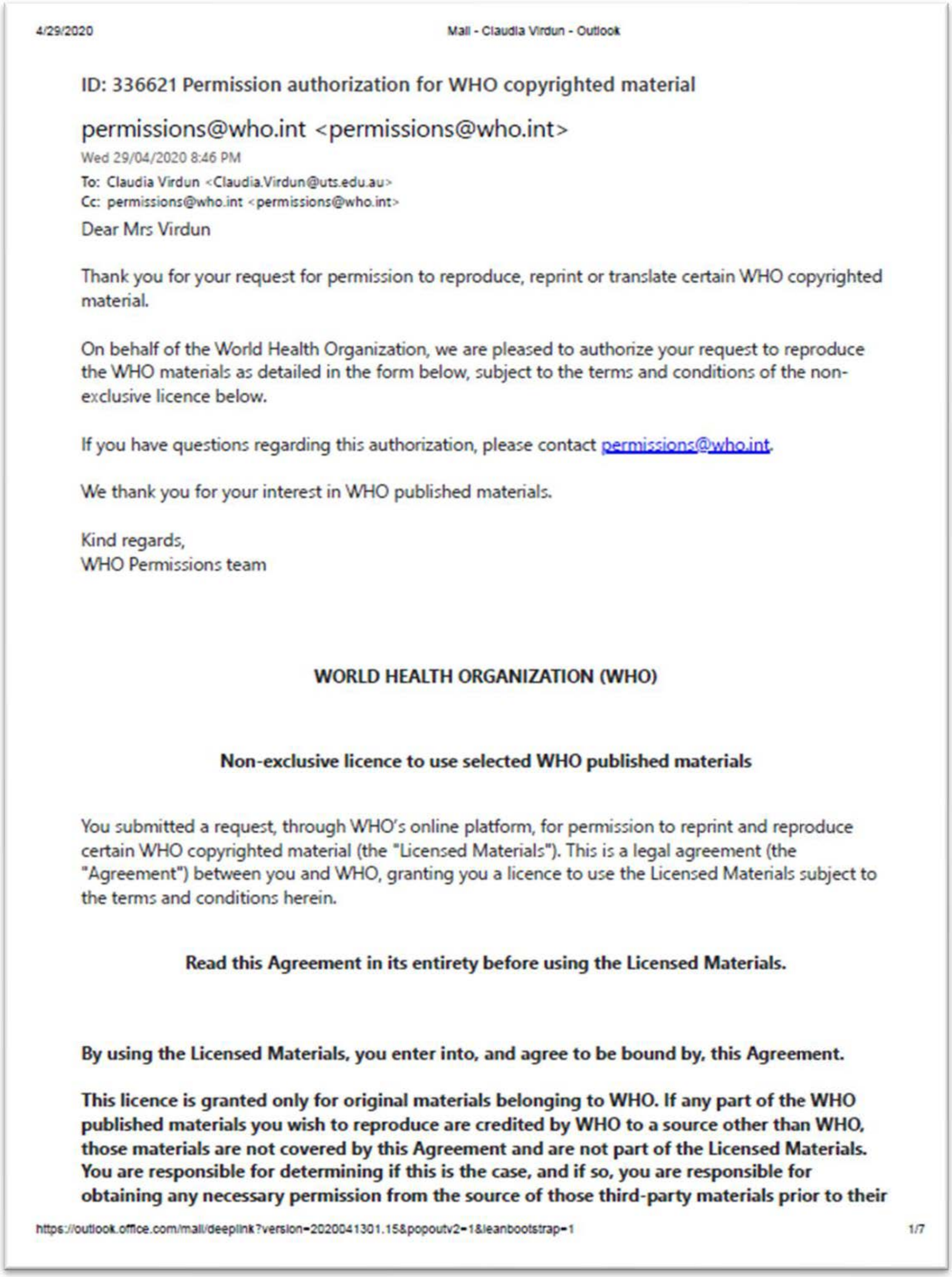

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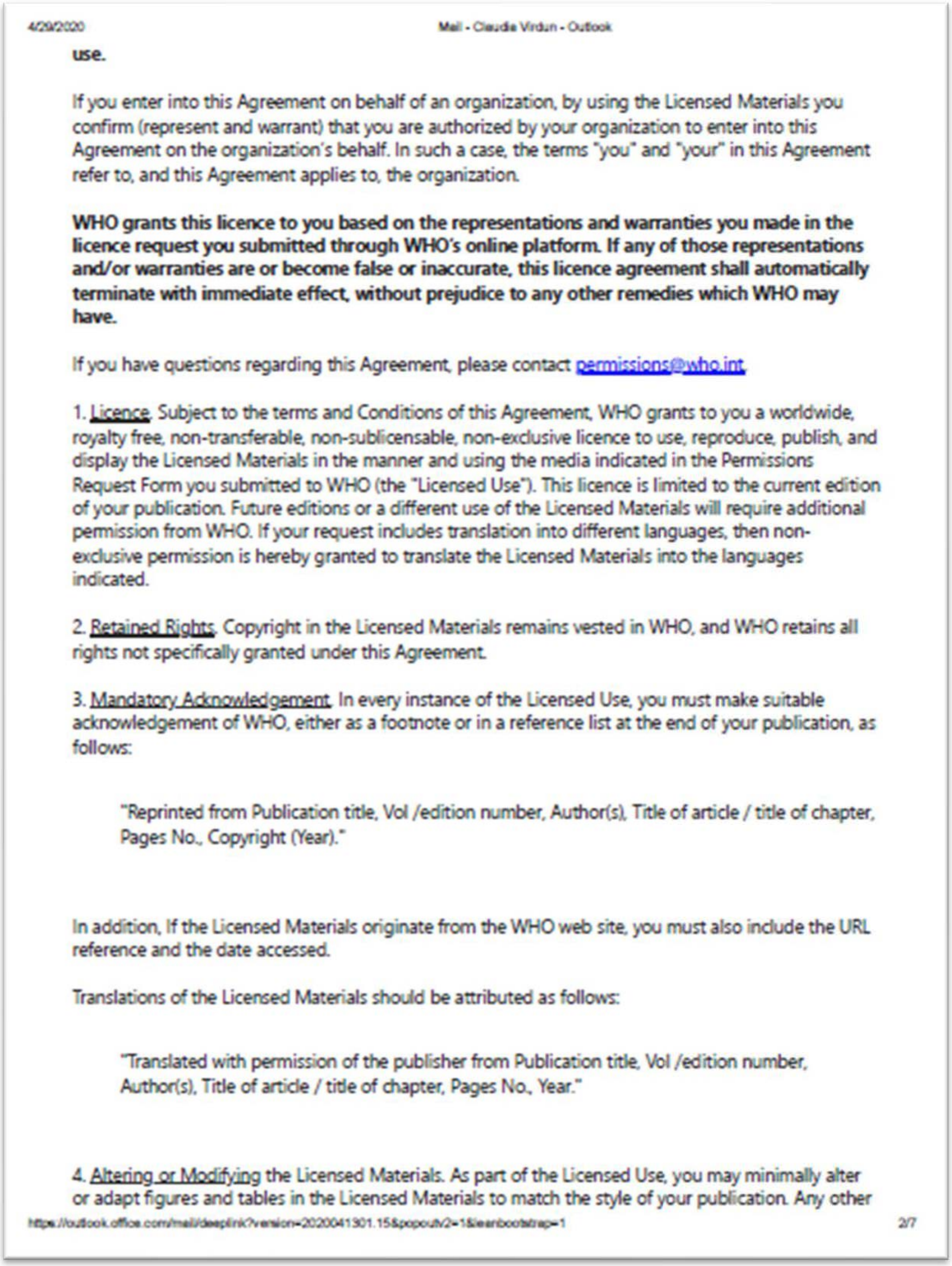

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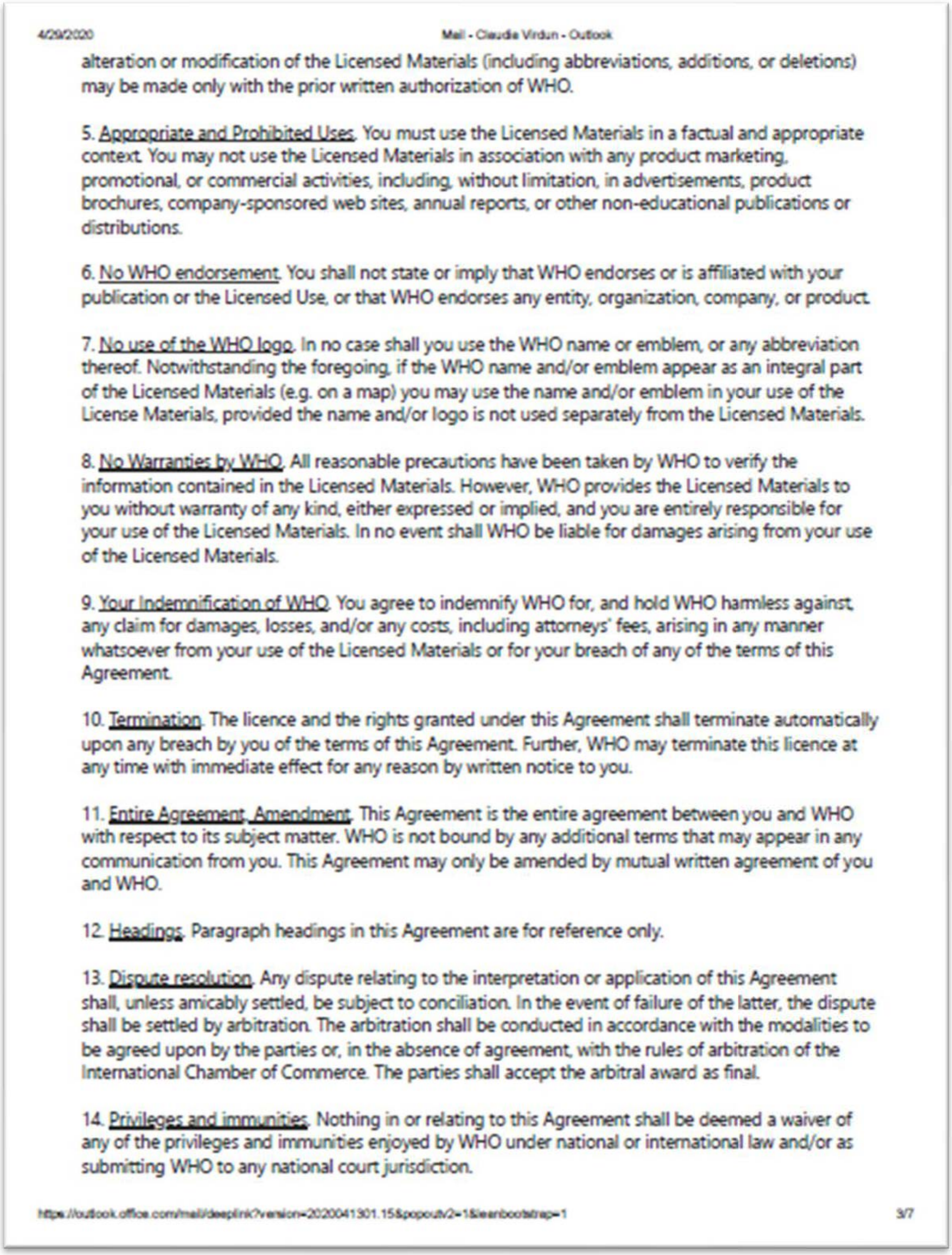

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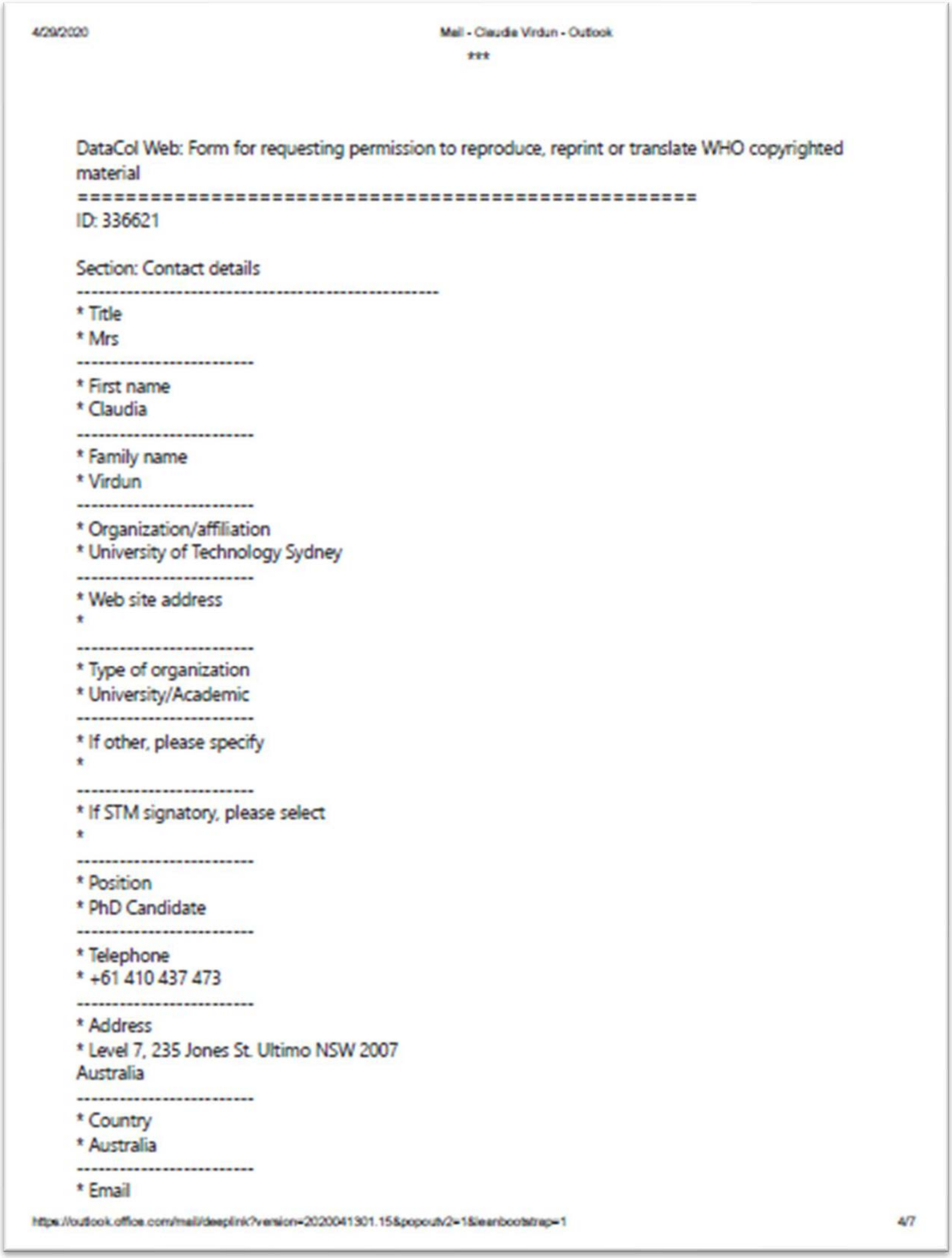

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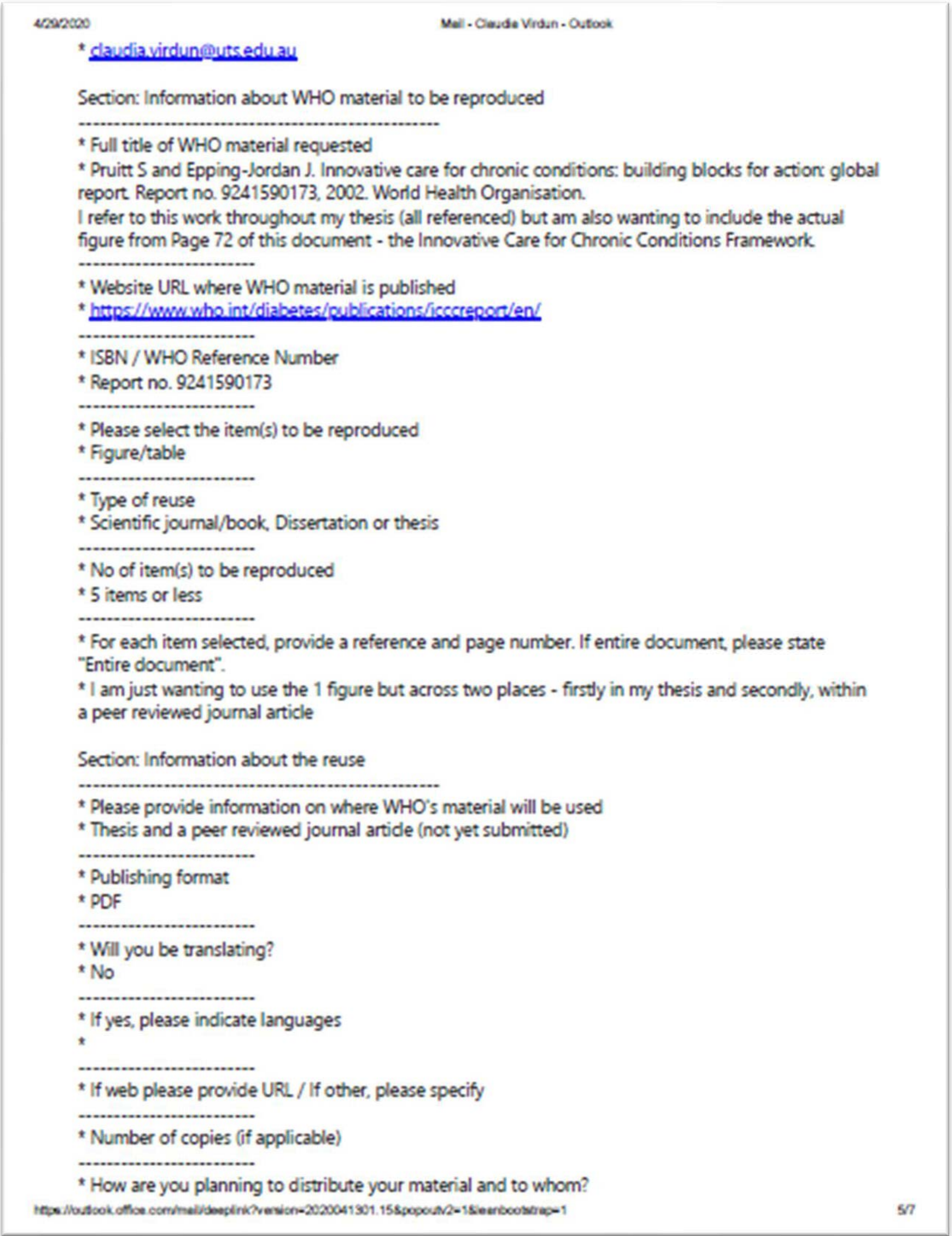

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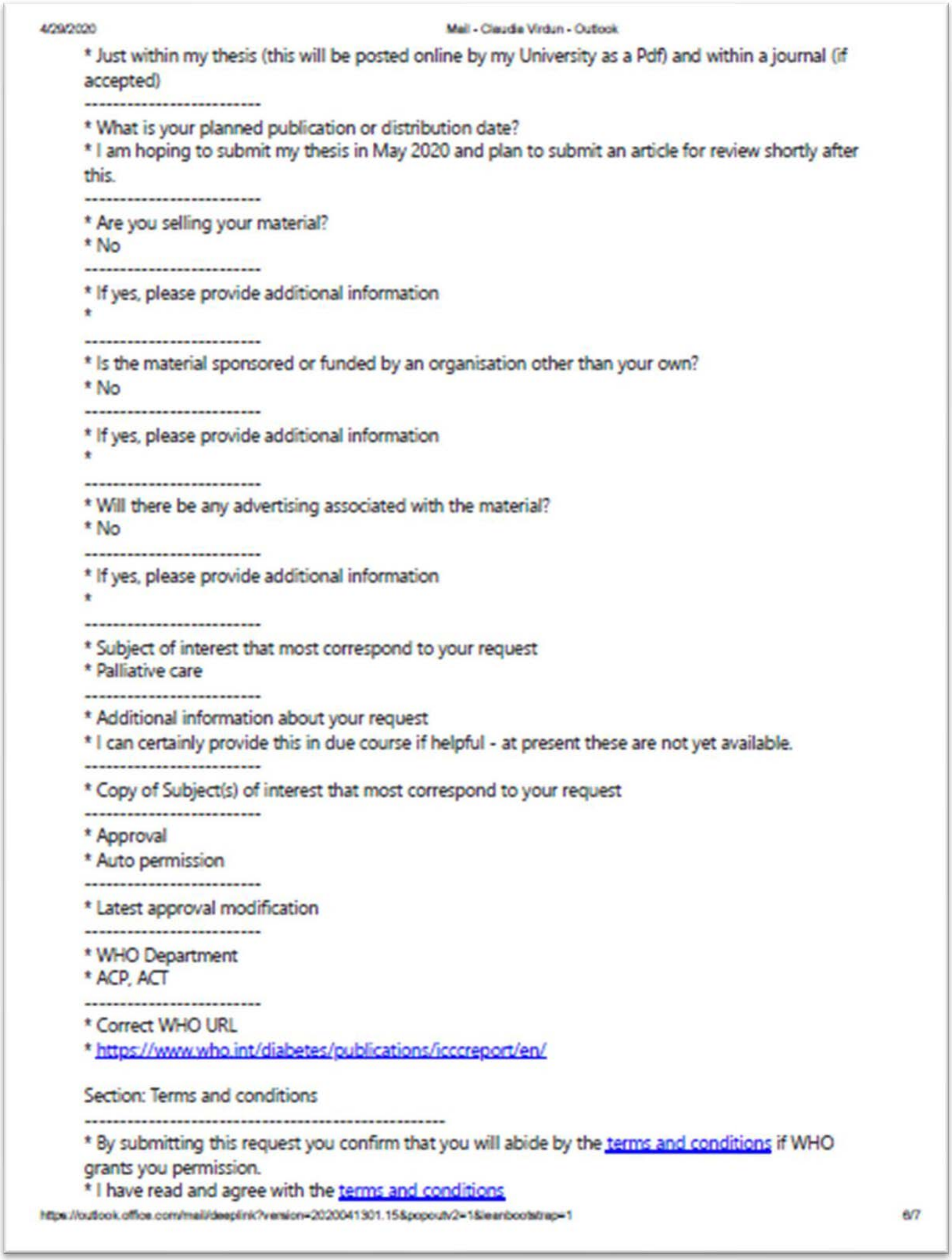

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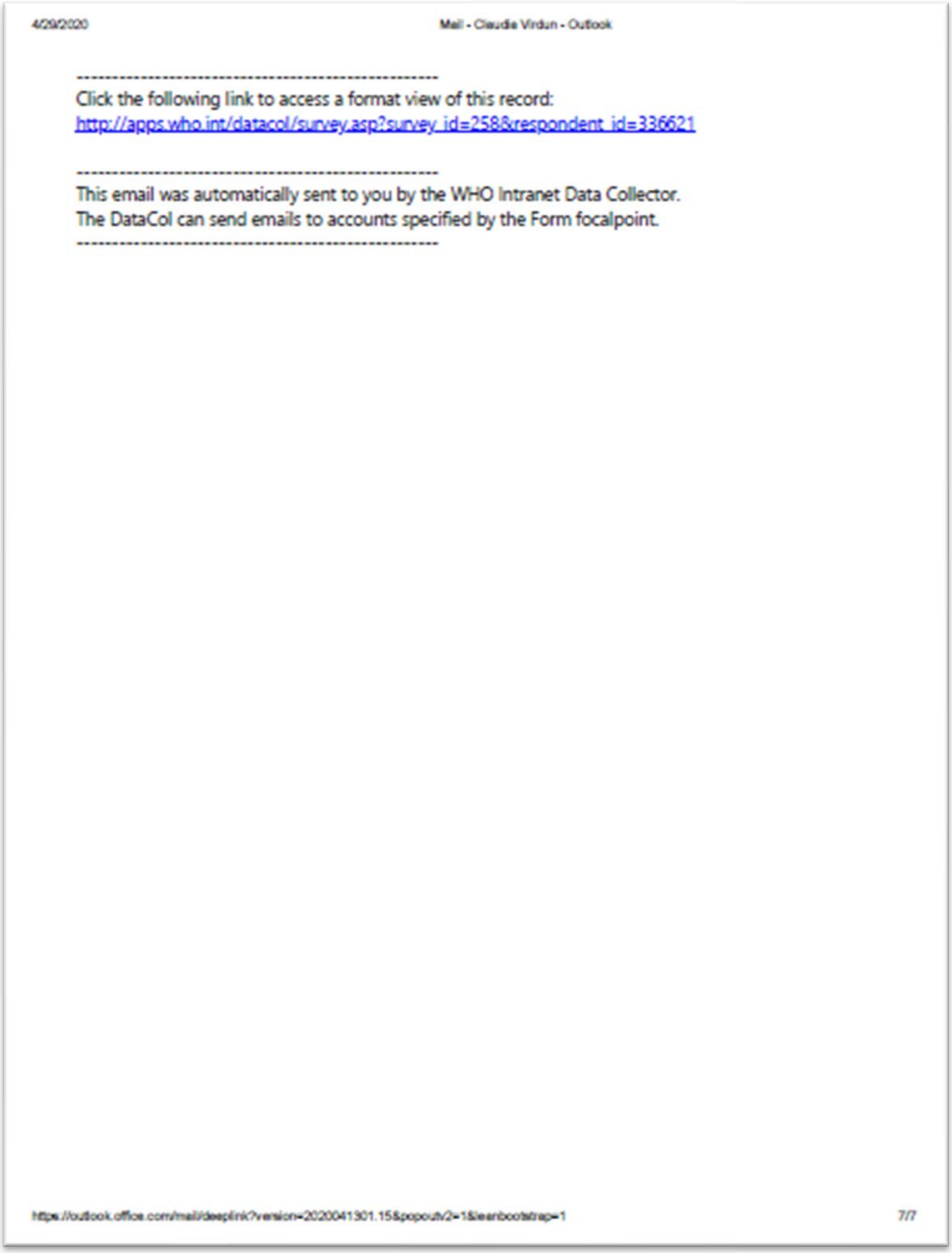

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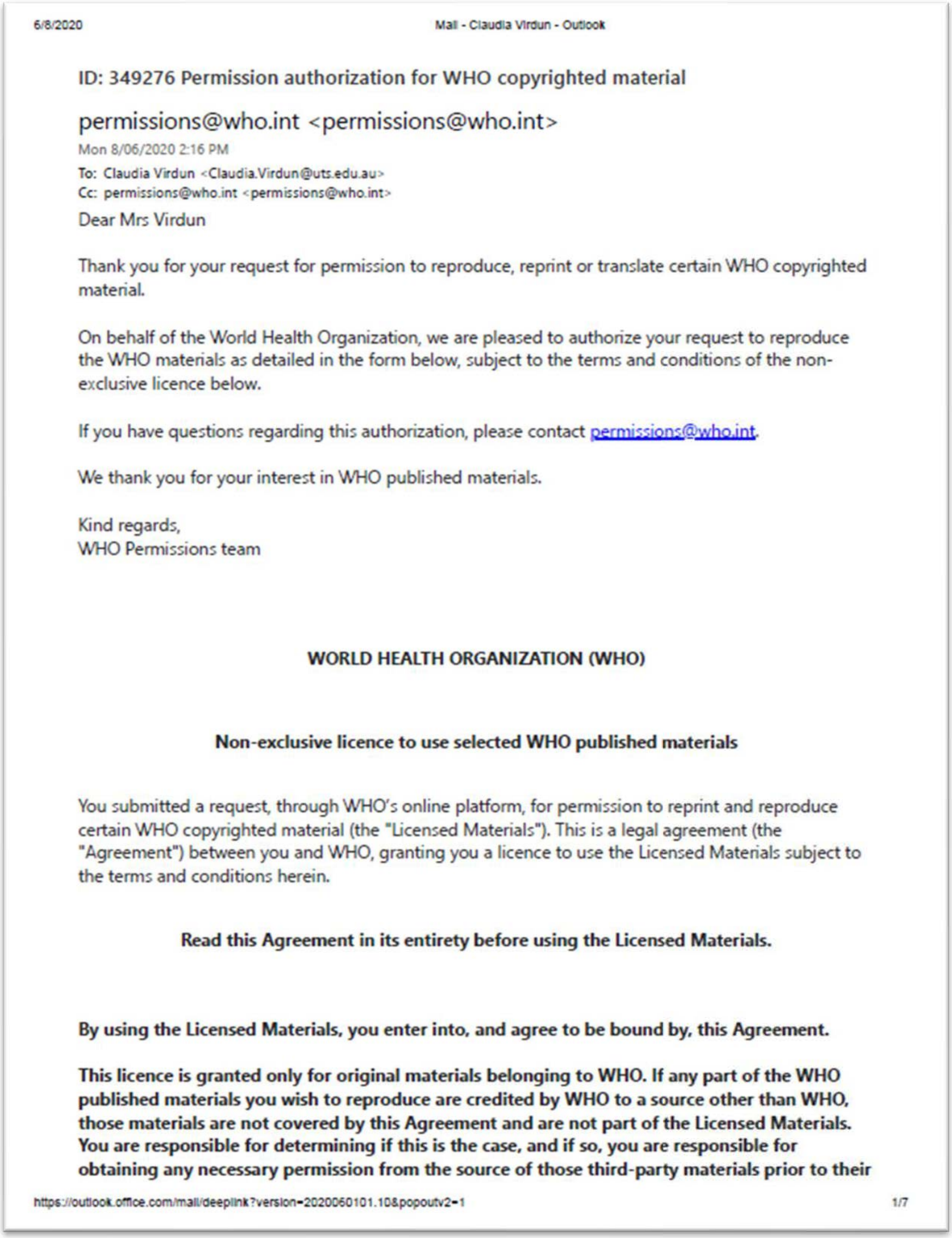

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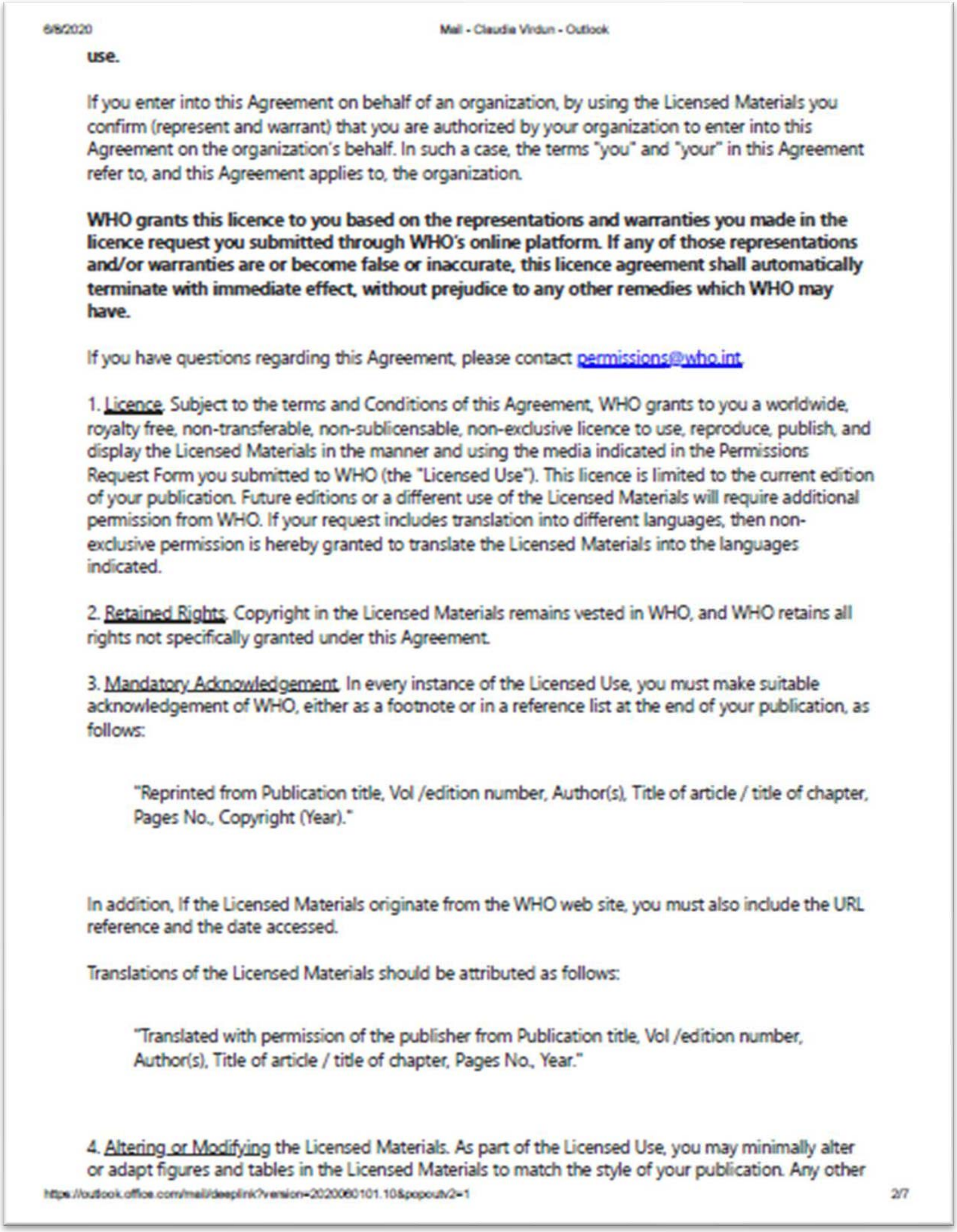

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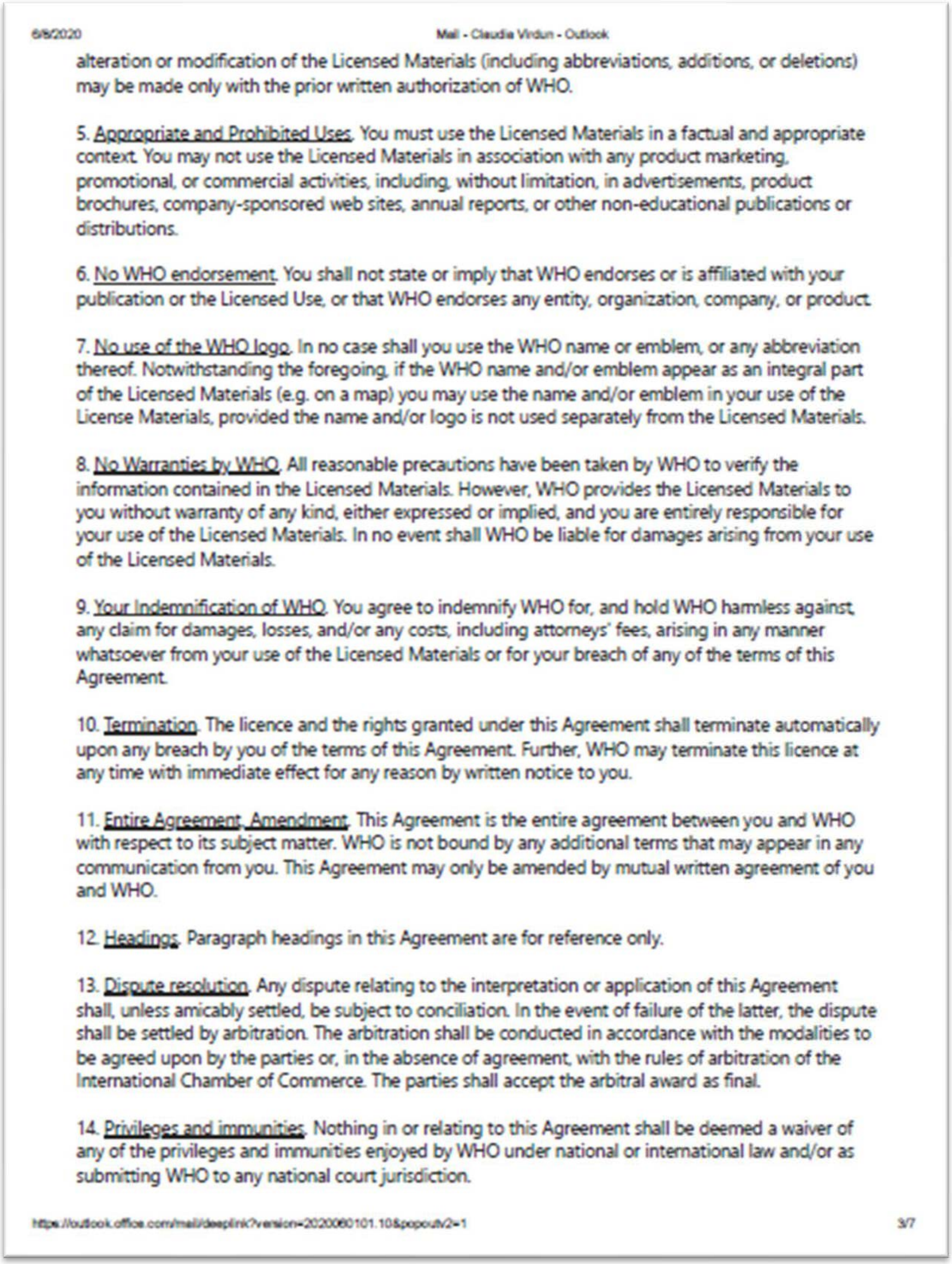

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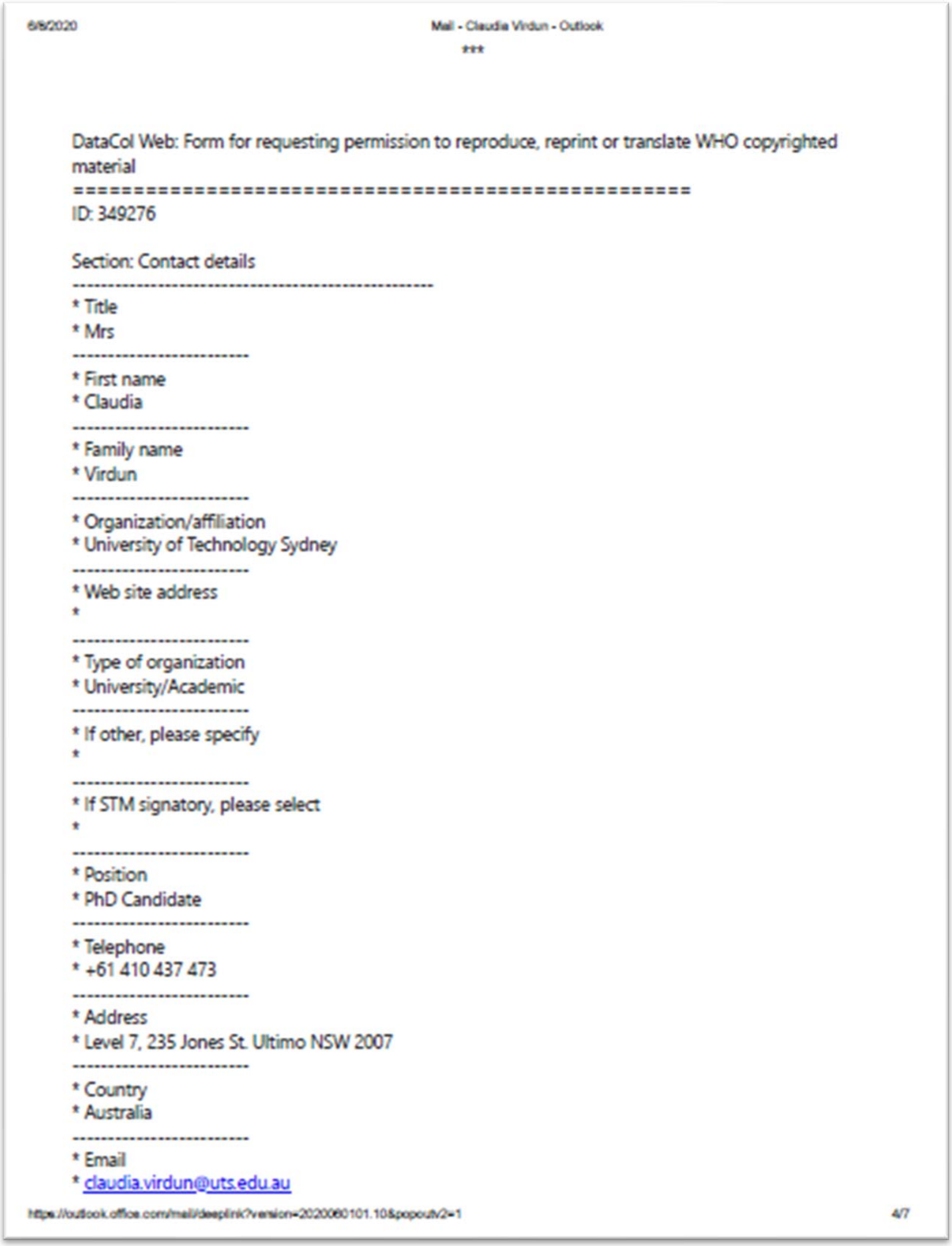

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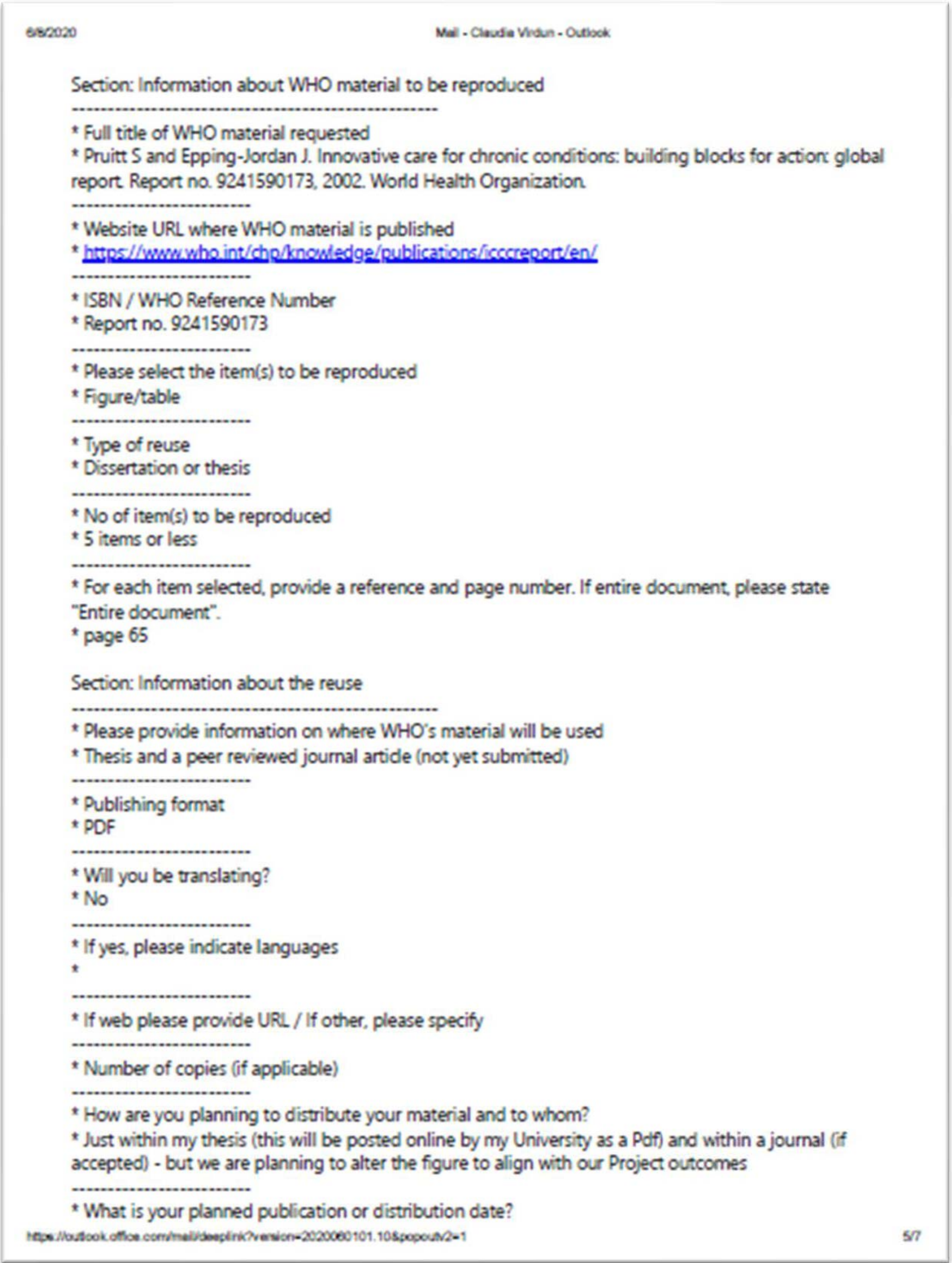

6/8/2020 Mail - Claudia Virdun - Outlook

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* Pruitt S and Epping-Jordan J. Innovative care for chronic conditions: building blocks for action: global report. Report no. 9241590173, 2002. World Health Organization.

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* Report no. 9241590173

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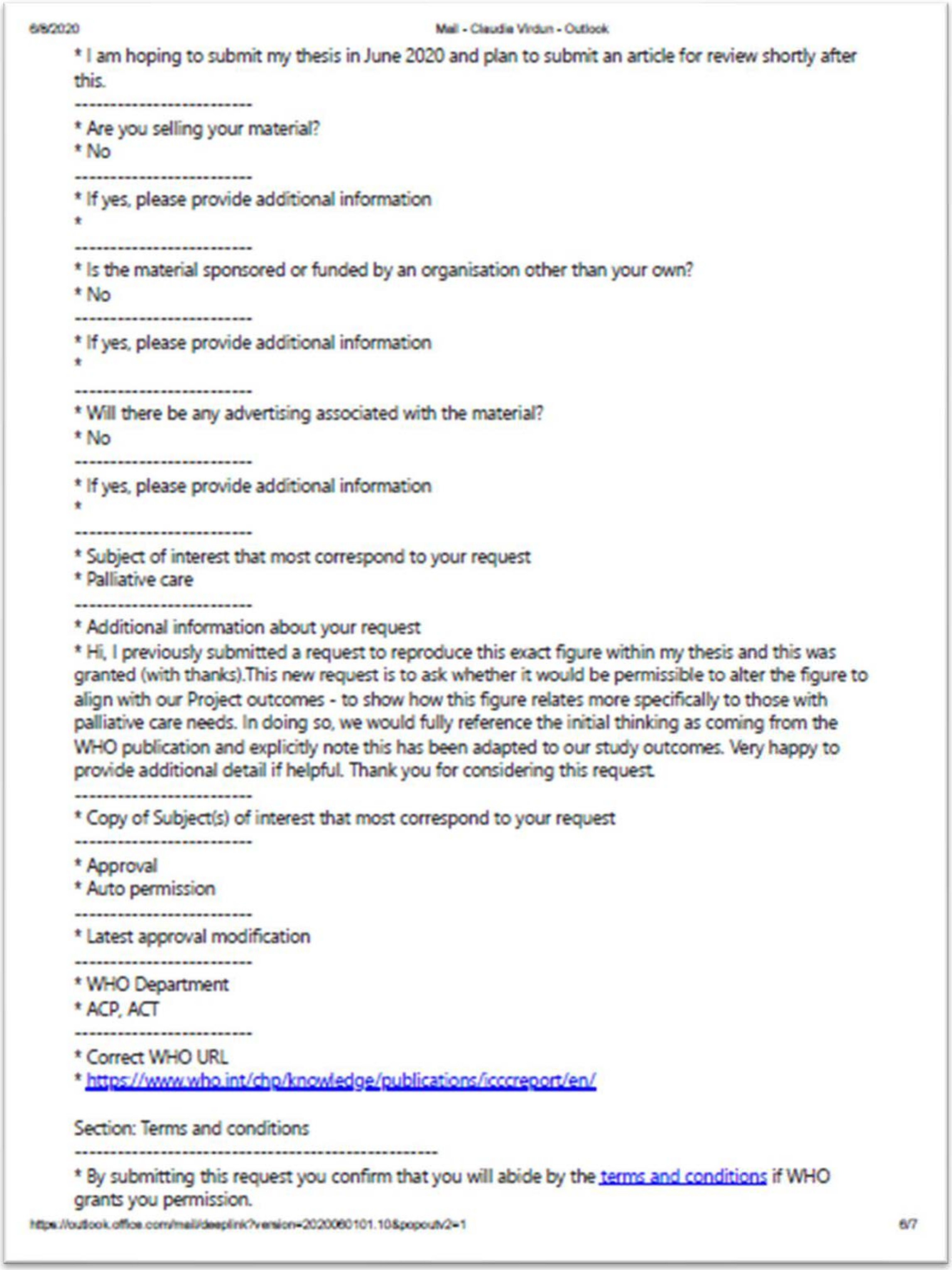

* I am hoping to submit my thesis in June 2020 and plan to submit an article for review shortly after this.

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* Hi, I previously submitted a request to reproduce this exact figure within my thesis and this was granted (with thanks).This new request is to ask whether it would be permissible to alter the figure to align with our Project outcomes - to show how this figure relates more specifically to those with palliative care needs. In doing so, we would fully reference the initial thinking as coming from the WHO publication and explicitly note this has been adapted to our study outcomes. Very happy to provide additional detail if helpful. Thank you for considering this request.

----

* Copy of Subject(s) of interest that most correspond to your request

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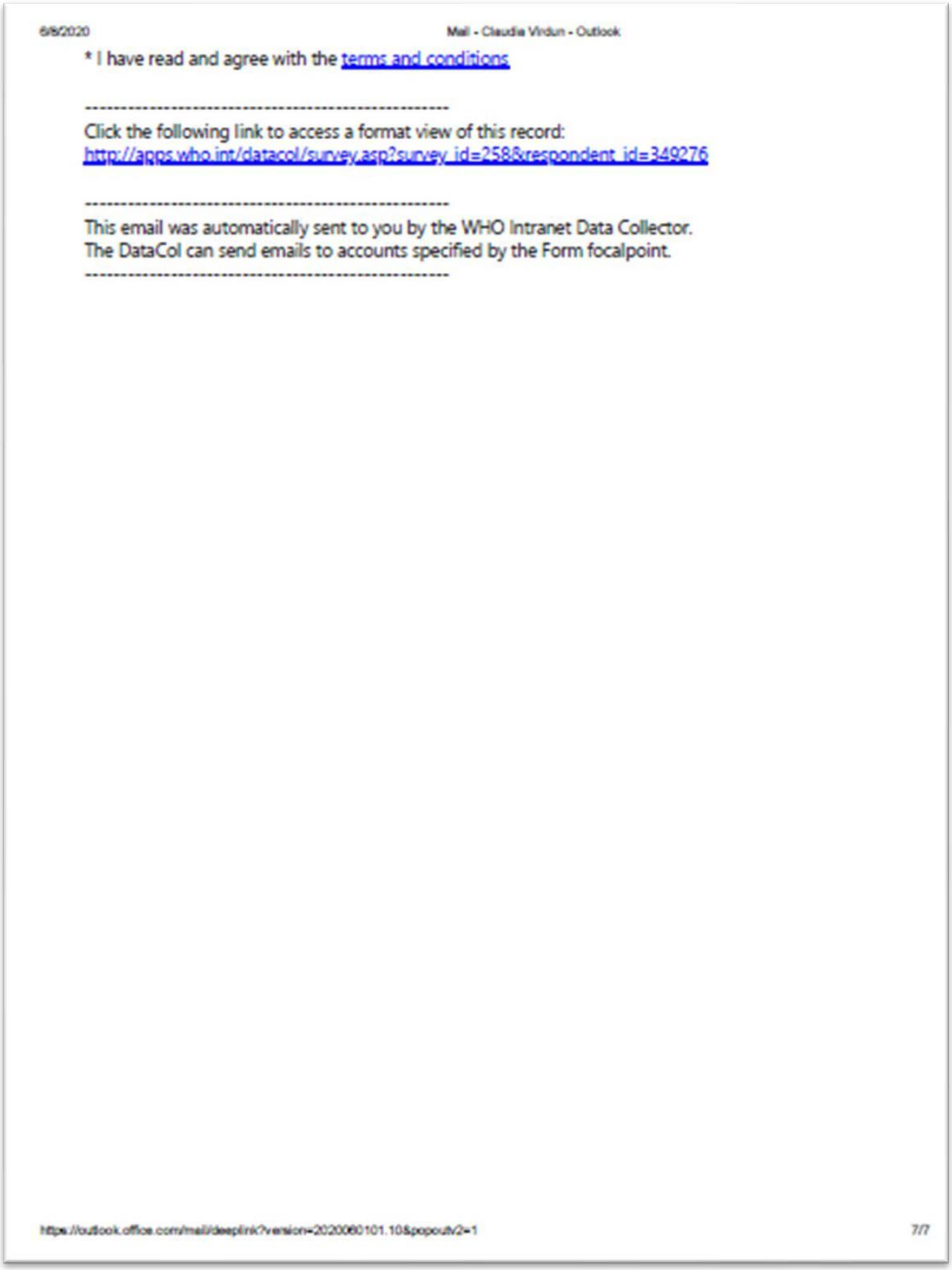

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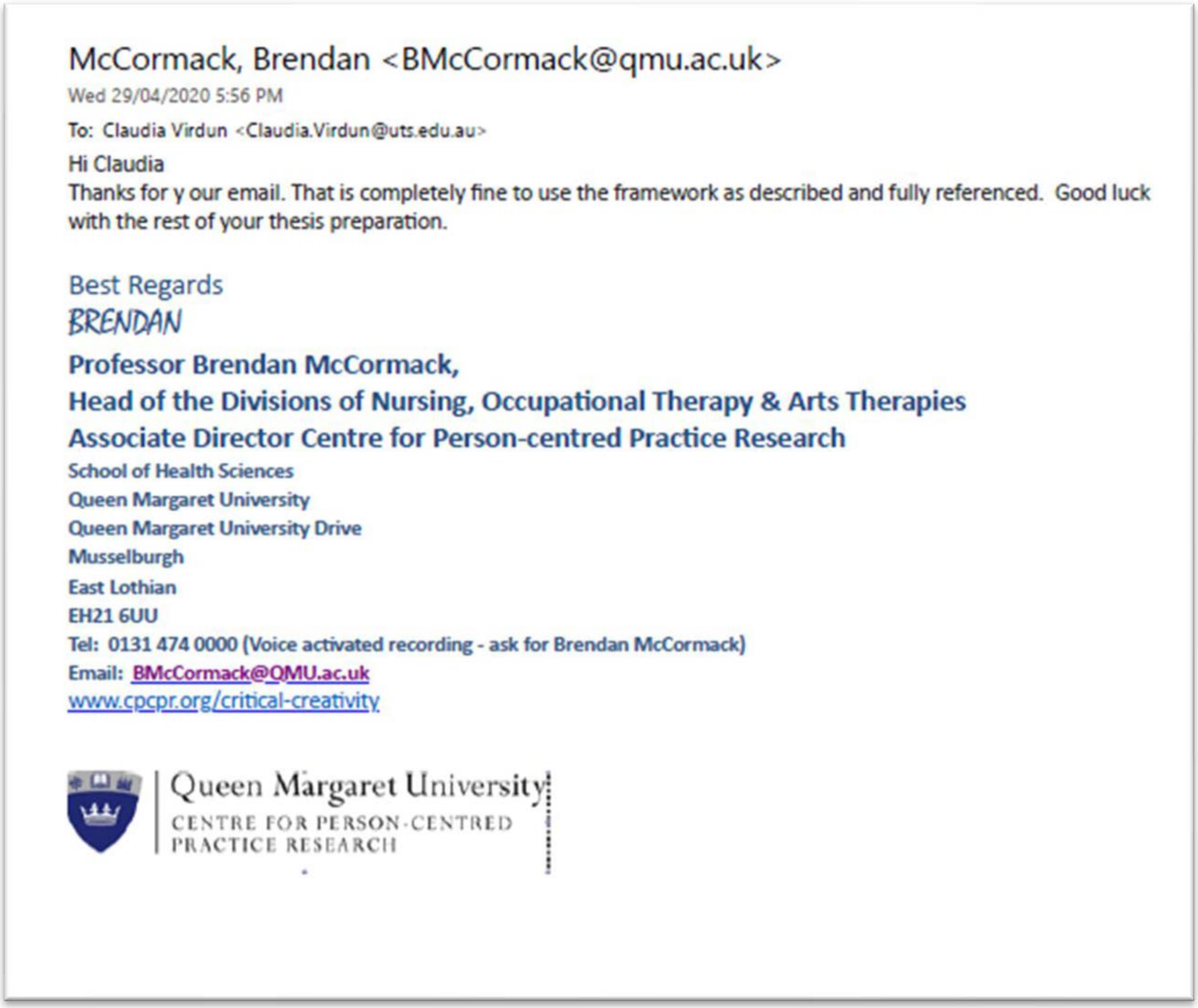
The Person-centred Practice Framework (2019 revision)

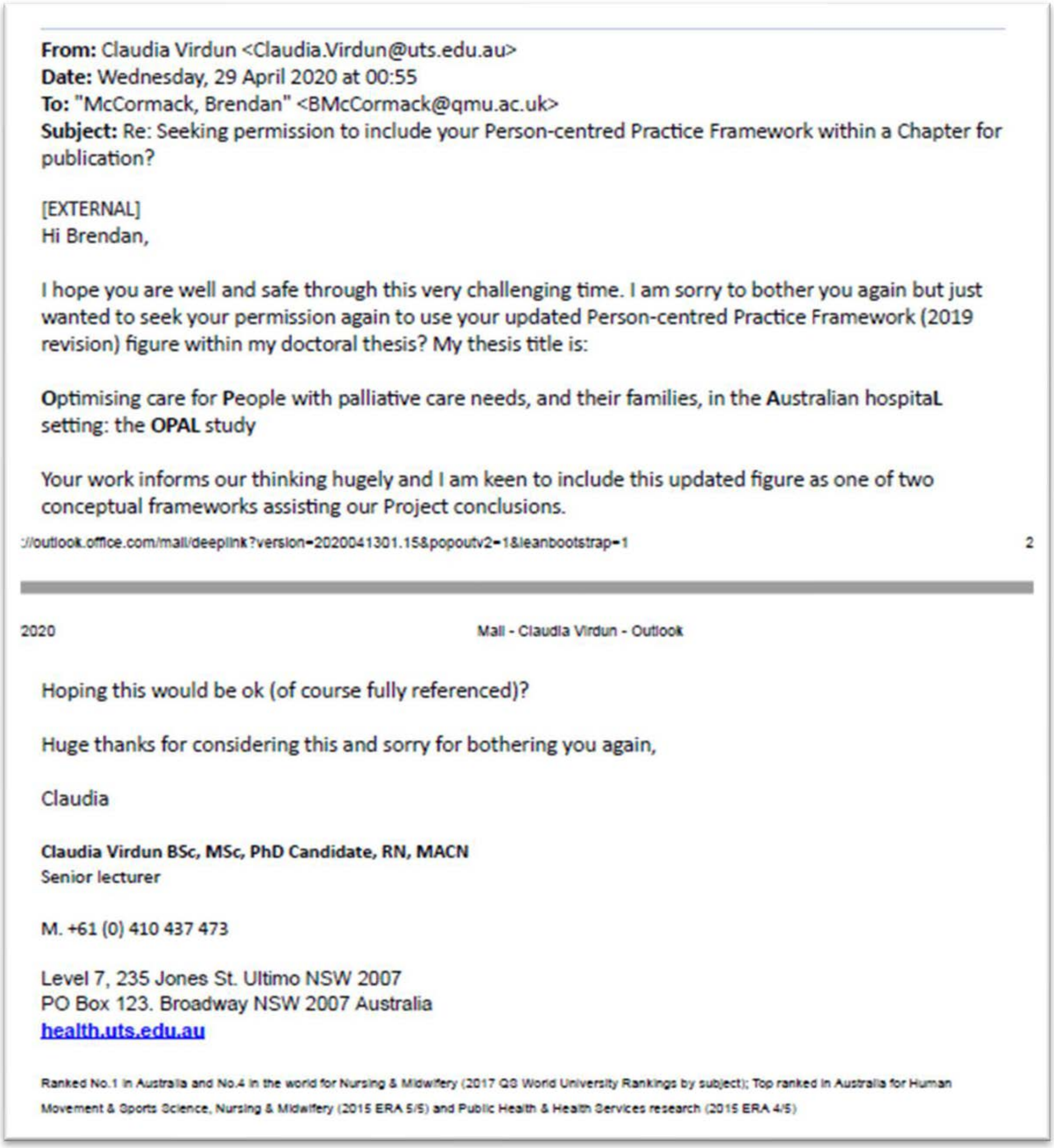


McCormack, Brendan <BMcCormack@qmu.ac.uk>
Wed 29/04/2020 5:56 PM
To: Claudia Virdun <Claudia.Virdun@uts.edu.au>

Hi Claudia
Thanks for y our email. That is completely fine to use the framework as described and fully referenced. Good luck with the rest of your thesis preparation.

Best Regards
BRENDAN
Professor Brendan McCormack,
Head of the Divisions of Nursing, Occupational Therapy & Arts Therapies
Associate Director Centre for Person-centred Practice Research
School of Health Sciences
Queen Margaret University
Queen Margaret University Drive
Musselburgh
East Lothian
EH21 6UU
Tel: 0131 474 0000 (Voice activated recording - ask for Brendan McCormack)
Email: BMcCormack@QMU.ac.uk
www.cpcpr.org/critical-creativity

Queen Margaret University
CENTRE FOR PERSON-CENTRED
PRACTICE RESEARCH



From: Claudia Virdun <Claudia.Virdun@uts.edu.au>
Date: Wednesday, 29 April 2020 at 00:55
To: "McCormack, Brendan" <BMcCormack@qmu.ac.uk>
Subject: Re: Seeking permission to include your Person-centred Practice Framework within a Chapter for publication?

[EXTERNAL]
Hi Brendan,

I hope you are well and safe through this very challenging time. I am sorry to bother you again but just wanted to seek your permission again to use your updated Person-centred Practice Framework (2019 revision) figure within my doctoral thesis? My thesis title is:

Optimising care for **P**eople with palliative care needs, and their families, in the **A**ustralian hospita**L** setting: the **OPAL** study

Your work informs our thinking hugely and I am keen to include this updated figure as one of two conceptual frameworks assisting our Project conclusions.

://outlook.office.com/mail/deeplink?version=2020041301.15&popoutv2=1&leanbootstrap=1 2

2020 Mail - Claudia Virdun - Outlook

Hoping this would be ok (of course fully referenced)?

Huge thanks for considering this and sorry for bothering you again,

Claudia

Claudia Virdun BSc, MSc, PhD Candidate, RN, MACN
Senior lecturer

M. +61 (0) 410 437 473

Level 7, 235 Jones St. Ultimo NSW 2007
PO Box 123. Broadway NSW 2007 Australia
health.uts.edu.au

Ranked No.1 in Australia and No.4 in the world for Nursing & Midwifery (2017 QS World University Rankings by subject); Top ranked in Australia for Human Movement & Sports Science, Nursing & Midwifery (2015 ERA 5/5) and Public Health & Health Services research (2015 ERA 4/5)

Appendix 6: Protocol for Study 2

Document Approval

Version	Approval date (St Vincent's HREC)
Version 1.0_Aug 17, 2018	October 3, 2018
Version 2.0_February 21, 2019	March 25, 2019
Version 3.0_May 9, 2019	May 27, 2019
Version 4.0_Sept 27, 2019	Oct 10, 2019

Protocol Title

Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families / carers: a qualitative study

Short Title

Consumer centred improvement measures for people with serious chronic illness: a qualitative study

Sponsor: University of Technology Sydney

PROJECT TEAM ROLES & RESPONSIBILITIES

Coordinating Principal Investigator: Professor Jane Phillips

Date: August 3, 2018

Organisation: University of Technology Sydney

Department: Faculty of Health, Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT)

Position: Director IMPACCT, Professor of Palliative Nursing, IMPACCT

Telephone no.: +61 2 9514 4822

Email: Jane.Phillips@uts.edu.au

Responsibilities: Chief supervisor for the researcher (Claudia Virdun) completing this work as part of her PhD studies. Overall lead for research design, implementation and reporting.

Principal Investigator – St Vincent's Hospital Sydney: Dr Christopher Pene

Date: August 10, 2018

Organisation: St Vincent's Hospital Sydney

Department: Palliative Medicine

Position: Supportive & Palliative Medicine consultant

Telephone no.: 02 8382 9444

Email: christopher.pene@svha.org.au

Responsibilities: Support and oversight for this research being completed at St Vincent's Hospital

Principal Investigator – St George Hospital, Sydney: Linda Magann

Date: August 16, 2018

Organisation: St George Hospital, Sydney

Department: Palliative Care

Position: Clinical Nurse Consultant, Palliative Care

Telephone no.: 91131089/ pager 502; [redacted]

Email: linda.magann@health.nsw.gov.au

Responsibilities: Support and oversight for this research being completed at St George Hospital

Principal Investigator – Westmead Hospital: Dr Sally Greenaway

Date: August 15, 2018

Organisation: Westmead Hospital, WSLHD

Department: The Crown Princess Mary Cancer Centre, Westmead

Position: Director: Supportive and Palliative Medicine; Senior Staff Specialist: Clinical Haematology

Telephone no.: 61 2 8890 5555; +61 [redacted]

Email: sally.greenaway@health.nsw.gov.au

Responsibilities: Support and oversight for this research being completed at Westmead Hospital

Principal Investigator – Broken Hill Hospital: Dr Sarah Wenham

Date: August 10, 2018

Organisation: NSW Far West LHD

Department: FWLHD Cancer & Palliative Care

Position: Specialist Palliative Care Physician

Telephone no.: [redacted]

Email: sarah.wenham@health.nsw.gov.au

Responsibilities: Support and oversight for this research being completed at Broken Hill Hospital

Principal Investigator – Blacktown Hospital: Helen Smith

Date: February 22, 2109

Organisation: Western Sydney Local Health District

Department: Supportive and Palliative Care

Position: CNC2 Supportive and Palliative Care

Telephone no.: [redacted]

Email: helen.smith@health.nsw.gov.au

Responsibilities: Support and oversight for this research being completed at Blacktown Hospital

Co-Investigator: Claudia Virdun

Date: August 3, 2018

Organisation: University of Technology Sydney

Department: Faculty of Health, Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT)

Position: PhD Candidate

Telephone no.: [redacted]

Email: claudia.virdun@uts.edu.au

Responsibilities: Recruitment of participants after they opt-in to the study (having been given information via a care coordinator, nurse consultant or nurse practitioner involved in their care). Interviewing all participants. Lead in initial data analysis for review by full supervision team. Key contact for this research and lead for all reporting.

Co Investigator: Dr Tim Luckett

Date: August 3, 2018

Organisation: University of Technology Sydney

Department: Faculty of Health, Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT)

Position: Senior Lecturer

Telephone no.: 9514 4861

Email: tim.luckett@uts.edu.au

Responsibilities: Co-supervisor for this research along with Professor Jane Phillips (Chief supervisor), Professor Karl Lorenz (co-supervisor) and Professor Patricia Davidson (co-supervisor).

Co Investigator: Professor Karl Lorenz

Date: August 3, 2018

Organisation: Stanford University, California

Department: School of Medicine

Position: General practitioner and palliative care physician, and Section Chief of the VA Palo Alto-Stanford Palliative Care Program and Professor of Medicine at Stanford University School of Medicine

Email: kalorenz@stanford.edu

Responsibilities: Co-supervisor for this research along with Professor Jane Phillips (Chief supervisor), Dr Tim Luckett (co-supervisor) and Professor Patricia Davidson (co-supervisor)

Co Investigator: Professor Patricia Davidson

Date: August 3, 2018

Organisation: Johns Hopkins University

Department: School of Nursing

Position: Dean of Johns Hopkins University School of Nursing, USA; Adjunct Professor of Nursing and Member of IMPACCT, UTS; Professor of Cardiovascular Research at St Vincent's Hospital Sydney.

Email: pdavidson@jhu.edu

Responsibilities: Co-supervisor for this research along with Professor Jane Phillips (Chief supervisor), Dr Tim Luckett (co-supervisor) and Professor Karl Lorenz (co-supervisor)

Summary

Study Title

Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families: a qualitative study

Objectives

To seek the perspectives of Australians living with serious chronic illness, who are considered to have palliative care needs, and their families/carers about their recent hospitalisation experiences to:

a) Determine the relevance of the elements noted within international research to be important for optimal inpatient palliative care,[1, 2] and how they might apply to their future care needs; and

b) Understand whether and how this population would like to contribute to future palliative care service improvements within the hospital setting

Study design

Qualitative interview study based on semi-structured interviews

Planned sample size
30 patients and up to 30 family / carer participants

Selection criteria

Inclusion:

- Clinical indicators of one or multiple life-limiting conditions in accordance with the Supportive and Palliative Care Indicators Tool (SPICT™ [3])
- Australia-modified Karnofsky Performance Status (AKPS)[4] score between 30 and 70
- 1 or more admissions to hospital within the previous 12 months
- Patient aware they have a serious chronic illness
- Patient is comfortable talking about their serious chronic illness and related care needs
- Willingness to give verbal informed consent and willingness to participate in and comply with the study
- Family member / carer of someone with advanced dementia who has had at least 1 hospital admission within the previous 12 months
- Bereaved family member or carer whose loved one had at least 1 admission to hospital in their last 12 months of life and their bereavement is within 2 years

Exclusion:

- Patients less than 18 years of age
- Patients and / or family members / carers who cannot converse in English
- Patients with cognitive impairment that impairs their ability to describe prior hospitalisations and care experiences

Study procedures

Purposive sampling will be utilised to identify eligible participants. Patient screening will be performed by a senior medical clinician, care coordinator, nurse consultant or nurse practitioner known to each patient. If eligible for the study, the staff member will provide information for the patient (invitation to participate letter and participant information sheet / consent form) and ask whether the patient or carer is happy to be contacted by a researcher to discuss this further. If so, the screening clinician will record verbal consent for the provision of the person's contact details (name, phone number, address and email) to the research team. Once received, the researcher will contact the potential participant to discuss the study in greater detail. If the patient indicates they are interested and willing to discuss study participation in greater detail, the researcher (Claudia Virdun) will establish contact and provide sufficient detail to enable verbal consent, as appropriate. If the potential participant indicates they do not wish to participate, this will be recorded and no further contact will be made. If participation is confirmed and consent gained, the researcher will book the semi-structured interview to be conducted at a date and time that is mutually acceptable to participants and the interviewer (telephone interview). At this first contact, the researcher will ask the patient whether they have a family member or carer who may be interested in participating in the study and if so, whether they could pass on the researcher's contact details to them, to allow that person to make contact if they would be interested and willing to participate. If that family member expresses interest in participation (by contacting the researcher via phone or email), they will be sent a participant information sheet / consent form and be contacted by the researcher (Claudia Virdun) to discuss the research in greater detail, prior to obtaining verbal consent, as appropriate. When completing the consenting process, the researcher will discuss the preferences for the participants in relation to completing the interview independently or together (patient and family member / carer) and will work in line with such stated preferences. In order to be inclusive of patients with advanced dementia / cognitive impairment, we will ask screening clinicians to review their patient caseloads and for those who are eligible with noted cognitive impairments, consider eligible family members / carers who may be interested in participating. They will then follow the same procedure as outlined above – namely, the screening clinician will provide the invitation letter and information sheet to the family member / carer and ask whether they would be willing to be contacted by the researcher. If they are willing, the researcher will make contact and discuss participation in greater detail to establish whether participation will proceed or not. In addition to the above, screening and recruitment for bereaved caregivers will occur via designated bereavement counsellors, where this service is available within participating sites. If they identify a potential participant, they will provide study information for the carer to consider and ask whether they would like to be contacted by the research team for additional information. If that carer is willing to be contacted, the researcher will make contact and discuss the study in greater detail, and establish whether the person would like to participate further or not. If they are keen to participate, the researcher will complete a verbal consent process and book an interview time. Finally, if a family member / carer of a patient who has or has died from a serious, chronic illness hears of the study via word of mouth and/or circulated information via professional networks (for example – Palliative Care NSW, Carers NSW, Health Consumers NSW) and contacts the research team, they will be screened for eligibility before being given the participant information sheet and consent form for further discussion. That is, there are 3 main components involved in recruitment: 1) Via clinicians screening and approaching eligible patients / family members; 2) Via bereavement services within participating sites and 3) Via snowballing and contacts established following circulated information about the study.

Statistical considerations

Semi-structured interviews will be undertaken until data saturation is reached. Demographic data will be gathered, and reported descriptively, to understand the study sample. Interview transcripts will be transcribed verbatim, inductively coded and entered into NVivo to support data management. Thematic data analysis will occur in accordance with the four step process articulated by Green, Willis [5] inclusive of data immersion, coding, categorising and generation of themes. Two workshops will be held, to verify and further develop the developed study themes to inform innovation and solution development for focused improvement work in Australian hospital based palliative care.

Study duration

Recruitment and interviewing are expected to be completed within 9 months –January – September 2019. Data analysis and reporting will be complete by February 2020.

BACKGROUND

Disease Background*

The majority of expected deaths in Australia continue to occur within the hospital setting[6, 7], where optimal palliative care, cannot be assured[2, 8-10]. Significant data exists from patients and families about what is important for their care[1, 2] but this is yet to be confirmed within the Australian population. The importance of measuring the quality of palliative care provision is clear[10-14], but how to achieve this at a system level is not yet realised with global variance in approaches noted[15]. Furthermore, it is noted that consumers have rarely contributed to the development of current quality indicators for palliative care and that this is a key area for improvement[15].

Rationale for Performing the Study*

Understanding what is important for optimal palliative care provision in the hospital setting, from the perspectives of patients and families / carers, is crucial to informing innovations and driving improvements[1, 2]. There is considerable data available to answer this question, but it is yet to be confirmed by Australian patients and families / carers. This study seeks to address this issue through a content validation of domains of importance found in prior systematic reviews[1, 2].

Building on the understanding of what is important for optimal palliative care within the Australian hospital setting, this study will work to understand how best to measure patient outcomes and/or experiences in line with such areas of importance. Utilising a process of co-design for measure development, seeks to prioritise consumer identified areas of importance and acceptability for data access[16]. Importantly, this study seeks to find key measures that can act as levers for change and innovation, through their accessibility both to patients and clinicians[17].

Finally, the Australian Commission for Safety and Quality in Healthcare has recently published a framework for clinical governance and within this states key areas for partnering with patients / consumers[18]. This document lists a number of areas for patient / consumer involvement, including: '*Provide feedback to the health service organisation or clinician about care experiences; Consider being involved in the governance of the organisation, when opportunities exist; Consider being involved in the development and review of health information for consumers, when opportunities exist'* [18] , p.17. It is unclear how people with serious chronic illness, and their families / carers, may like to contribute to such organisational processes and this study seeks to understand this to inform future engagement strategies.

This research study conforms to and will be undertaken in accordance with the National Statement on Ethical Conduct in Human Research 2007 (updated 2018)[19], the Australian Code for the Responsible Conduct of Research (2018)[20] and the National Statement on Ethical Conduct in Human Research, National Health and Medical Research Council NSW Supplement, A User Guide 2008.

STUDY OBJECTIVES*

To seek the perspectives of Australians living with serious chronic illness, who are considered to have palliative care needs, and their families/carers about their recent hospitalisation experiences to:

a) Determine the relevance of the elements noted within international research to be important for optimal inpatient palliative care,[1, 2] and how they might apply to their future care needs; and

b) Understand whether and how this population would like to contribute to future palliative care service improvements within the hospital setting

STUDY Design*

Design*

An exploratory study using qualitative methods based on semi-structured interviews.

Study Groups

Interviews will be held with patients and also with their nominated family member / carer and with bereaved caregivers. Interviews can be held independently or together, depending on the preferences of the participants.

Two workshops will be held following analysis to verify and further develop themes. Workshop participants will be stakeholders including: consumer representatives (including some people who participated in the interviews) and professionals with expertise in palliative care policy, research or clinical care.

number of participants*

Qualitative interviews: It is anticipated a minimum of 30 patients and up to 30 family / carer participants will be required to achieve data saturation. The work of Guest, Bunce [21] suggests a sample size 12 will achieve data saturation for carefully selected participant samples. Given the breadth of areas of importance noted in prior work[1, 2], we have extended the sample number to 30, to account for patients and/or families talking to a few areas of importance only (and not necessarily all). Therefore, we hope by increasing the sample size, we will achieve data saturation across all domains of importance.
Workshops: It is anticipated a maximum of 15 clinical and/or policy representatives and a maximum of 3 consumer representatives in workshop 1 and a maximum of 10 consumers will participate in workshop 2. These numbers are based on enabling full participation for all attendees whilst reflecting a diversity of views.

number of SITES

We are aiming to work across 6 sites – St Vincent’s Hospital, St George Hospital, Westmead Hospital, Blacktown Hospital, Broken Hill hospital and the University of Technology Sydney and have support identified at each site (principal investigators and screening clinicians as required). We are hoping to recruit 5-10 patients per hospital site (and their linkages to family / carer participants), up to a maximum of 30 patient participants. Screening, recruitment and interviewing procedures will be the same at all sites.

The workshops will be held at the University of Technology Sydney.

duration

Recruitment and interviewing are expected to be completed within 9 months: January 2019 – September 2019. Data analysis and reporting will be complete by November 2019. Workshops will then be run between November 2019 and January 2020, with final reporting completed by February 2020.

Participant section

Inclusion Criteria* – Qualitative interviews

- Clinical indicators of one or multiple life-limiting conditions in accordance with the Supportive and Palliative Care Indicators Tool (SPICT$^{\text{TM}\,3}$)
- Australia-modified Karnofsky Performance Status (AKPS)[4] score between 30 and 70
- 1 or more admissions to hospital within the previous 12 months
- Patient aware they have a serious chronic illness
- Patient is comfortable talking about their serious chronic illness and related care needs
- Willingness to give verbal informed consent and willingness to participate in and comply with the study
- Family member / carer of someone with advanced dementia who has had at least 1 hospital admission within the previous 12 months
- Bereaved family member or carer whose loved one had at least 1 admission to hospital in their last 12 months of life and their bereavement is within 2 years

Exclusion Criteria*

- Patients less than 18 years of age
- Patients and family members / carers who cannot converse in English
- Patients with cognitive impairment that impairs their ability to describe prior hospitalisations and care experiences

Participant section - workshops

Inclusion Criteria*

Workshop 1

Inclusion:

- An identified professional leader (either clinical or policy focused) in hospital based palliative care, employed in a position related to this; or
- A consumer representative invited through the UTS Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT) Consumer Advisory Group, the NSW Translational Cancer Research Network (TCRN) Consumer Advisory Panel or noted within the Palliative Care Australia (PCA) National Register of Palliative Care Consumers and Carers.

Workshop 2

Inclusion:

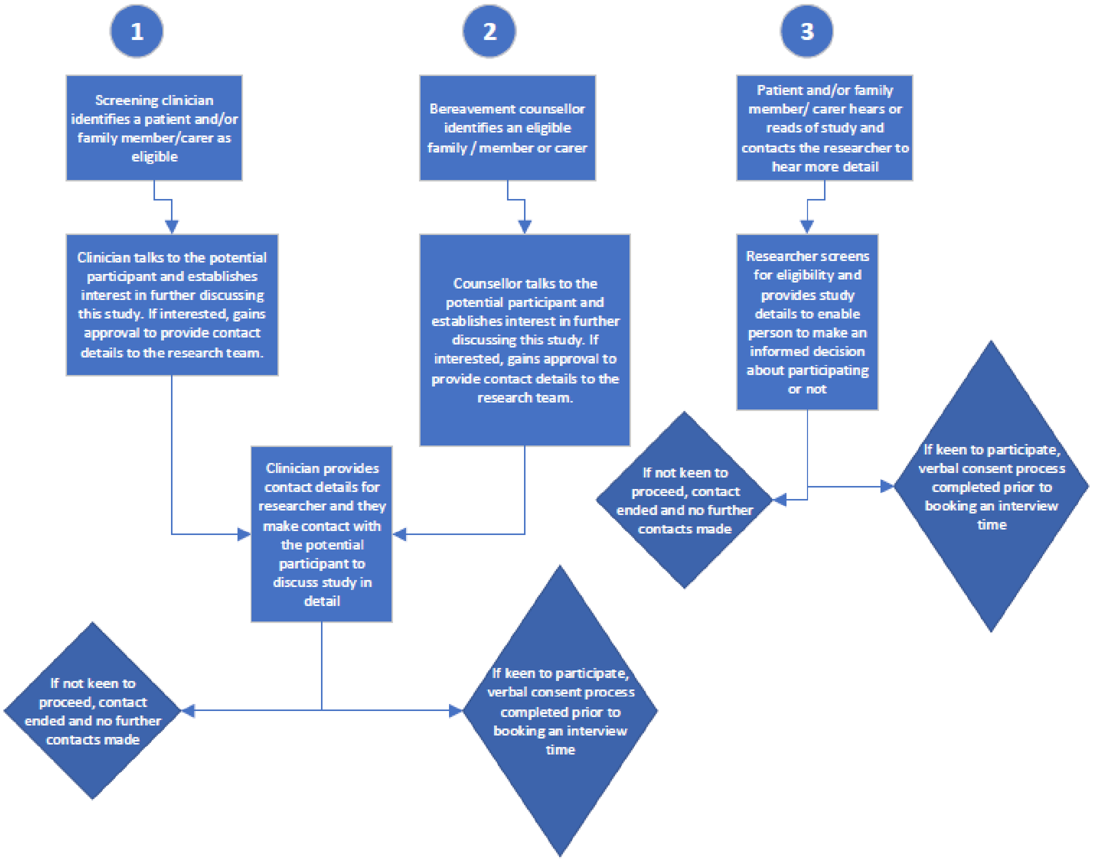
- A consumer representative invited through the UTS Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT) Consumer Advisory Group, the NSW Translational Cancer Research Network (TCRN) Consumer Advisory Panel or noted within the Palliative Care Australia (PCA) National Register of Palliative Care Consumers and Carers;
- A participant in this study's interviews who contacted the research team via a snowballing process to contribute to this study and noted they would like to be contacted with a summary of study results when available (asked at time of consenting for participation and noted on consent form)

Exclusion:

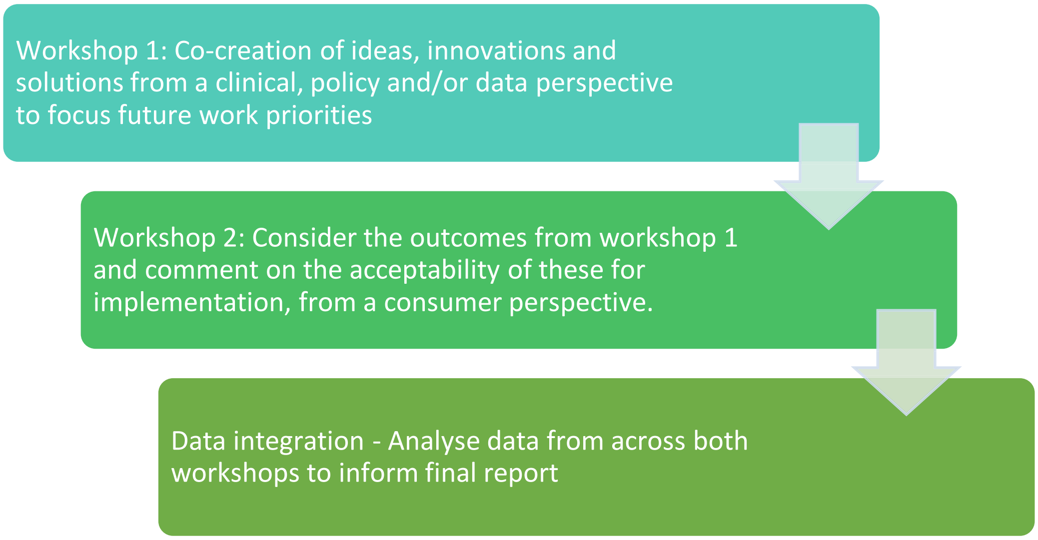
- Any participant in this study's interviews who contacted the research team via a snowballing process for this study but who stated they did not want to be contacted with a summary of findings or who was distressed during the interview;
- Any participant in this study's interviews who was recruited via clinical staff at participating recruitment sites rather than via a snowballing approach.

STUDY Outline*

Study Flow Chart – Qualitative interviews



Study Flow Chart – Workshops



Workshop 1: Co-creation of ideas, innovations and solutions from a clinical, policy and/or data perspective to focus future work priorities

Workshop 2: Consider the outcomes from workshop 1 and comment on the acceptability of these for implementation, from a consumer perspective.

Data integration - Analyse data from across both workshops to inform final report

Investigation plan*

Qualitative interviews:

A senior medical clinician, nurse practitioner, nurse consultant or care coordinator (clinician) initially screens their patient caseload to note who is eligible for study recruitment. At this time, the clinician known to the patient, discusses the study (supported by a standard script) and then provides an invitation to participate letter and participant information sheet to the patient, for their review. The clinician known to the patient will be able to answer high level questions about this study but for additional detail, will refer the patient through to the researcher. If the patient is interested in this study, the screening clinician will ask whether the patient or carer is happy to be contacted by a researcher to discuss this further. If so, the screening clinician will record verbal approval for the provision of the person's contact details (name, phone number, address and email) to the research team. Once received, the researcher will contact the potential participant to discuss the study in greater detail. If the patient indicates they are interested and willing to discuss study participation in greater detail, the researcher (Claudia Virdun) will provide sufficient detail to enable verbal consent, as appropriate. If the potential participant indicates they do not wish to participate, this will be recorded and no further contact will be made. If participation is confirmed and consent gained, the researcher will book the semi-structured interview to be conducted at a date and time that is mutually acceptable to participants and the interviewer (telephone interview). In order to be inclusive of patients with advanced dementia / cognitive impairment, we will ask screening clinicians to review their patient caseloads and for those who are eligible with noted cognitive impairments, consider family members / carers who may be interested in participating. They will then follow the same procedure as outlined above – namely, the screening clinician will provide the invitation letter and information sheet to the family member / carer and ask whether they would be willing to be contacted by the researcher. If they are willing, the researcher will make contact and discuss participation in greater detail to establish whether participation will proceed or not. In addition to the above, screening and recruitment for bereaved caregivers will occur via designated bereavement counsellors, where this service is available within participating sites. If they identify a potential participant, they will provide study information for the carer to consider and ask whether they would like to be contacted by the research team for additional information. If that carer is willing to be contacted, the researcher will make contact and discuss the study in greater detail, and establish whether the person would like to participate further or not. If they are keen to participate, the researcher will complete a verbal consent process and book an interview time. Finally, if a family member / carer of a patient who has or has died from a serious, chronic illness hears of the study via word of mouth and/or circulated information via professional networks (for example – Palliative Care NSW, Carers NSW, Health Consumers NSW) and contacts the research team, they will be screened for eligibility before being given the participant information sheet and consent form for further discussion. That is, there are 3 main components involved in recruitment: 1)Via clinicians screening and approaching eligible patients / family members; 2) Via bereavement services within participating sites and 3) Via snowballing and contacts established following circulated information about the study.

The researcher will then have 2 conversations with the participant:

1) Provision of study information, obtaining verbal consent (supported by a standard script) as appropriate, identification of possible family / caregiver involvement, and scheduling a 1-hour appointment for the interview;

2) Semi-structured interview (up to 1 hour).

This study proposes using verbal consent (supported by a standard script) as experience gained through our previous research with patients who have serious chronic illnesses suggests that almost half of patients who provide verbal consent over the telephone and say that they have completed a written consent form do not subsequently return this to the research team via post, despite being sent reply-paid envelopes and receiving reminder telephone calls. This study is being conducted in a patient population with high levels of symptoms and disability, as well as frequent medical and treatment appointments. Families / carers are often preoccupied with caring for patients and under considerable stress. The requirement to return a signed consent form via post can be burdensome for both patients and caregivers in this situation. Many participants also find it difficult to understand why written informed consent is needed when they have given verbal consent, despite team efforts to explain that this is an ethical requirement. Finally, participants sometimes make errors in completing their consent form, requiring further burden to the participant in terms of follow-up from the team and needing to re-post the form.
All interviews will be audio-recorded and written notes taken by researcher. Interviews will be transcribed verbatim and analysed according to the study analysis plan.
Participants may withdraw at any time throughout the study. Such withdrawals will be noted and ongoing patient recruitment prioritised to try and enable 30 patient participants, as able. There are no discrete outcome measures for this study given our research aims. Rather, we seek to confirm earlier work (from an Australian population perspective) and create new knowledge in relation to co-design of measures and participation in clinical governance work.
Workshops:
The research team will invite eligible participants to each workshop via email. An initial invitation email will be sent, with 2 reminders sent at 1-week intervals after which a refusal will be assumed. If the potential participant is interested in attending, a participant information sheet and consent form will be emailed to them. In addition to this, an opportunity to discuss the study in greater detail (by phone, email or face to face) will be provided. Signed consent forms can be posted or emailed back to the research team or given to the team by hand prior to the commencement of the workshop. Each workshop will be co-facilitated with a member of the research team and a consumer representative from the UTS IMPACCT Consumer Advisory Group.

Each workshop will be facilitated with the co-creation design choices framework[22] informing work undertaken inclusive of consideration to project preconditions, participants, results and co-creation activities[22]. Both workshops will be audio-recorded and field notes taken by the researcher. Participants may withdraw at any time throughout the study. There are no discrete outcome measures for this study given our research aim. Rather, we seek to verify earlier work, co-create priorities for action and co-create new knowledge, ideas, innovations and solutions in relation to focused improvements in palliative care within the Australian hospital setting.

Study Procedure Risks*

Qualitative interviews:
The risks associated with this study are perceived to be low. The only foreseeable risk is one of discomfort or possible distress related to participation in the semi-structured interviews. Participants will be asked about what is and has been important for their care and to describe good care and episodes where care could have been better. It is possible some of this discussion may cause discomfort and/or distress especially if there were episodes of care that were distressing for the patient / family member or carer. To minimise these potential study procedure risks, the researcher will outline support services that are available to participants and are free of charge, offered by participating sites (a facilitated link back to their treating team) as well as other relevant local/national support services (General Practitioner and phonelines – Beyond Blue and LifeLine). This information will be included in the participant information sheet and given to participants again at the conclusion of the interview. Additionally, participants will be advised that they are not obliged to answer interview questions and can end the interview at any time without giving a reason and with no consequence to their care. Finally, the researcher is an experienced palliative care nurse and will ensure any distress is managed at the time, through support, linkage to clinical care as needed (via the original referring clinician who screened the patient for this study) and ending any conversation that is causing distress. If distress is not the issue, but the patient appears fatigued, the researcher will offer to end the interview with the option to reschedule or finalise the interview at that time. Indeed, all patient participants will be advised of how many more questions are remaining within the interview and asked whether they are able to continue so as to proactively account for possible fatigue.
Workshops:
The risks associated with the workshops are also perceived to be low. The main risk is one of discomfort or possible distress related to participation in the workshop when engaging with stories and experiences recounted in prior studies in relation to palliative care experiences (however – these will be de-identified higher level data presented in theme format with supporting qualitative data in the form of quotes, only). To minimise potential risks, the researcher will : 1) Outline clearly the fact this workshop is working with deidentified data at theme level (not at the level of personal stories and experience); and 2) Disclose that this workshop will be discussing potentially emotionally distressing information noting therefore that participants are free to leave the workshop at any time and that if they do so, a research team member will check they are OK and provide linkage to relevant local/national support services (General Practitioner and phonelines – Beyond Blue and LifeLine). This information will also be included in the participant information sheet. A second risk is that relationships may be affected if participants know each other and say something that others disagree with. Each workshop will also commence with expressly stated rules in relation to supportive participation and confidentiality (i.e. Chatham House rules). Finally, the research team include experienced palliative care nurses and researchers and will ensure any distress or differences of opinion are managed at the time, moving away from any conversation that is causing distress or conflict.

Recruitment and Screening*

Qualitative interviews:

A nonprobabilistic, purposive sampling will be utilised to identify eligible participants at each participating site. Patient screening will be performed by a senior medical clinician, care coordinator, nurse consultant or nurse practitioner ('clinician') known to each patient. A screening tool for each disease category (cancer, heart/vascular, kidney, respiratory, liver, neurological or other) has been developed to assist clinicians in their screening process. Discussion with a nurse practitioner (St Vincent's) and 2 clinical nurse consultants (St George and Westmead) indicated this was a straightforward process and they would be willing and able to perform such screening without undue stress. If eligible for the study, the staff member will provide information for the patient (invitation letter and participant information sheet / consent form) and ask whether the patient is happy to be contacted by the research team. If the patient indicates they are willing to discuss study participation in greater detail, the researcher (Claudia Virdun), will phone and provide sufficient detail to enable informed verbal consent, as appropriate.

Workshops:

A nonprobabilistic, purposive sampling will be utilised to identify eligible participants. Some pragmatic decisions will be taken in relation to consumer representation as funding availability will not extend to supported travel costs (consumer representatives will be paid for their time and catering provided at each workshop). Therefore, consumer representatives within the Sydney metropolitan area only, will be invited. Key clinical and policy stakeholders will be identified through the expertise of the research team and again, given travel costs will not be provided, representatives from within the Sydney metropolitan area will be selected, unless they can self-fund travel. The only exception to this will be to invite one representative from a rural and remote perspective.

Informed Consent Process*

Qualitative interviews:

Eligible participants will be provided with an invitation letter and participant information sheet which provides detailed information about study procedures and participant involvement. The researcher will use her first contact phone call to talk through the participant information sheet to ensure it is well understood and to emphasise that participation is entirely voluntary and withdrawal from the study is possible at any time. Verbal informed consent will be collected from all participants prior to study enrolment, documented by the researcher on a verbal consent form template and the audio-recording of such gaining of consent, filed for retrieval as needed. The filing of the audio files and consent forms (re-identifiable data) will be kept in a separate, password protected location to all other study data (not-identifiable data). Information will be provided at this time, and within the participant information sheet, about the fact participants can request a review of their responses and contributions prior to data analysis and/or a copy of the summated data prior to publication. If they would like access to either sources of data, they will be asked to provide an email or postal address to facilitate this.

Workshops:

Eligible participants will be provided with an invitation letter and participant information sheet which provides detailed information about workshop procedures and participant involvement. The research team will also provide opportunities for additional information for each participant either by phone, email or in person to enable fully informed consent. Written informed consent will be collected from all participants prior to each workshop and filed for retrieval as needed. The filing of the consent forms (re-identifiable data) will be kept in a separate, password protected location to all other study data (not-identifiable data). Information will be provided at this time, and within the participant information sheet, about the fact participants can request a review of their responses and contributions prior to data analysis and/or a copy of the summated data prior to publication. If they would like access to either sources of data, they will be asked to provide an email or postal address to facilitate this.

Enrolment Procedure*

The participant will be enrolled into the study after the informed verbal consent (interviews) or written consent (workshops) process has been completed and the participant has met the inclusion criteria and none of the exclusion criteria. The participant will receive a unique study ID and this will be documented on all study documents and recordings.

Randomisation Procedure

Not applicable for this study.

TISSUE COLLECTION/BIOBANKING

Not applicable for this study.

SAFETY*

No threats to safety are anticipated given this study will purely focus on semi-structured interviews, following gaining of informed consent and with the opportunity to withdraw at any time if distress or fatigue is noted.

Adverse Event Reporting*

As this study involves semi-structured interviews only, no adverse events are anticipated.

BLINDING AND UNBLINDING

Not applicable for this study.

OUTCOMES AND FUTURE PLANS

Participants will be asked whether they would like to see results as part of the consent process. If so, specific contact details (email or post) will be noted and a summary of findings will be sent after data analysis is complete. All data will be not-identifiable from the point of transcription where data will be linked to a unique study ID and then theming work will also further anonymise all data. In addition to this, there are 3 other uses for this data: 1) peer reviewed publication/s; 2) contribute to the researcher’s doctoral thesis and 3) inform future work to develop measurement tools and/or quality indicators in relation to palliative care provision within the hospital setting. This study is anticipated to conclude by February 2020. Follow up research is likely to focus on validating tool or measure developments, testing feasibility and acceptability with health care professionals and considering data sources to inform quality indicator developments.

STATISTICAL CONSIDERATIONS*

Semi-structured interviews will be undertaken until data saturation is reached. Demographic data will be gathered, and reported descriptively, to understand the study sample. Interview transcripts will be transcribed verbatim, inductively coded and entered into NVivo to support data management. Thematic data analysis will occur in accordance with the four step process articulated by Green, Willis [5] inclusive of data immersion, coding, categorising and generation of themes. Family / carer and patient data will be coded as independent data and reported as such. Data analysis from the workshops will be informed by the principles of co-creation[22, 23] inclusive of descriptive analysis and reporting on areas of consensus, disagreements and prioritisation. Demographic data will also be gathered (participant's professional background, current role, and whether they are based in a rural or metropolitan setting) and reported descriptively, to understand the participating sample. A focus on verification of prior work and acceptability and feasibility for future work will be maintained throughout data analysis.

CONFIDENTIALITY AND STORAGE AND ARCHIVING OF STUDY DOCUMENTS*

Data will be collected, used, stored, accessed, archived and destroyed according to the National Statement 2007 (updated 2018)[19]. Ethical considerations in relation to collection and use of data have been closely reviewed to ensure we are collecting data specifically in line with our stated research aims only. Consent data will be stored within a locked file within a password protected location. All other study data will be collected using unique identifier codes and will be kept in a different file location.

Data storage will include:

- soft copies of data will be stored on a password protected UTS endorsed Cloud storage;
- hard copies of research data and associated record keeping metadata will be stored by the research team in a locked filing cabinet with all identifying information removed, and independent from the administrative files for the study. Only authorised staff will have access to these materials;
- all identifiable data (e.g. consent forms, etc.) will be kept in a separate locked file, away from the study documents. On completion of the study, these data will be archived with the study material, in a separate file with no link between these data and the study materials.

At completion of the study, all data collection forms and study materials (both hard copy and electronic) will be prepared for collation and archiving consistent with the jurisdictional regulations regarding the retention and disposal of research data, as advised by the National Statement[19]. This includes retention, archiving and disposal controls as outlined by the University of Technology Sydney Records Management Policy and the policy *The*

General retention and disposal authority: higher and further education records (GA47) as approved by the State Archives and Records Authority of NSW.

Other study documents

- Cover letter signed by the Coordinating Principal Investigator, Professor Jane Phillips
- Evidence of support from Professor Phillip's 'Head of Department'
- Human Research Ethics Application form
- Invitation to participate letter
- Approval to provide contact details to research team
- Participant information sheet and consent form (patient, family / carer and family/carer-aged care versions)
- Interview guide (patient and family / carer versions)
- Screening tools (8 versions to account for differing diagnostic groups)
- Standard script to assist with participant eligibility
- Standard script to assist with verbal consent procedure
- Participant information sheet and consent form (workshop version)

RESOURCES

This research is supported by an Australian Government Research Training Program Scholarship. No additional funding is being sought.

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Appendix 7: Ethics approval for Study 2 including amendments, UTS ratification, site specific approvals and a version of the Participant Information Sheet and Consent Form

Original approval: October 2018

ST VINCENT'S
HEALTH NETWORK
SYDNEY

Inspired by You

4 October 2018
Updated 16 November 2018

Prof Jane Phillips
IMPACCT
Ultimo NSW 2007

Dear Jane

SVH File Number: 18/191
Project Title: Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families: a qualitative study
HREC Reference Number: HREC/18/SVH/218

Thank you for your letter, dated **23 September 2018**, responding to issues raised regarding the above project, which was first considered by the St Vincent's Hospital HREC at its meeting held on **13 September 2018.**

This project meets the requirements of the National Statement on Ethical Conduct in Human Research. I am pleased to advise that the Committee at an Executive meeting on **3 October 2018** has granted ethical and scientific approval of the above **multi centre** project.

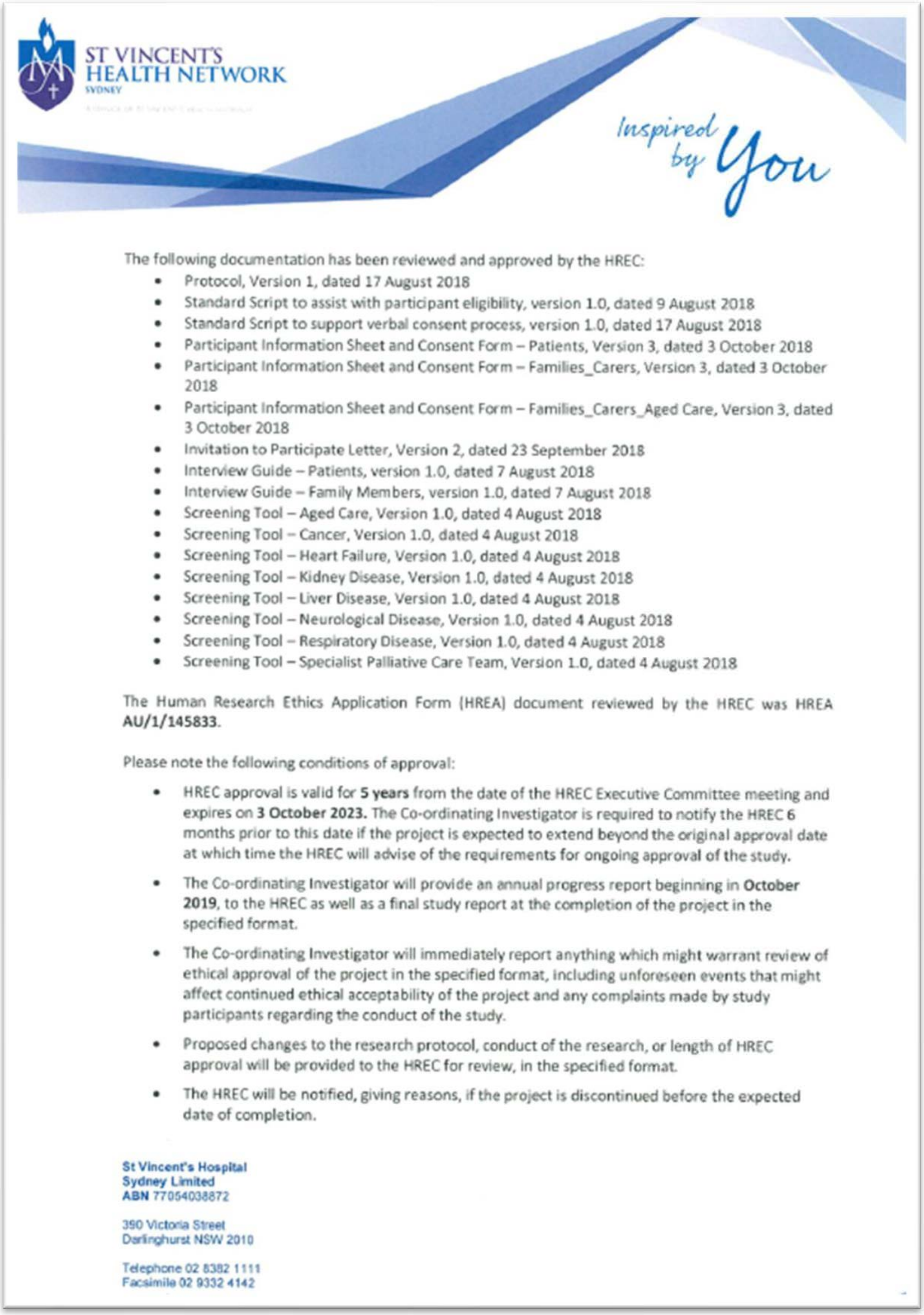
You are reminded that this letter constitutes *ETHICAL* and *SCIENTIFIC* approval only. You must not commence this research project at a site until a completed Site Specific Assessment Form/Access Request and associated documentation have been submitted to the site Research Governance Officer and authorised. A copy of this letter must be forwarded to all site investigators for submission to the relevant Research Governance Officer.

Please note that it is not considered best practice to store research data on personal hardware. No identifiable participant data can leave a site. There always needs to be data security measures in place and a clear plan for permanent destruction of data needs to be adhered to at completion of the project.

The project is approved to be conducted at:

- **St Vincent's Hospital, Sydney**
- **St George Hospital**
- **Westmead Hospital**
- **Broken Hill Hospital**

If a new site(s) is to be added please inform the HREC in writing and submit a Site Specific Assessment Form (SSA) to the Research Governance Officer at the new site.



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SYDNEY

Inspired by You

The following documentation has been reviewed and approved by the HREC:

- Protocol, Version 1, dated 17 August 2018
- Standard Script to assist with participant eligibility, version 1.0, dated 9 August 2018
- Standard Script to support verbal consent process, version 1.0, dated 17 August 2018
- Participant Information Sheet and Consent Form – Patients, Version 3, dated 3 October 2018
- Participant Information Sheet and Consent Form – Families_Carers, Version 3, dated 3 October 2018
- Participant Information Sheet and Consent Form – Families_Carers_Aged Care, Version 3, dated 3 October 2018
- Invitation to Participate Letter, Version 2, dated 23 September 2018
- Interview Guide – Patients, version 1.0, dated 7 August 2018
- Interview Guide – Family Members, version 1.0, dated 7 August 2018
- Screening Tool – Aged Care, Version 1.0, dated 4 August 2018
- Screening Tool – Cancer, Version 1.0, dated 4 August 2018
- Screening Tool – Heart Failure, Version 1.0, dated 4 August 2018
- Screening Tool – Kidney Disease, Version 1.0, dated 4 August 2018
- Screening Tool – Liver Disease, Version 1.0, dated 4 August 2018
- Screening Tool – Neurological Disease, Version 1.0, dated 4 August 2018
- Screening Tool – Respiratory Disease, Version 1.0, dated 4 August 2018
- Screening Tool – Specialist Palliative Care Team, Version 1.0, dated 4 August 2018

The Human Research Ethics Application Form (HREA) document reviewed by the HREC was HREA **AU/1/145833**.

Please note the following conditions of approval:

- HREC approval is valid for **5 years** from the date of the HREC Executive Committee meeting and expires on **3 October 2023.** The Co-ordinating Investigator is required to notify the HREC 6 months prior to this date if the project is expected to extend beyond the original approval date at which time the HREC will advise of the requirements for ongoing approval of the study.
- The Co-ordinating Investigator will provide an annual progress report beginning in **October 2019**, to the HREC as well as a final study report at the completion of the project in the specified format.
- The Co-ordinating Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including unforeseen events that might affect continued ethical acceptability of the project and any complaints made by study participants regarding the conduct of the study.
- Proposed changes to the research protocol, conduct of the research, or length of HREC approval will be provided to the HREC for review, in the specified format.
- The HREC will be notified, giving reasons, if the project is discontinued before the expected date of completion.

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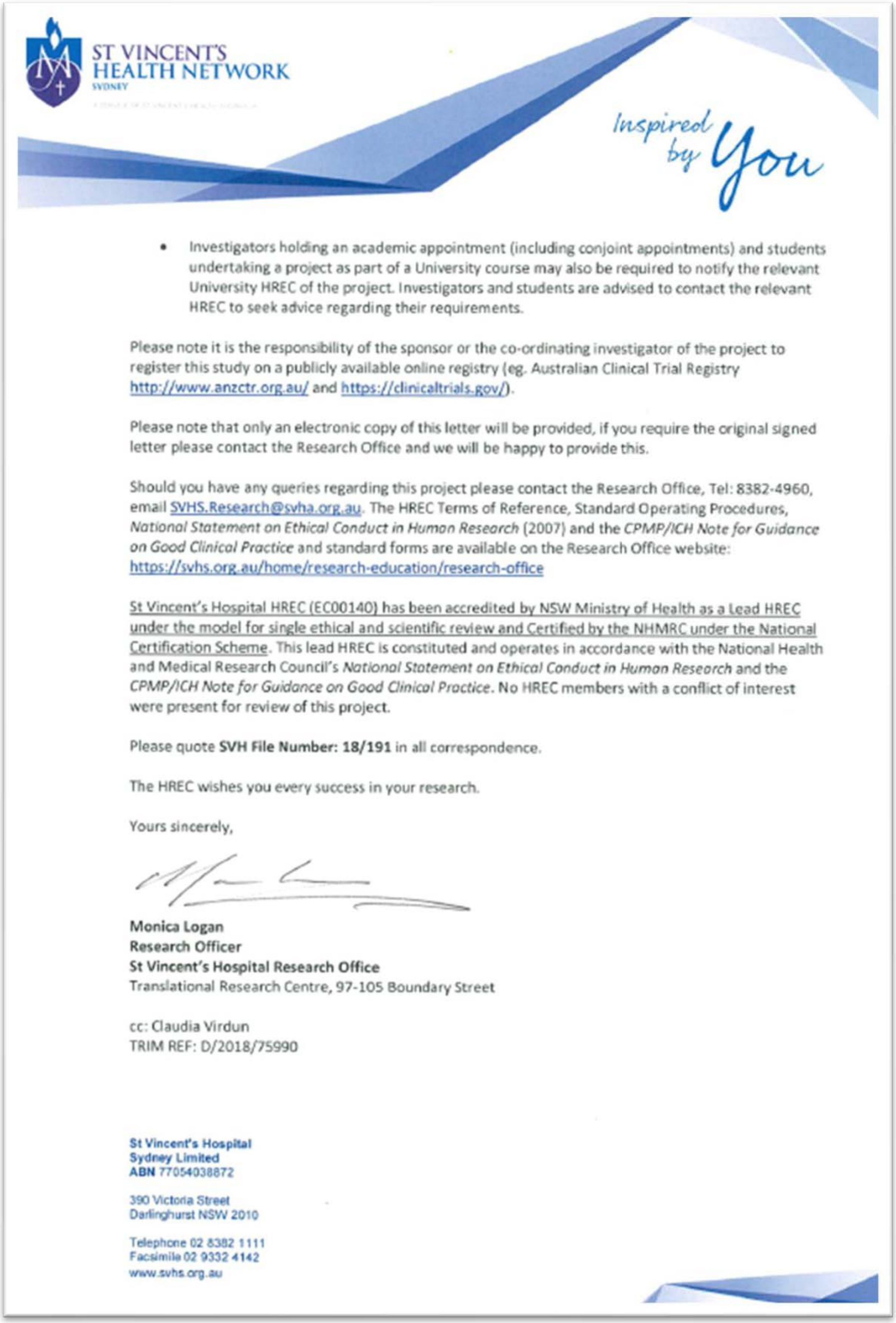

ST VINCENT'S
HEALTH NETWORK
SYDNEY

- Investigators holding an academic appointment (including conjoint appointments) and students undertaking a project as part of a University course may also be required to notify the relevant University HREC of the project. Investigators and students are advised to contact the relevant HREC to seek advice regarding their requirements.

Please note it is the responsibility of the sponsor or the co-ordinating investigator of the project to register this study on a publicly available online registry (eg. Australian Clinical Trial Registry http://www.anzctr.org.au/ and https://clinicaltrials.gov/).

Please note that only an electronic copy of this letter will be provided, if you require the original signed letter please contact the Research Office and we will be happy to provide this.

Should you have any queries regarding this project please contact the Research Office, Tel: 8382-4960, email SVHS.Research@svha.org.au. The HREC Terms of Reference, Standard Operating Procedures, *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice* and standard forms are available on the Research Office website: https://svhs.org.au/home/research-education/research-office

St Vincent's Hospital HREC (EC00140) has been accredited by NSW Ministry of Health as a Lead HREC under the model for single ethical and scientific review and Certified by the NHMRC under the National Certification Scheme. This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*. No HREC members with a conflict of interest were present for review of this project.

Please quote **SVH File Number: 18/191** in all correspondence.

The HREC wishes you every success in your research.

Yours sincerely,

Monica Logan
Research Officer
St Vincent's Hospital Research Office
Translational Research Centre, 97-105 Boundary Street

cc: Claudia Virdun
TRIM REF: D/2018/75990

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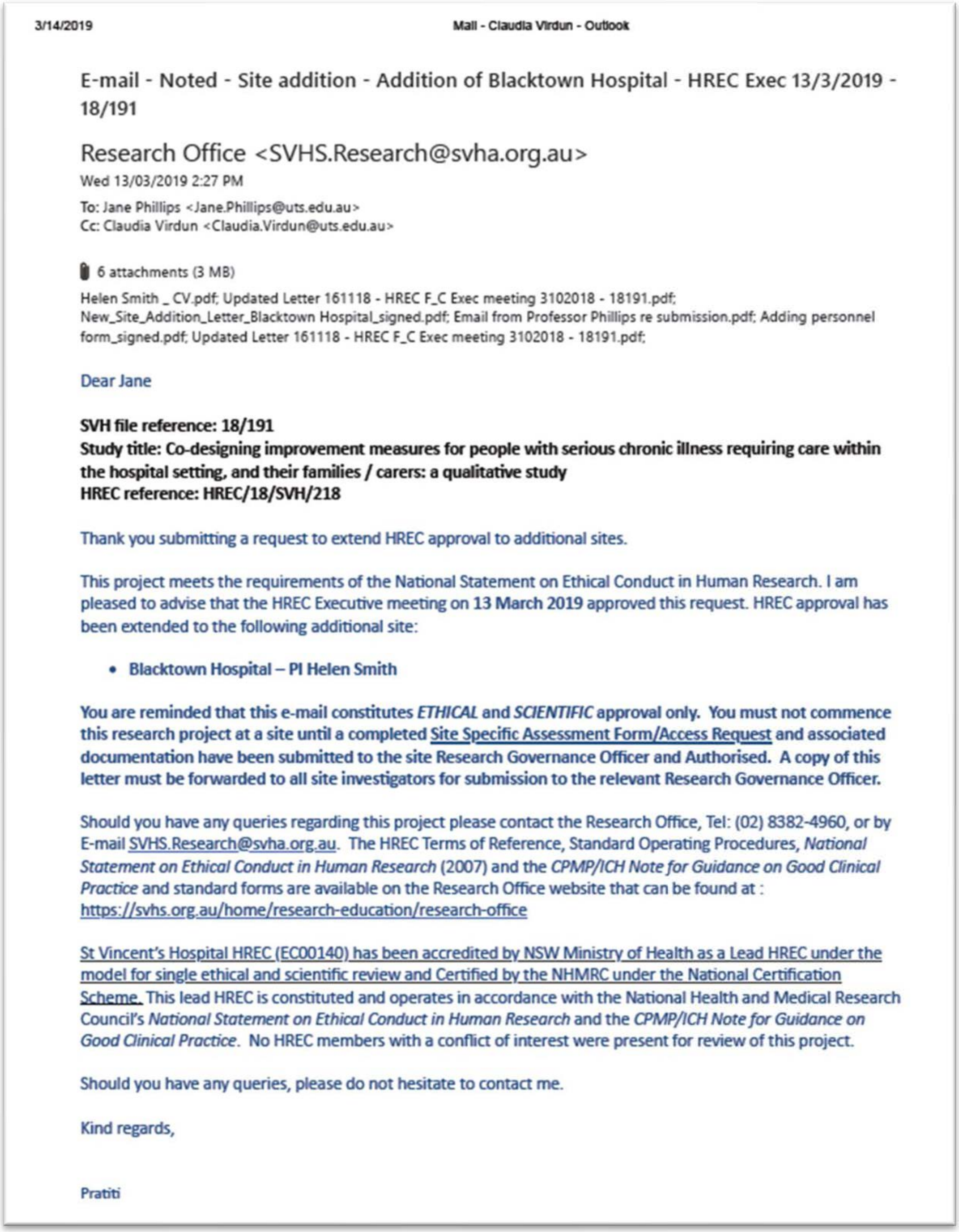
Amendment: adding a new site (Blacktown Hospital) _March 2019



3/14/2019 Mail - Claudia Virdun - Outlook

E-mail - Noted - Site addition - Addition of Blacktown Hospital - HREC Exec 13/3/2019 - 18/191

Research Office <SVHS.Research@svha.org.au>
Wed 13/03/2019 2:27 PM
To: Jane Phillips <Jane.Phillips@uts.edu.au>
Cc: Claudia Virdun <Claudia.Virdun@uts.edu.au>

6 attachments (3 MB)

Helen Smith _ CV.pdf; Updated Letter 161118 - HREC F_C Exec meeting 3102018 - 18191.pdf; New_Site_Addition_Letter_Blacktown Hospital_signed.pdf; Email from Professor Phillips re submission.pdf; Adding personnel form_signed.pdf; Updated Letter 161118 - HREC F_C Exec meeting 3102018 - 18191.pdf;

Dear Jane

SVH file reference: 18/191
Study title: Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families / carers: a qualitative study
HREC reference: HREC/18/SVH/218

Thank you submitting a request to extend HREC approval to additional sites.

This project meets the requirements of the National Statement on Ethical Conduct in Human Research. I am pleased to advise that the HREC Executive meeting on **13 March 2019** approved this request. HREC approval has been extended to the following additional site:

- **Blacktown Hospital – PI Helen Smith**

You are reminded that this e-mail constitutes *ETHICAL* and *SCIENTIFIC* approval only. You must not commence this research project at a site until a completed Site Specific Assessment Form/Access Request and associated documentation have been submitted to the site Research Governance Officer and Authorised. A copy of this letter must be forwarded to all site investigators for submission to the relevant Research Governance Officer.

Should you have any queries regarding this project please contact the Research Office, Tel: (02) 8382-4960, or by E-mail SVHS.Research@svha.org.au. The HREC Terms of Reference, Standard Operating Procedures, *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice* and standard forms are available on the Research Office website that can be found at : https://svhs.org.au/home/research-education/research-office

St Vincent's Hospital HREC (EC00140) has been accredited by NSW Ministry of Health as a Lead HREC under the model for single ethical and scientific review and Certified by the NHMRC under the National Certification Scheme. This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*. No HREC members with a conflict of interest were present for review of this project.

Should you have any queries, please do not hesitate to contact me.

Kind regards,

Pratiti

Pratiti Ghosh | Administrative Officer | St. Vincent's Health Network
Translational Research Centre | 97-105 Boundary Street Darlinghurst NSW 2010
T +61 2 8382 4959
pratiti.ghosh@svha.org.au
https://svhs.org.au/home/research-education/research-office

Dear research team,

Please find attached a letter outlining our application to add a new site (Blacktown Hospital) to our study. Our study details are:

- **SVH file reference: 18/191**
- **Study title: Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families / carers: a qualitative study**
- **HREC reference: HREC/18/SVH/218**

I have also attached a CV for the noted principal investigator (Helen Smith) and the required form to add her to our research team, an email approving this application from Professor Phillips and our original approval letter for your reference.

We are also submitting an application for some amendments to be made to our research protocol and related documents affected. Within this amendment submission, we note that we are hoping to add a new site, if approved.

Please let me know if you have any additional questions at all.

With thanks for your time in reviewing this request,

Claudia

Claudia Virdun RN, MSc, PhD Candidate
Senior lecturer

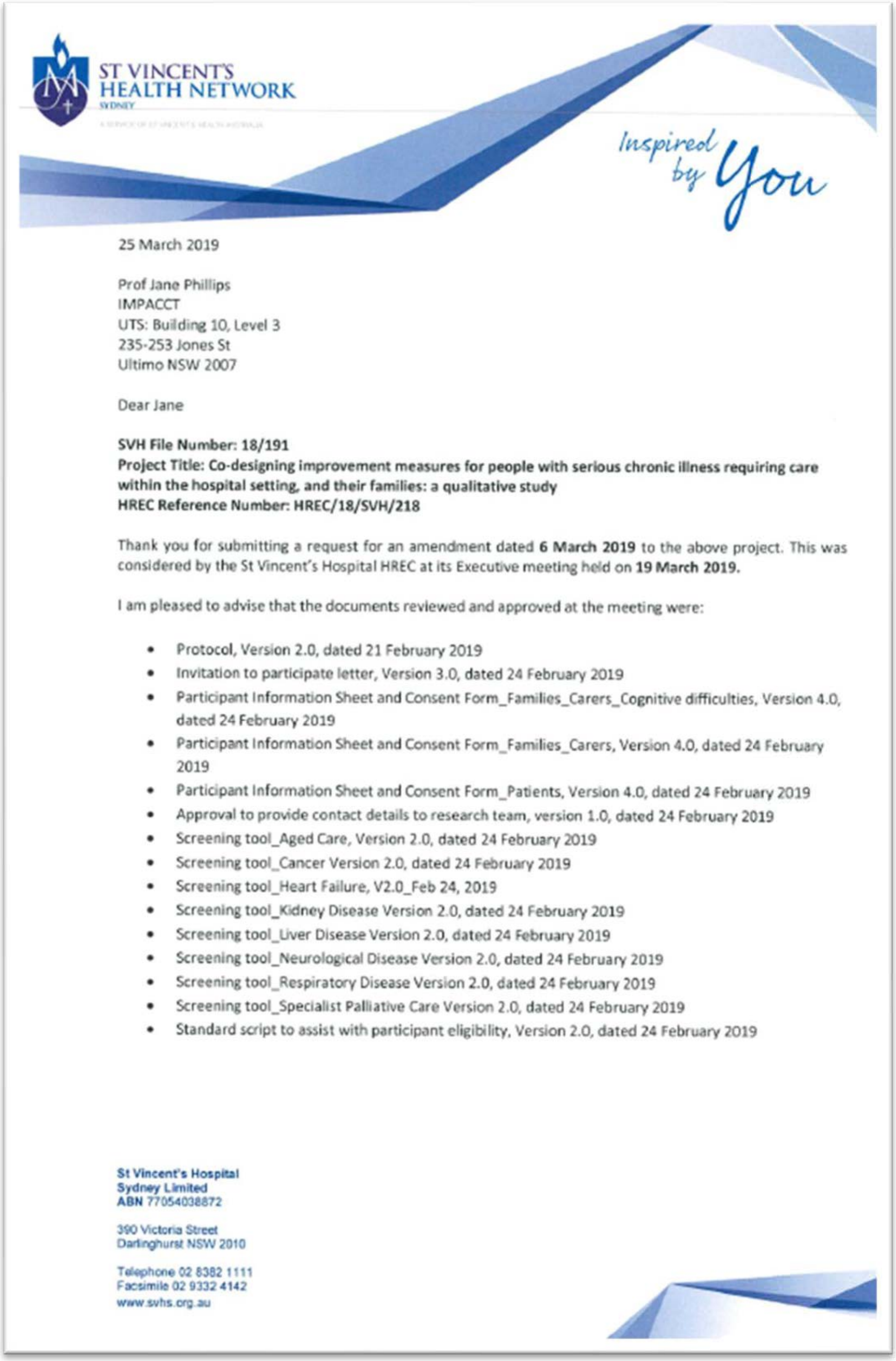
M. +61 (0) [redacted]

Level 7, 235 Jones St. Ultimo NSW 2007
PO Box 123. Broadway NSW 2007 Australia

health.uts.edu.au

Ranked No.1 in Australia and No.4 in the world for Nursing & Midwifery (2017 QS World University Rankings by subject); Top ranked in Australia for Human Movement & Sports Science, Nursing & Midwifery (2015 ERA 5/5) and Public Health & Health Services research (2015 ERA 4/5)

Amendment: small change to recruitment process (March, 2019)



ST VINCENT'S
HEALTH NETWORK
SYDNEY

Inspired by You

25 March 2019

Prof Jane Phillips
IMPACCT
UTS: Building 10, Level 3
235-253 Jones St
Ultimo NSW 2007

Dear Jane

SVH File Number: 18/191
Project Title: Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families: a qualitative study
HREC Reference Number: HREC/18/SVH/218

Thank you for submitting a request for an amendment dated **6 March 2019** to the above project. This was considered by the St Vincent's Hospital HREC at its Executive meeting held on **19 March 2019.**

I am pleased to advise that the documents reviewed and approved at the meeting were:

- Protocol, Version 2.0, dated 21 February 2019
- Invitation to participate letter, Version 3.0, dated 24 February 2019
- Participant Information Sheet and Consent Form_Families_Carers_Cognitive difficulties, Version 4.0, dated 24 February 2019
- Participant Information Sheet and Consent Form_Families_Carers, Version 4.0, dated 24 February 2019
- Participant Information Sheet and Consent Form_Patients, Version 4.0, dated 24 February 2019
- Approval to provide contact details to research team, version 1.0, dated 24 February 2019
- Screening tool_Aged Care, Version 2.0, dated 24 February 2019
- Screening tool_Cancer Version 2.0, dated 24 February 2019
- Screening tool_Heart Failure, V2.0_Feb 24, 2019
- Screening tool_Kidney Disease Version 2.0, dated 24 February 2019
- Screening tool_Liver Disease Version 2.0, dated 24 February 2019
- Screening tool_Neurological Disease Version 2.0, dated 24 February 2019
- Screening tool_Respiratory Disease Version 2.0, dated 24 February 2019
- Screening tool_Specialist Palliative Care Version 2.0, dated 24 February 2019
- Standard script to assist with participant eligibility, Version 2.0, dated 24 February 2019

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This amendment has also been reviewed by the Research Governance Officer at St Vincent's Hospital. The following site specific documents are required for governance review:

- Invitation to participate letter, Version 3.0, dated 24 February 2019
- Participant Information Sheet and Consent Form_Families_Carers_Cognitive difficulties, Version 4.0, dated 24 February 2019
- Participant Information Sheet and Consent Form_Families_Carers, Version 4.0, dated 24 February 2019
- Participant Information Sheet and Consent Form_Patients, Version 4.0, dated 24 February 2019
- Approval to provide contact details to research team, version 1.0, dated 24 February 2019

Please submit via email only to svhs.research@svha.org.au.

Please note that this letter constitutes ongoing ETHICAL and SCIENTIFIC review only. For multi-site projects reviewed by the HREC after 1 July 2007 a copy of this letter must be forwarded to all Principal Investigators at every site approved by SVH HREC for submission to the relevant Research Governance Officer along with a copy of the approved documents prior to implementation of the amendment.

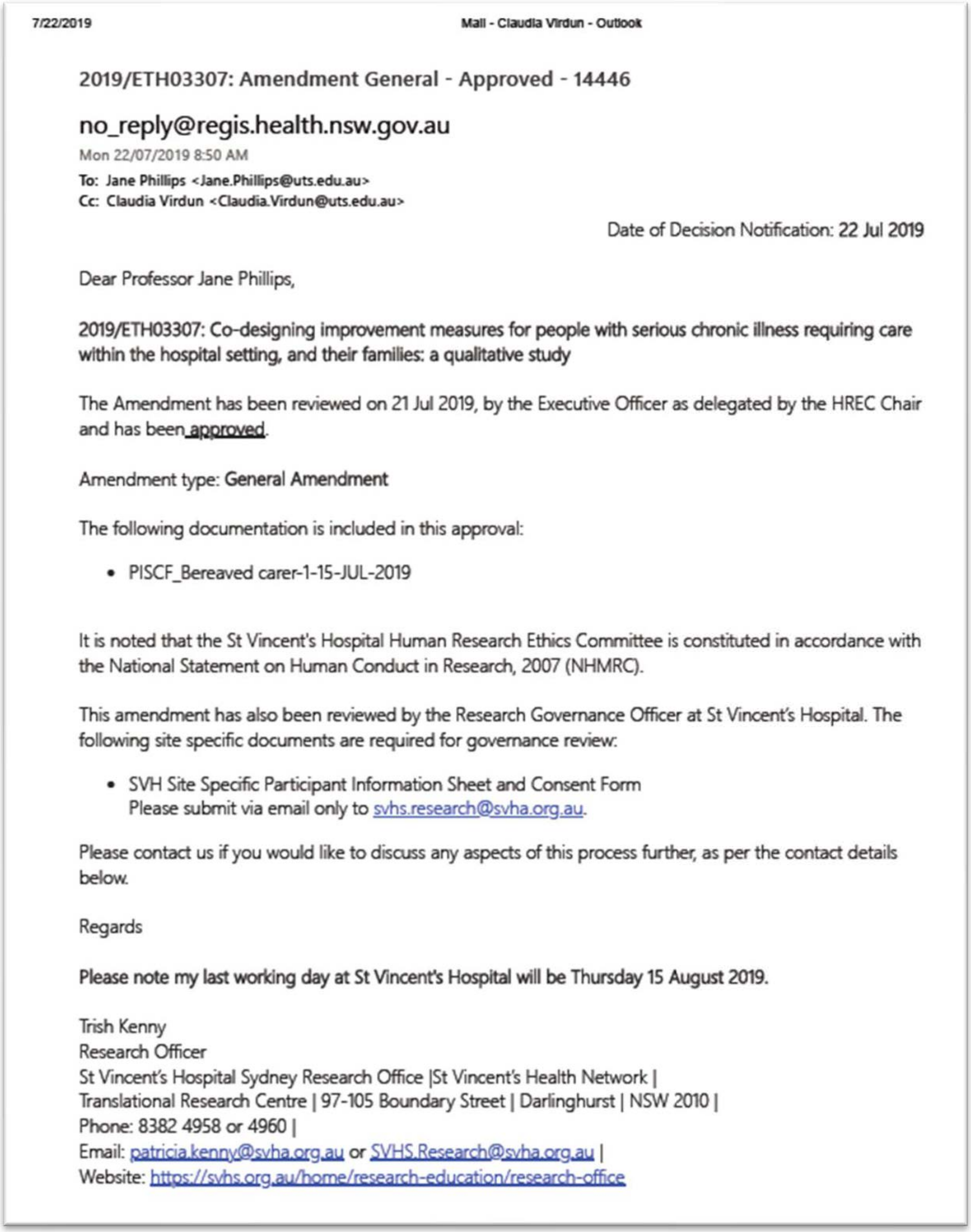
Should you have any queries regarding this project please contact the Research Office, Tel: (02) 8382-4960, email SVHS.Research@svha.org.au. Further relevant information is available on the Research Office website found at: https://svhs.org.au/home/research-education/research-office

Yours sincerely,

Monica Logan
Research Officer
St Vincent's Hospital Research Office
Translational Research Centre
97-105 Boundary Street
Darlinghurst NSW 2010

cc: Claudia Virdun
TRIM REF: D/2019/17444

Amendment: Adding the option to recruit via bereavement services (July 2019)



7/22/2019 Mail - Claudia Virdun - Outlook

2019/ETH03307: Amendment General - Approved - 14446

no_reply@regis.health.nsw.gov.au

Mon 22/07/2019 8:50 AM

To: Jane Phillips <Jane.Phillips@uts.edu.au>

Cc: Claudia Virdun <Claudia.Virdun@uts.edu.au>

Date of Decision Notification: **22 Jul 2019**

Dear Professor Jane Phillips,

2019/ETH03307: Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families: a qualitative study

The Amendment has been reviewed on 21 Jul 2019, by the Executive Officer as delegated by the HREC Chair and has been approved.

Amendment type: **General Amendment**

The following documentation is included in this approval:

- PISCF_Bereaved carer-1-15-JUL-2019

It is noted that the St Vincent's Hospital Human Research Ethics Committee is constituted in accordance with the National Statement on Human Conduct in Research, 2007 (NHMRC).

This amendment has also been reviewed by the Research Governance Officer at St Vincent's Hospital. The following site specific documents are required for governance review:

- SVH Site Specific Participant Information Sheet and Consent Form
  Please submit via email only to svhs.research@svha.org.au.

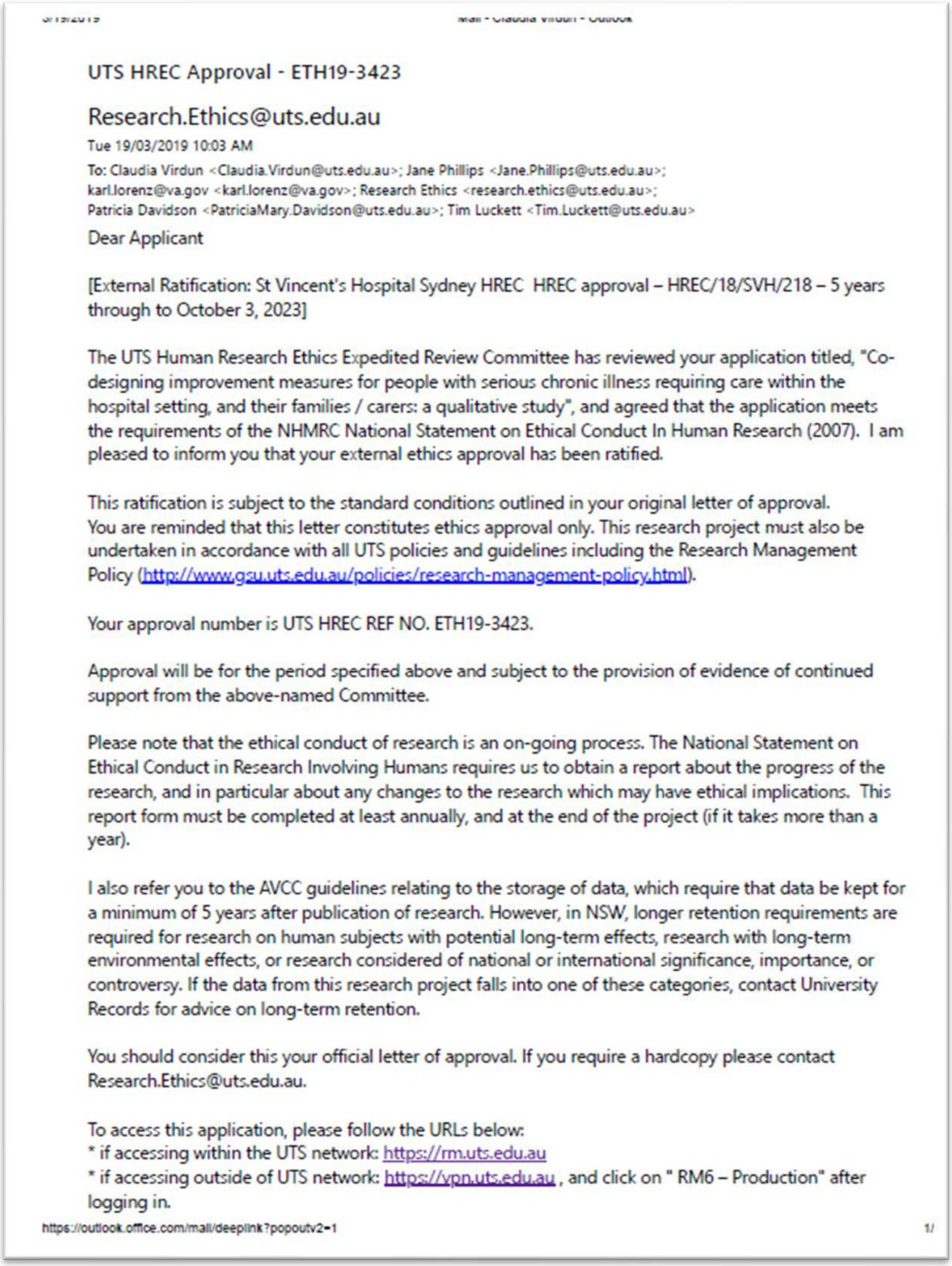
Please contact us if you would like to discuss any aspects of this process further, as per the contact details below.

Regards

Please note my last working day at St Vincent's Hospital will be Thursday 15 August 2019.

Trish Kenny
Research Officer
St Vincent's Hospital Sydney Research Office |St Vincent's Health Network |
Translational Research Centre | 97-105 Boundary Street | Darlinghurst | NSW 2010 |
Phone: 8382 4958 or 4960 |
Email: patricia.kenny@svha.org.au or SVHS.Research@svha.org.au |
Website: https://svhs.org.au/home/research-education/research-office

UTS Ratification of approval



UTS HREC Approval - ETH19-3423

Research.Ethics@uts.edu.au

Tue 19/03/2019 10:03 AM

To: Claudia Virdun <Claudia.Virdun@uts.edu.au>; Jane Phillips <Jane.Phillips@uts.edu.au>; karl.lorenz@va.gov <karl.lorenz@va.gov>; Research Ethics <research.ethics@uts.edu.au>; Patricia Davidson <PatriciaMary.Davidson@uts.edu.au>; Tim Luckett <Tim.Luckett@uts.edu.au>

Dear Applicant

[External Ratification: St Vincent's Hospital Sydney HREC HREC approval – HREC/18/SVH/218 – 5 years through to October 3, 2023]

The UTS Human Research Ethics Expedited Review Committee has reviewed your application titled, "Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families / carers: a qualitative study", and agreed that the application meets the requirements of the NHMRC National Statement on Ethical Conduct In Human Research (2007). I am pleased to inform you that your external ethics approval has been ratified.

This ratification is subject to the standard conditions outlined in your original letter of approval. You are reminded that this letter constitutes ethics approval only. This research project must also be undertaken in accordance with all UTS policies and guidelines including the Research Management Policy (http://www.gsu.uts.edu.au/policies/research-management-policy.html).

Your approval number is UTS HREC REF NO. ETH19-3423.

Approval will be for the period specified above and subject to the provision of evidence of continued support from the above-named Committee.

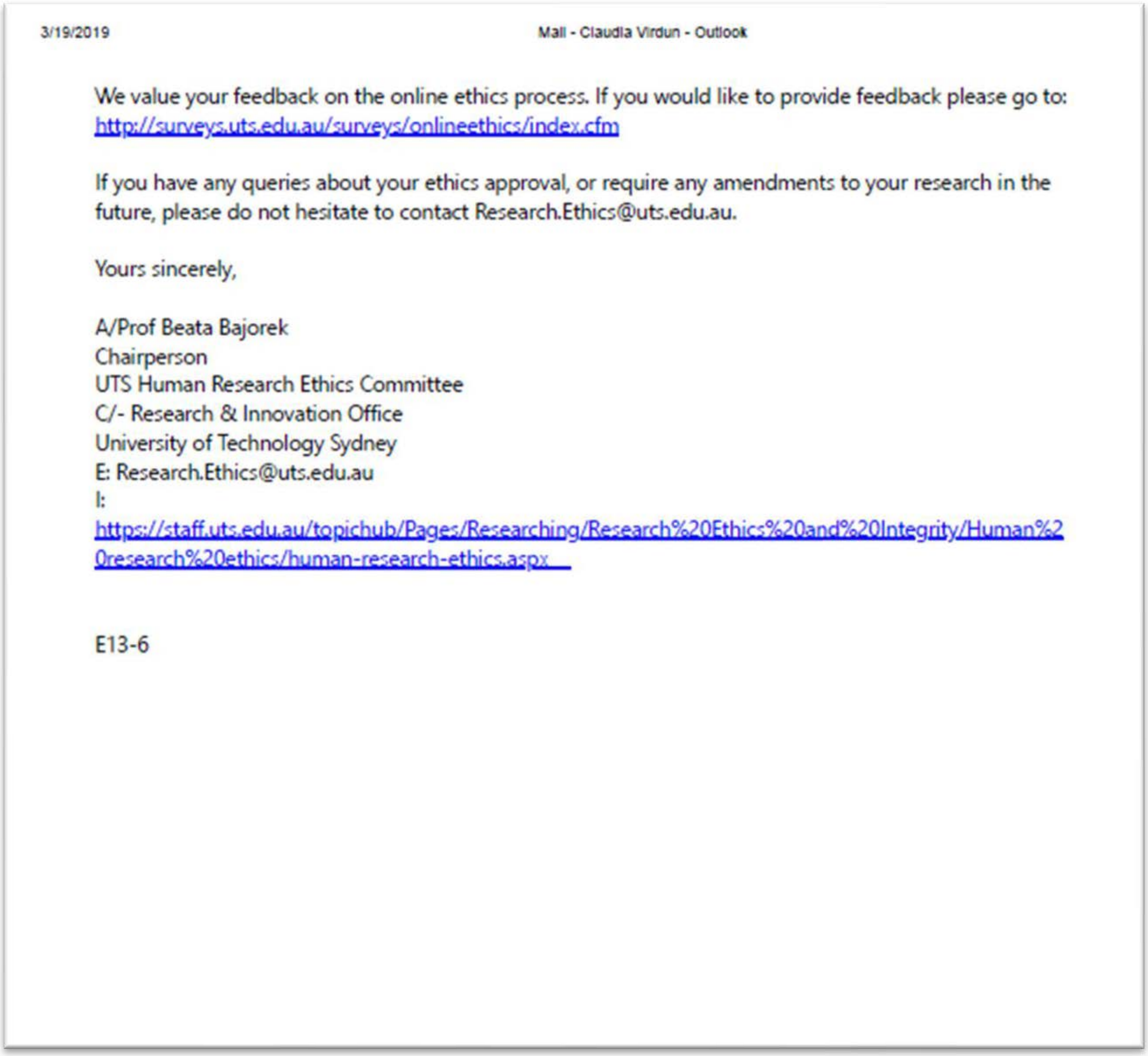
Please note that the ethical conduct of research is an on-going process. The National Statement on Ethical Conduct in Research Involving Humans requires us to obtain a report about the progress of the research, and in particular about any changes to the research which may have ethical implications. This report form must be completed at least annually, and at the end of the project (if it takes more than a year).

I also refer you to the AVCC guidelines relating to the storage of data, which require that data be kept for a minimum of 5 years after publication of research. However, in NSW, longer retention requirements are required for research on human subjects with potential long-term effects, research with long-term environmental effects, or research considered of national or international significance, importance, or controversy. If the data from this research project falls into one of these categories, contact University Records for advice on long-term retention.

You should consider this your official letter of approval. If you require a hardcopy please contact Research.Ethics@uts.edu.au.

To access this application, please follow the URLs below:
* if accessing within the UTS network: https://rm.uts.edu.au
* if accessing outside of UTS network: https://vpn.uts.edu.au , and click on " RM6 – Production" after logging in.

https://outlook.office.com/mail/deeplink?popoutv2=1 1/



3/19/2019 Mail - Claudia Virdun - Outlook

We value your feedback on the online ethics process. If you would like to provide feedback please go to: http://surveys.uts.edu.au/surveys/onlineethics/index.cfm

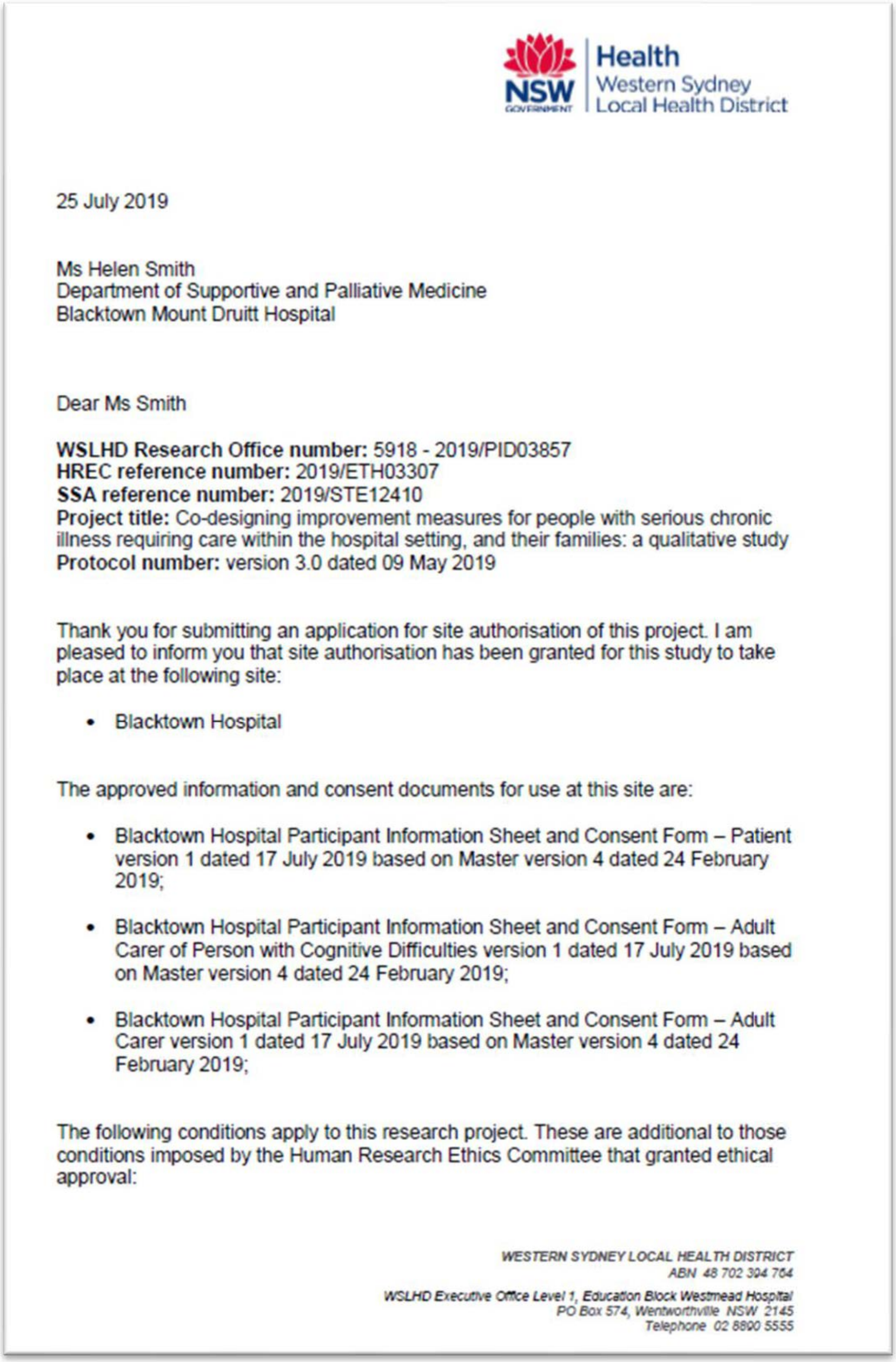
If you have any queries about your ethics approval, or require any amendments to your research in the future, please do not hesitate to contact Research.Ethics@uts.edu.au.

Yours sincerely,

A/Prof Beata Bajorek
Chairperson
UTS Human Research Ethics Committee
C/- Research & Innovation Office
University of Technology Sydney
E: Research.Ethics@uts.edu.au
I:
https://staff.uts.edu.au/topichub/Pages/Researching/Research%20Ethics%20and%20Integrity/Human%20research%20ethics/human-research-ethics.aspx

E13-6

Site specific approval: Blacktown Hospital



NSW GOVERNMENT
Health
Western Sydney
Local Health District

25 July 2019

Ms Helen Smith
Department of Supportive and Palliative Medicine
Blacktown Mount Druitt Hospital

Dear Ms Smith

WSLHD Research Office number: 5918 - 2019/PID03857
HREC reference number: 2019/ETH03307
SSA reference number: 2019/STE12410
Project title: Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families: a qualitative study
Protocol number: version 3.0 dated 09 May 2019

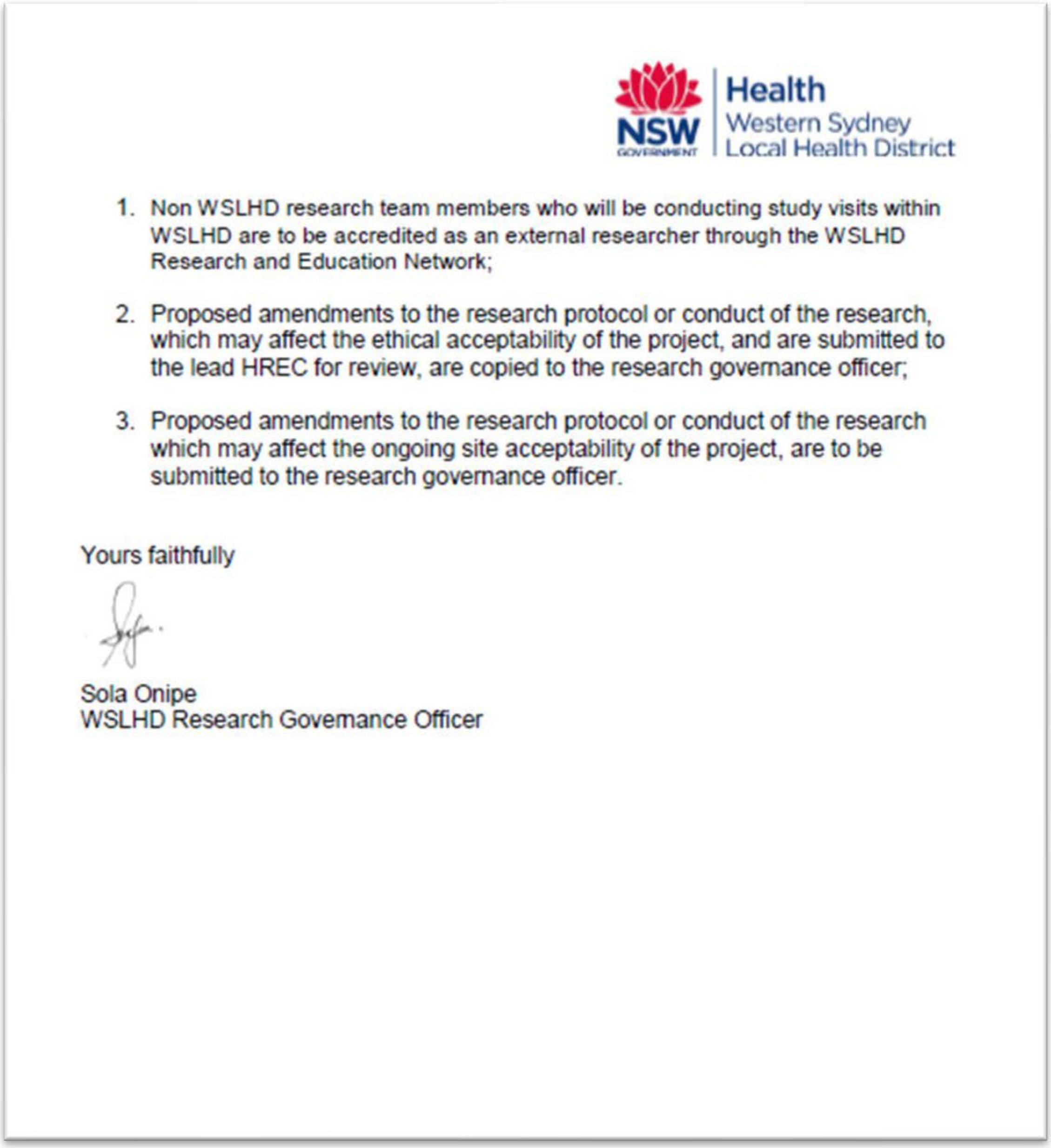
Thank you for submitting an application for site authorisation of this project. I am pleased to inform you that site authorisation has been granted for this study to take place at the following site:

- Blacktown Hospital

The approved information and consent documents for use at this site are:

- Blacktown Hospital Participant Information Sheet and Consent Form – Patient version 1 dated 17 July 2019 based on Master version 4 dated 24 February 2019;
- Blacktown Hospital Participant Information Sheet and Consent Form – Adult Carer of Person with Cognitive Difficulties version 1 dated 17 July 2019 based on Master version 4 dated 24 February 2019;
- Blacktown Hospital Participant Information Sheet and Consent Form – Adult Carer version 1 dated 17 July 2019 based on Master version 4 dated 24 February 2019;

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:



NSW Government
Health
Western Sydney
Local Health District

1. Non WSLHD research team members who will be conducting study visits within WSLHD are to be accredited as an external researcher through the WSLHD Research and Education Network;

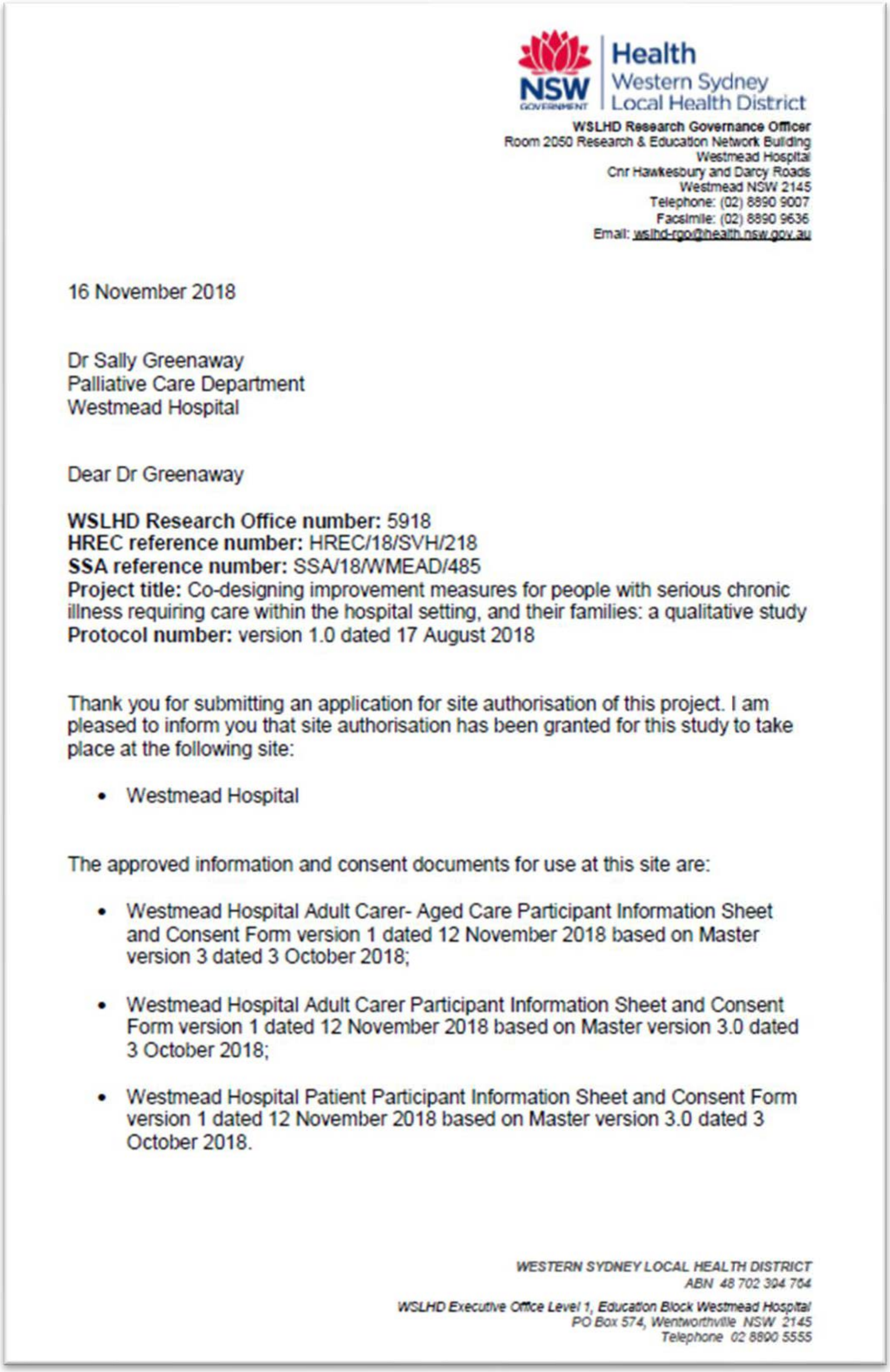
2. Proposed amendments to the research protocol or conduct of the research, which may affect the ethical acceptability of the project, and are submitted to the lead HREC for review, are copied to the research governance officer;

3. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to the research governance officer.

Yours faithfully

Sola Onipe
WSLHD Research Governance Officer

Site specific approval: Westmead Hospital



Health
Western Sydney
Local Health District

WSLHD Research Governance Officer
Room 2050 Research & Education Network Building
Westmead Hospital
Cnr Hawkesbury and Darcy Roads
Westmead NSW 2145
Telephone: (02) 8890 9007
Facsimile: (02) 8890 9636
Email: wslhd-rgo@health.nsw.gov.au

16 November 2018

Dr Sally Greenaway
Palliative Care Department
Westmead Hospital

Dear Dr Greenaway

WSLHD Research Office number: 5918
HREC reference number: HREC/18/SVH/218
SSA reference number: SSA/18/WMEAD/485
Project title: Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families: a qualitative study
Protocol number: version 1.0 dated 17 August 2018

Thank you for submitting an application for site authorisation of this project. I am pleased to inform you that site authorisation has been granted for this study to take place at the following site:

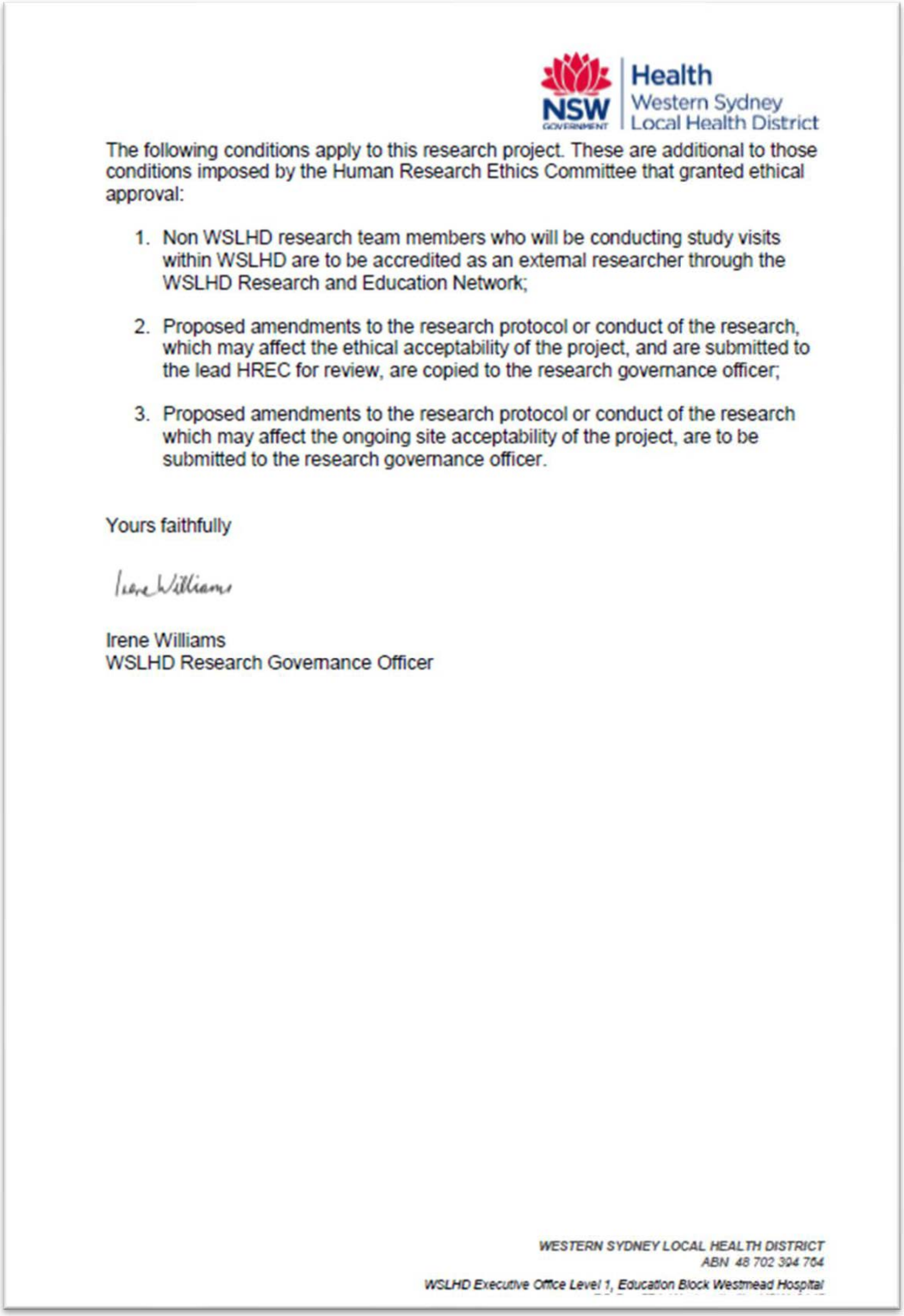
- Westmead Hospital

The approved information and consent documents for use at this site are:

- Westmead Hospital Adult Carer- Aged Care Participant Information Sheet and Consent Form version 1 dated 12 November 2018 based on Master version 3 dated 3 October 2018;
- Westmead Hospital Adult Carer Participant Information Sheet and Consent Form version 1 dated 12 November 2018 based on Master version 3.0 dated 3 October 2018;
- Westmead Hospital Patient Participant Information Sheet and Consent Form version 1 dated 12 November 2018 based on Master version 3.0 dated 3 October 2018.

WESTERN SYDNEY LOCAL HEALTH DISTRICT
ABN 48 702 394 764

WSLHD Executive Office Level 1, Education Block Westmead Hospital
PO Box 574, Wentworthville NSW 2145
Telephone 02 8890 5555



Health
Western Sydney
Local Health District

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Non WSLHD research team members who will be conducting study visits within WSLHD are to be accredited as an external researcher through the WSLHD Research and Education Network;
2. Proposed amendments to the research protocol or conduct of the research, which may affect the ethical acceptability of the project, and are submitted to the lead HREC for review, are copied to the research governance officer;
3. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to the research governance officer.

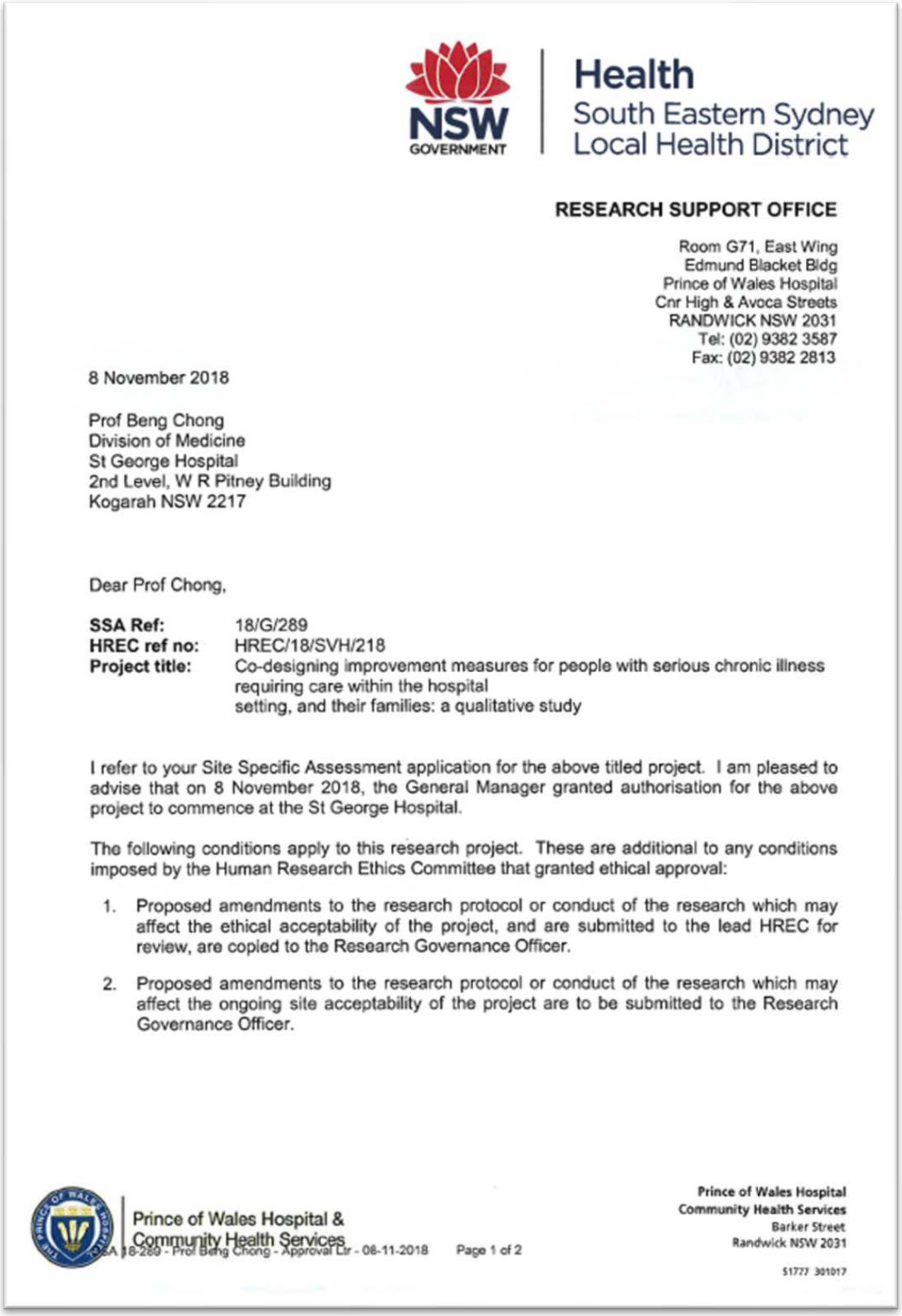
Yours faithfully

Irene Williams

Irene Williams
WSLHD Research Governance Officer

WESTERN SYDNEY LOCAL HEALTH DISTRICT
ABN 48 702 394 764
WSLHD Executive Office Level 1, Education Block Westmead Hospital

Site specific approval: St George Hospital



NSW GOVERNMENT
Health
South Eastern Sydney
Local Health District

RESEARCH SUPPORT OFFICE

Room G71, East Wing
Edmund Blacket Bldg
Prince of Wales Hospital
Cnr High & Avoca Streets
RANDWICK NSW 2031
Tel: (02) 9382 3587
Fax: (02) 9382 2813

8 November 2018

Prof Beng Chong
Division of Medicine
St George Hospital
2nd Level, W R Pitney Building
Kogarah NSW 2217

Dear Prof Chong,

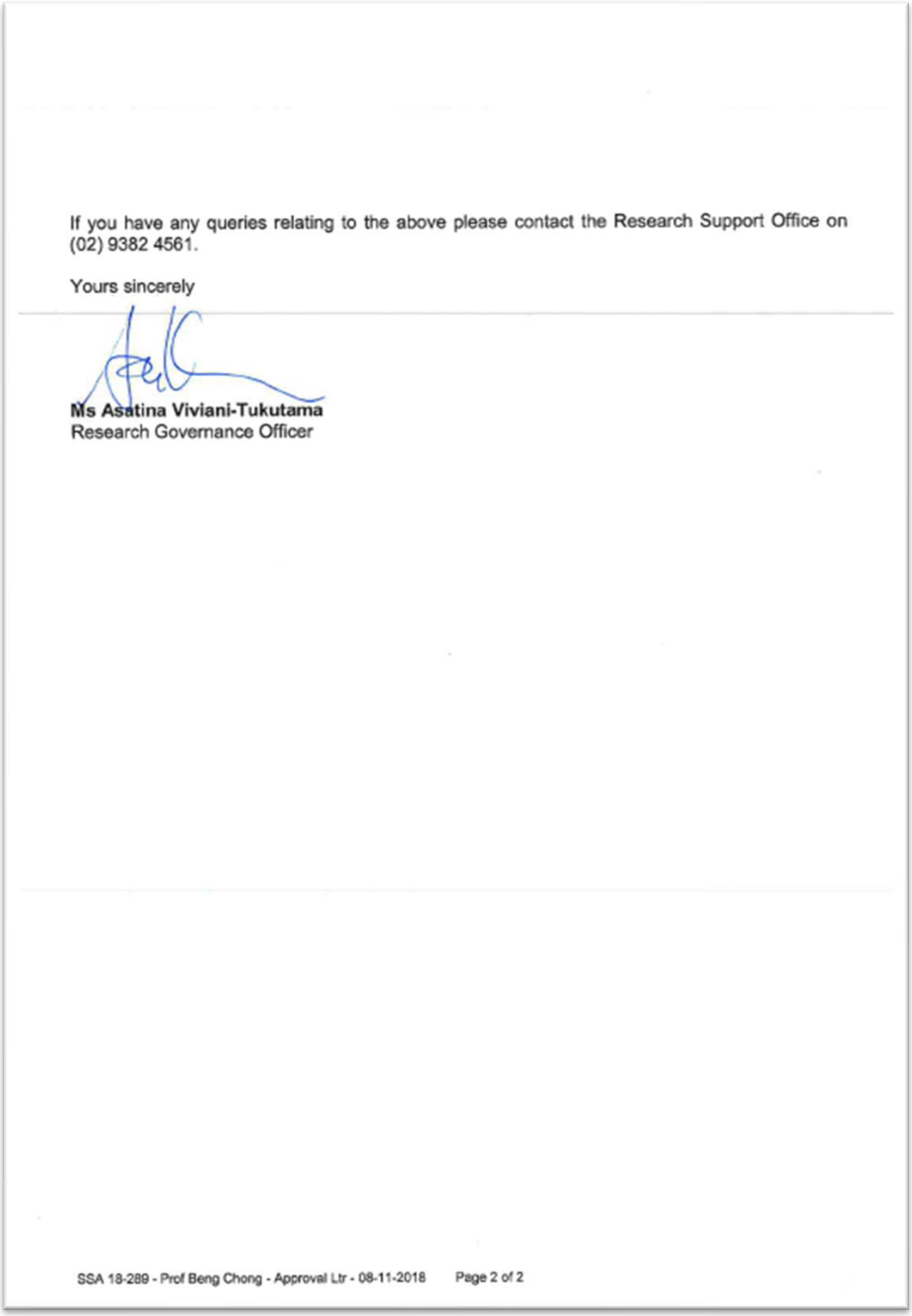
SSA Ref: 18/G/289
HREC ref no: HREC/18/SVH/218
Project title: Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families: a qualitative study

I refer to your Site Specific Assessment application for the above titled project. I am pleased to advise that on 8 November 2018, the General Manager granted authorisation for the above project to commence at the St George Hospital.

The following conditions apply to this research project. These are additional to any conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and are submitted to the lead HREC for review, are copied to the Research Governance Officer.

2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project are to be submitted to the Research Governance Officer.

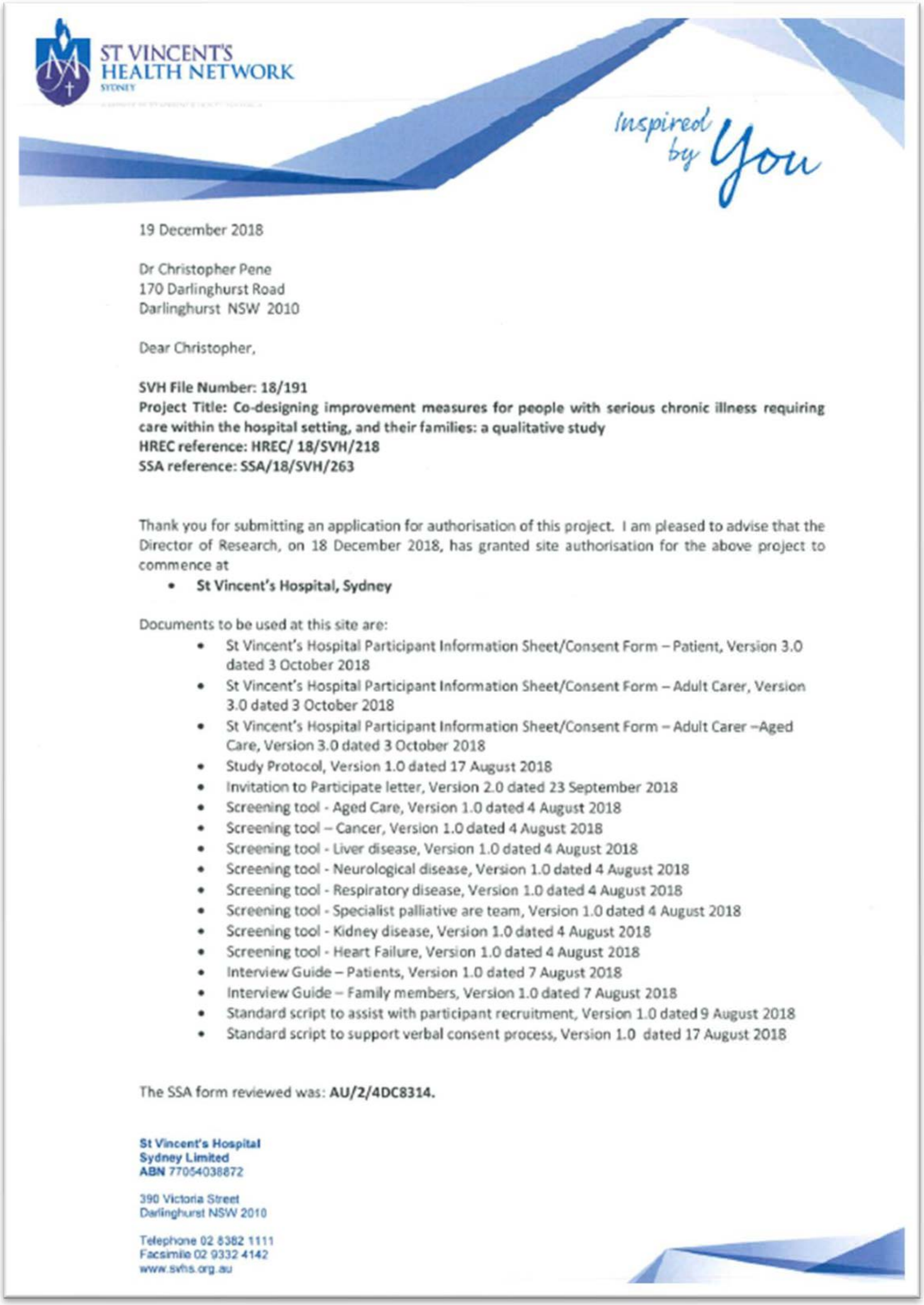


If you have any queries relating to the above please contact the Research Support Office on (02) 9382 4561.

Yours sincerely

Ms Asatina Viviani-Tukutama
Research Governance Officer

Site specific approval: St Vincent's Hospital



ST VINCENT'S
HEALTH NETWORK
SYDNEY

Inspired by You

19 December 2018

Dr Christopher Pene
170 Darlinghurst Road
Darlinghurst NSW 2010

Dear Christopher,

SVH File Number: 18/191
Project Title: Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families: a qualitative study
HREC reference: HREC/ 18/SVH/218
SSA reference: SSA/18/SVH/263

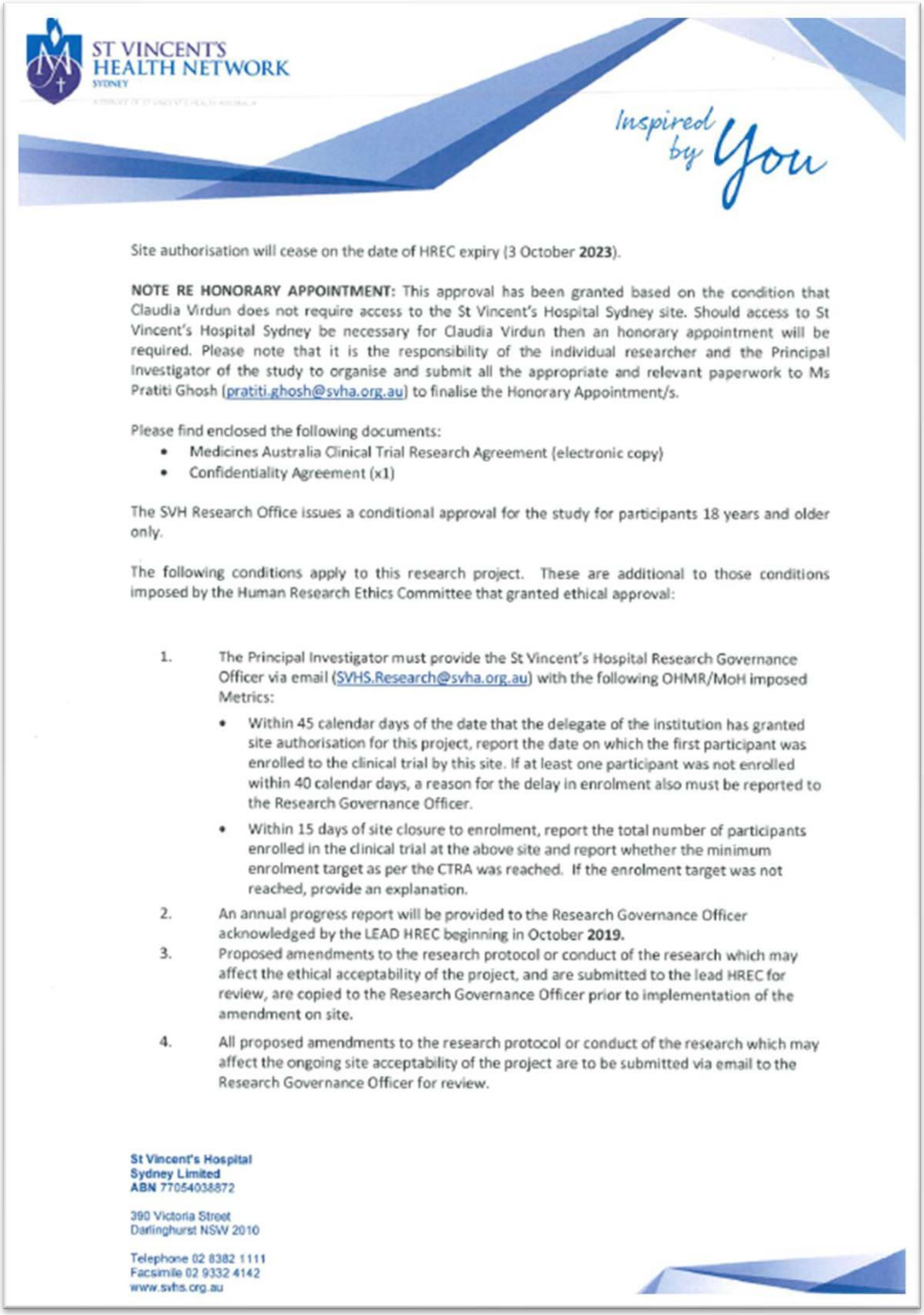
Thank you for submitting an application for authorisation of this project. I am pleased to advise that the Director of Research, on 18 December 2018, has granted site authorisation for the above project to commence at

- **St Vincent's Hospital, Sydney**

Documents to be used at this site are:

- St Vincent's Hospital Participant Information Sheet/Consent Form – Patient, Version 3.0 dated 3 October 2018
- St Vincent's Hospital Participant Information Sheet/Consent Form – Adult Carer, Version 3.0 dated 3 October 2018
- St Vincent's Hospital Participant Information Sheet/Consent Form – Adult Carer –Aged Care, Version 3.0 dated 3 October 2018
- Study Protocol, Version 1.0 dated 17 August 2018
- Invitation to Participate letter, Version 2.0 dated 23 September 2018
- Screening tool - Aged Care, Version 1.0 dated 4 August 2018
- Screening tool – Cancer, Version 1.0 dated 4 August 2018
- Screening tool - Liver disease, Version 1.0 dated 4 August 2018
- Screening tool - Neurological disease, Version 1.0 dated 4 August 2018
- Screening tool - Respiratory disease, Version 1.0 dated 4 August 2018
- Screening tool - Specialist palliative are team, Version 1.0 dated 4 August 2018
- Screening tool - Kidney disease, Version 1.0 dated 4 August 2018
- Screening tool - Heart Failure, Version 1.0 dated 4 August 2018
- Interview Guide – Patients, Version 1.0 dated 7 August 2018
- Interview Guide – Family members, Version 1.0 dated 7 August 2018
- Standard script to assist with participant recruitment, Version 1.0 dated 9 August 2018
- Standard script to support verbal consent process, Version 1.0 dated 17 August 2018

The SSA form reviewed was: **AU/2/4DC8314.**



ST VINCENT'S
HEALTH NETWORK
SYDNEY

Inspired by You

Site authorisation will cease on the date of HREC expiry (3 October **2023**).

NOTE RE HONORARY APPOINTMENT: This approval has been granted based on the condition that Claudia Virdun does not require access to the St Vincent's Hospital Sydney site. Should access to St Vincent's Hospital Sydney be necessary for Claudia Virdun then an honorary appointment will be required. Please note that it is the responsibility of the individual researcher and the Principal Investigator of the study to organise and submit all the appropriate and relevant paperwork to Ms Pratiti Ghosh (pratiti.ghosh@svha.org.au) to finalise the Honorary Appointment/s.

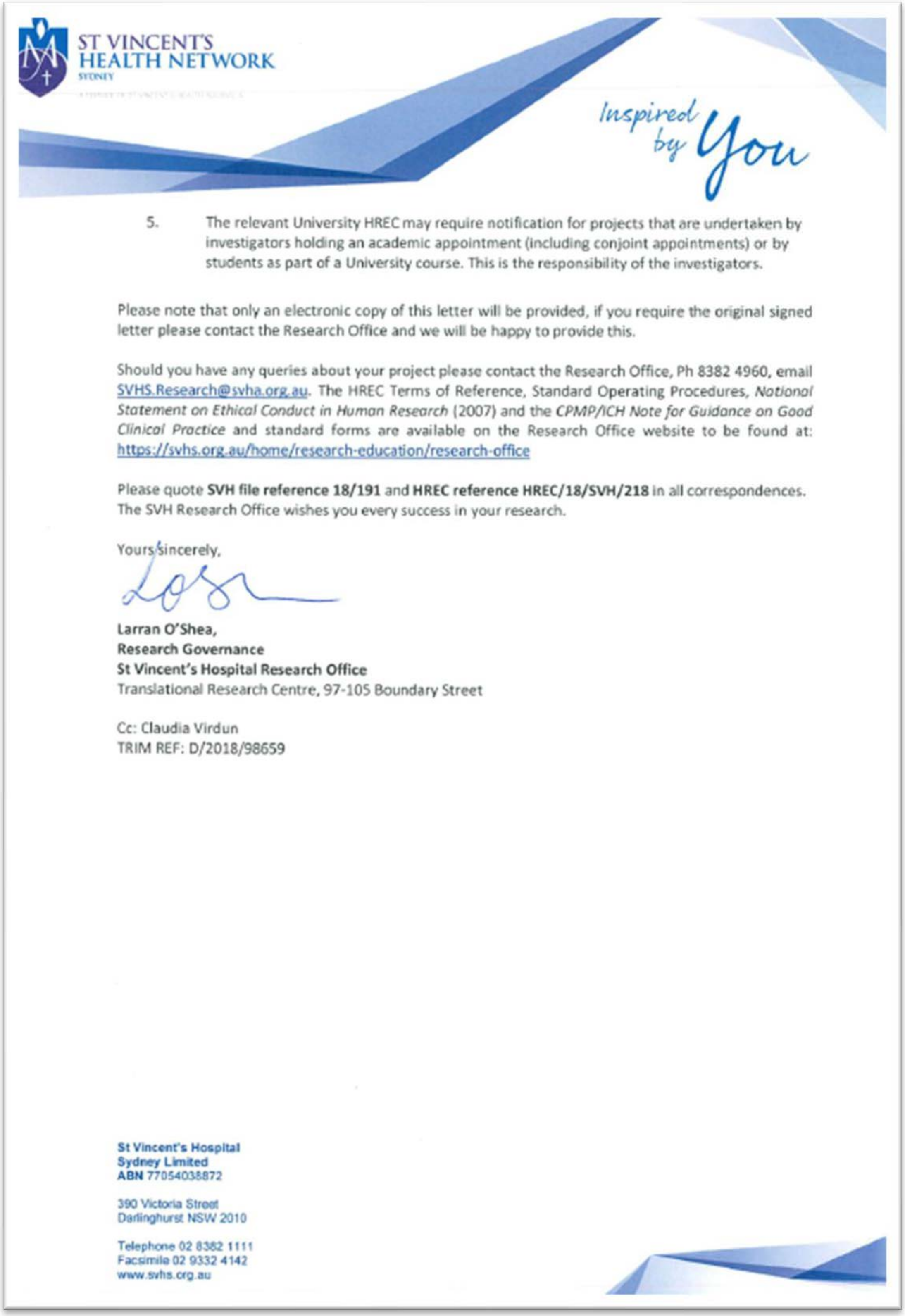
Please find enclosed the following documents:

- Medicines Australia Clinical Trial Research Agreement (electronic copy)
- Confidentiality Agreement (x1)

The SVH Research Office issues a conditional approval for the study for participants 18 years and older only.

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. The Principal Investigator must provide the St Vincent's Hospital Research Governance Officer via email (SVHS.Research@svha.org.au) with the following OHMR/MoH imposed Metrics:
    - Within 45 calendar days of the date that the delegate of the institution has granted site authorisation for this project, report the date on which the first participant was enrolled to the clinical trial by this site. If at least one participant was not enrolled within 40 calendar days, a reason for the delay in enrolment also must be reported to the Research Governance Officer.
    - Within 15 days of site closure to enrolment, report the total number of participants enrolled in the clinical trial at the above site and report whether the minimum enrolment target as per the CTRA was reached. If the enrolment target was not reached, provide an explanation.
2. An annual progress report will be provided to the Research Governance Officer acknowledged by the LEAD HREC beginning in October **2019.**
3. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and are submitted to the lead HREC for review, are copied to the Research Governance Officer prior to implementation of the amendment on site.
4. All proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project are to be submitted via email to the Research Governance Officer for review.



ST VINCENT'S
HEALTH NETWORK
SYDNEY

Inspired by You

5. The relevant University HREC may require notification for projects that are undertaken by investigators holding an academic appointment (including conjoint appointments) or by students as part of a University course. This is the responsibility of the investigators.

Please note that only an electronic copy of this letter will be provided, if you require the original signed letter please contact the Research Office and we will be happy to provide this.

Should you have any queries about your project please contact the Research Office, Ph 8382 4960, email SVHS.Research@svha.org.au. The HREC Terms of Reference, Standard Operating Procedures, *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice* and standard forms are available on the Research Office website to be found at: https://svhs.org.au/home/research-education/research-office

Please quote **SVH file reference 18/191** and **HREC reference HREC/18/SVH/218** in all correspondences. The SVH Research Office wishes you every success in your research.

Yours sincerely,

Larran O'Shea,
Research Governance
St Vincent's Hospital Research Office
Translational Research Centre, 97-105 Boundary Street

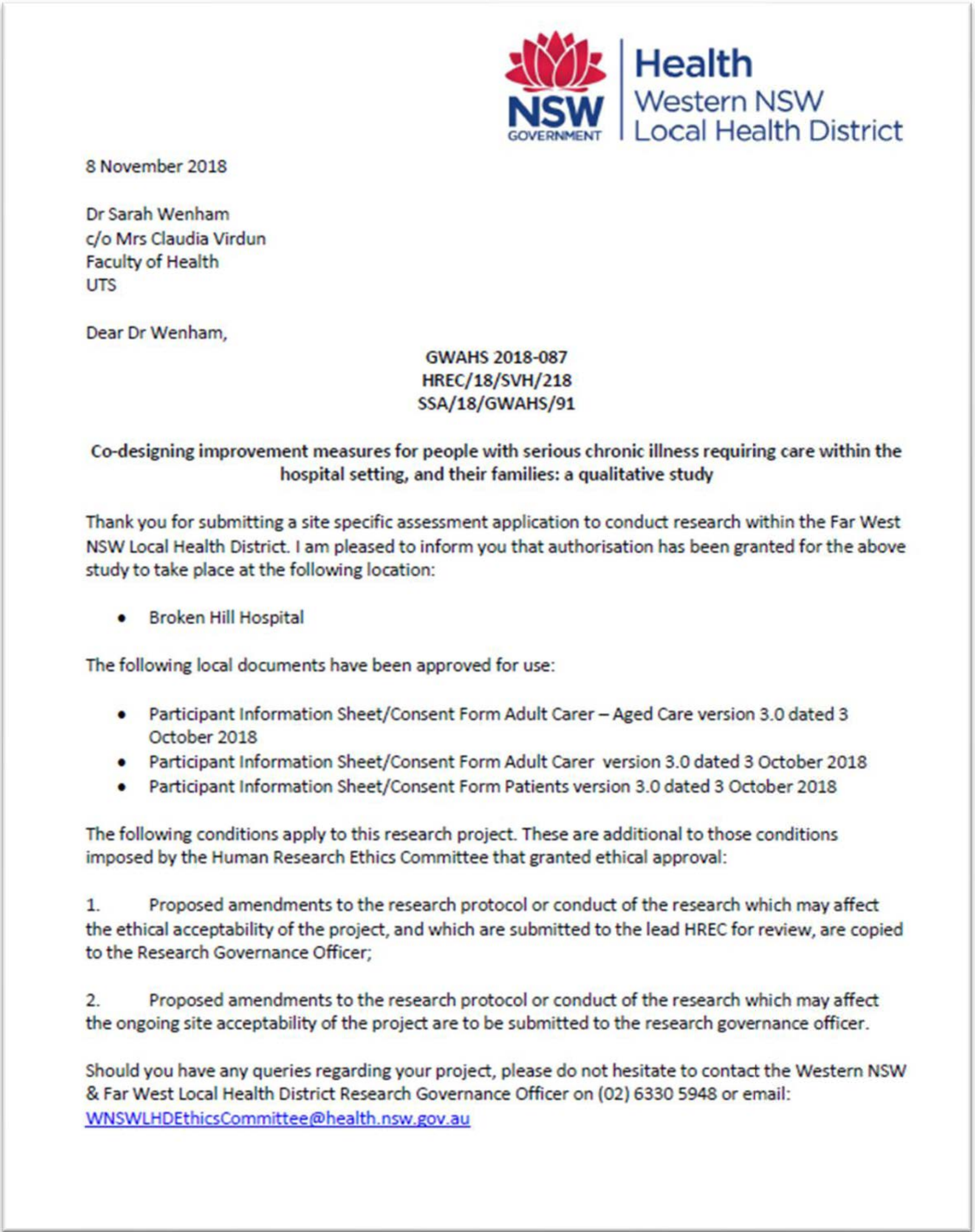
Cc: Claudia Virdun
TRIM REF: D/2018/98659

St Vincent's Hospital
Sydney Limited
ABN 77054038872

390 Victoria Street
Darlinghurst NSW 2010

Telephone 02 8382 1111
Facsimile 02 9332 4142
www.svhs.org.au

Site specific approval: Broken Hill Health Service



NSW GOVERNMENT
Health
Western NSW
Local Health District

8 November 2018

Dr Sarah Wenham
c/o Mrs Claudia Virdun
Faculty of Health
UTS

Dear Dr Wenham,

GWAHS 2018-087
HREC/18/SVH/218
SSA/18/GWAHS/91

Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families: a qualitative study

Thank you for submitting a site specific assessment application to conduct research within the Far West NSW Local Health District. I am pleased to inform you that authorisation has been granted for the above study to take place at the following location:

- Broken Hill Hospital

The following local documents have been approved for use:

- Participant Information Sheet/Consent Form Adult Carer – Aged Care version 3.0 dated 3 October 2018
- Participant Information Sheet/Consent Form Adult Carer version 3.0 dated 3 October 2018
- Participant Information Sheet/Consent Form Patients version 3.0 dated 3 October 2018

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to the Research Governance Officer;

2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project are to be submitted to the research governance officer.

Should you have any queries regarding your project, please do not hesitate to contact the Western NSW & Far West Local Health District Research Governance Officer on (02) 6330 5948 or email: WNSWLHDEthicsCommittee@health.nsw.gov.au

Please quote SSA Reference No. ***SSA/18/GWAHS/91*** in all correspondence.

The Western NSW & Far West Local Health Districts wish you every success in your research.

Yours sincerely,

Phil Sanders

Phil Sanders
Research Governance Officer
Western NSW LHD and Far West NSW LHD

Participant Information Sheet and Consent Form – this was edited lightly for each population (patient, family member or bereaved family member). Patient version provided as an example here.

Insert Header with institution's name or institution's letterhead

Participant Information Sheet/Consent Form

Health/Social Science Research - *Adult providing own consent*

[Insert site name]

Title	**Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families / carers: a qualitative study**
Short Title	Consumer centred improvement measures for people with serious chronic illness: a qualitative study
Protocol Number	SVH 18/191
Project Sponsor	University of Technology Sydney
Coordinating Principal Investigator/ Principal Investigator	Professor Jane Phillips
Associate Investigator(s) *(if required by institution)*	Claudia Virdun, Dr Tim Luckett, Professor Karl Lorenz, Professor Patricia Davidson
Location *(where CPI/PI will recruit)*	

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project, which is called: *Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families / carers: a qualitative study*. You have been invited because you have a serious chronic condition and one of your care providers thought you could offer important insights from recent hospitalisations to inform our ongoing work.

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

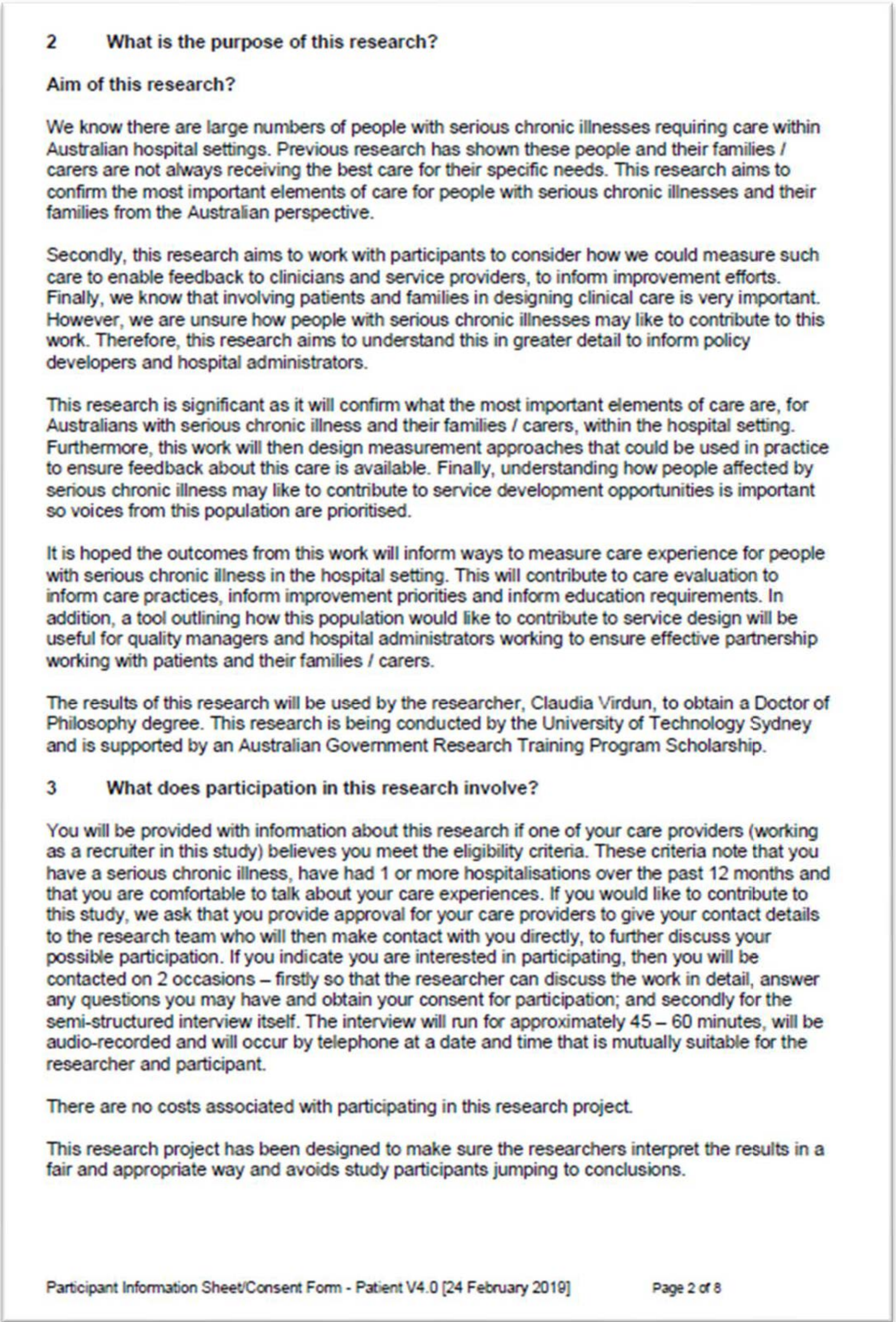
Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. You will receive the best possible care whether or not you take part.

If you decide you want to take part in the research project, you will be asked to provide verbal consent. By consenting you are telling us that you:
- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

Participant Information Sheet/Consent Form - Patient V4.0 [24 February 2019] Page 1 of 8



2 What is the purpose of this research?

Aim of this research?

We know there are large numbers of people with serious chronic illnesses requiring care within Australian hospital settings. Previous research has shown these people and their families / carers are not always receiving the best care for their specific needs. This research aims to confirm the most important elements of care for people with serious chronic illnesses and their families from the Australian perspective.

Secondly, this research aims to work with participants to consider how we could measure such care to enable feedback to clinicians and service providers, to inform improvement efforts. Finally, we know that involving patients and families in designing clinical care is very important. However, we are unsure how people with serious chronic illnesses may like to contribute to this work. Therefore, this research aims to understand this in greater detail to inform policy developers and hospital administrators.

This research is significant as it will confirm what the most important elements of care are, for Australians with serious chronic illness and their families / carers, within the hospital setting. Furthermore, this work will then design measurement approaches that could be used in practice to ensure feedback about this care is available. Finally, understanding how people affected by serious chronic illness may like to contribute to service development opportunities is important so voices from this population are prioritised.

It is hoped the outcomes from this work will inform ways to measure care experience for people with serious chronic illness in the hospital setting. This will contribute to care evaluation to inform care practices, inform improvement priorities and inform education requirements. In addition, a tool outlining how this population would like to contribute to service design will be useful for quality managers and hospital administrators working to ensure effective partnership working with patients and their families / carers.

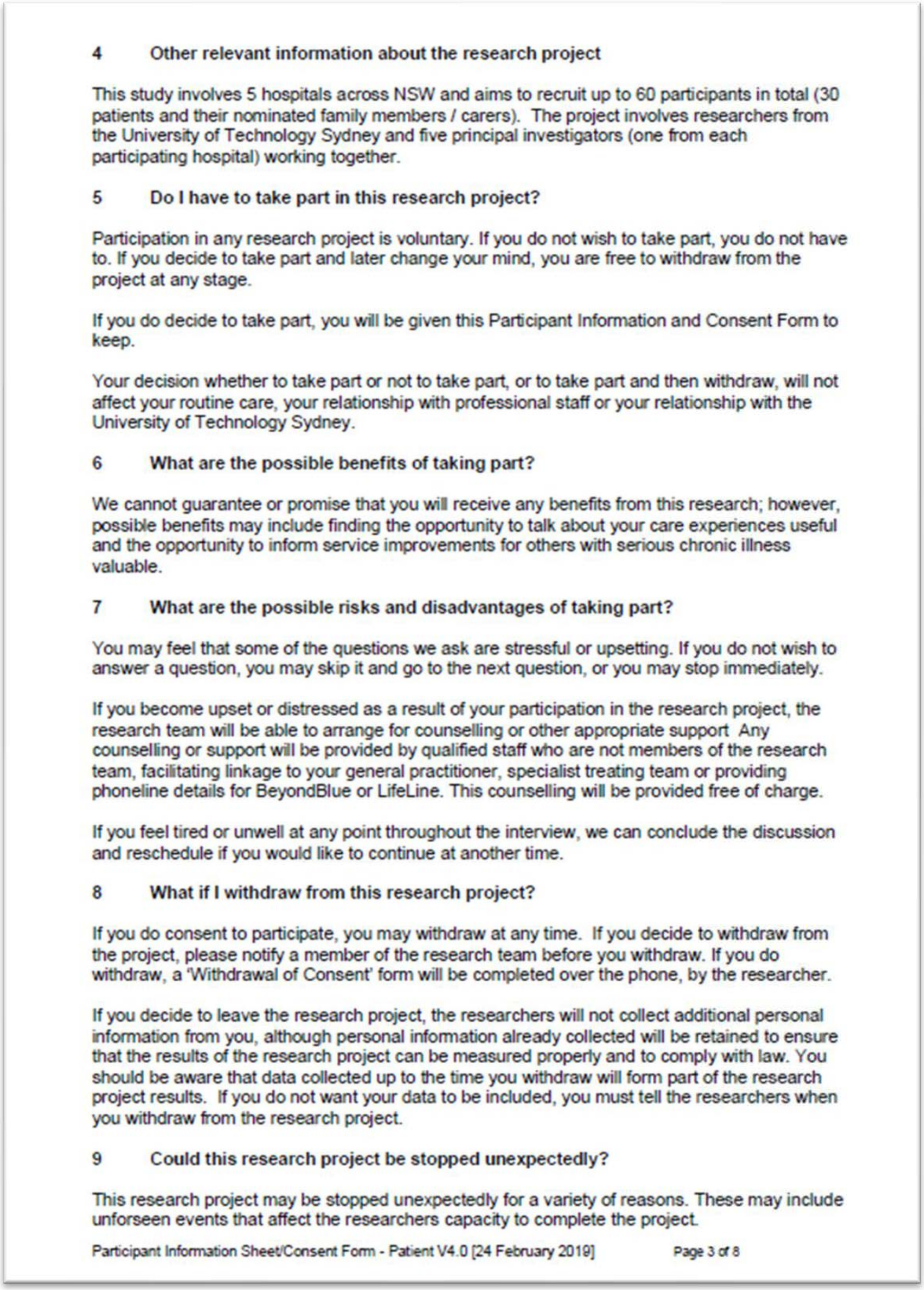
The results of this research will be used by the researcher, Claudia Virdun, to obtain a Doctor of Philosophy degree. This research is being conducted by the University of Technology Sydney and is supported by an Australian Government Research Training Program Scholarship.

3 What does participation in this research involve?

You will be provided with information about this research if one of your care providers (working as a recruiter in this study) believes you meet the eligibility criteria. These criteria note that you have a serious chronic illness, have had 1 or more hospitalisations over the past 12 months and that you are comfortable to talk about your care experiences. If you would like to contribute to this study, we ask that you provide approval for your care providers to give your contact details to the research team who will then make contact with you directly, to further discuss your possible participation. If you indicate you are interested in participating, then you will be contacted on 2 occasions – firstly so that the researcher can discuss the work in detail, answer any questions you may have and obtain your consent for participation; and secondly for the semi-structured interview itself. The interview will run for approximately 45 – 60 minutes, will be audio-recorded and will occur by telephone at a date and time that is mutually suitable for the researcher and participant.

There are no costs associated with participating in this research project.

This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way and avoids study participants jumping to conclusions.



4 Other relevant information about the research project

This study involves 5 hospitals across NSW and aims to recruit up to 60 participants in total (30 patients and their nominated family members / carers). The project involves researchers from the University of Technology Sydney and five principal investigators (one from each participating hospital) working together.

5 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you will be given this Participant Information and Consent Form to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine care, your relationship with professional staff or your relationship with the University of Technology Sydney.

6 What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, possible benefits may include finding the opportunity to talk about your care experiences useful and the opportunity to inform service improvements for others with serious chronic illness valuable.

7 What are the possible risks and disadvantages of taking part?

You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately.

If you become upset or distressed as a result of your participation in the research project, the research team will be able to arrange for counselling or other appropriate support Any counselling or support will be provided by qualified staff who are not members of the research team, facilitating linkage to your general practitioner, specialist treating team or providing phoneline details for BeyondBlue or LifeLine. This counselling will be provided free of charge.

If you feel tired or unwell at any point throughout the interview, we can conclude the discussion and reschedule if you would like to continue at another time.

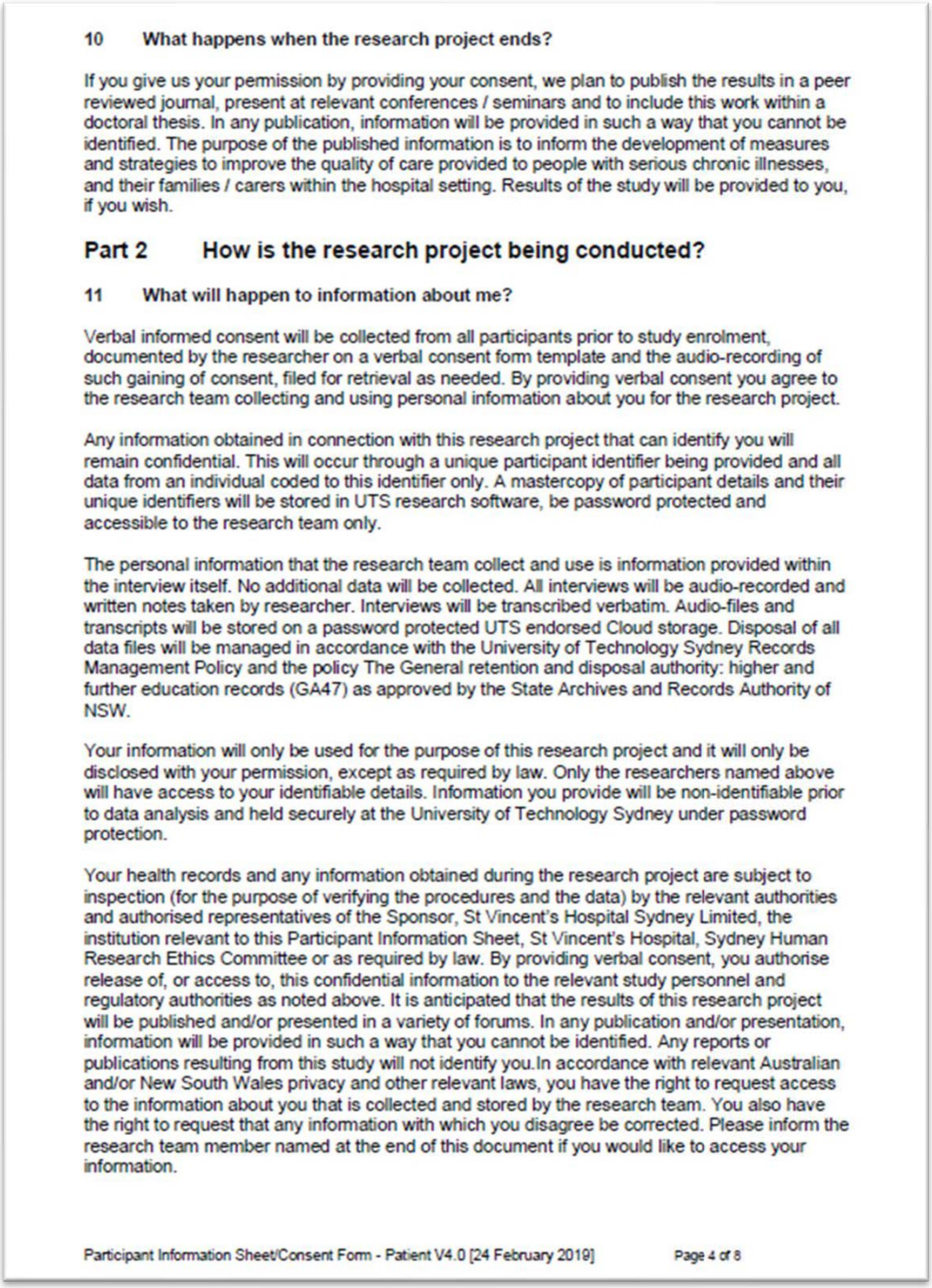
8 What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify a member of the research team before you withdraw. If you do withdraw, a 'Withdrawal of Consent' form will be completed over the phone, by the researcher.

If you decide to leave the research project, the researchers will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want your data to be included, you must tell the researchers when you withdraw from the research project.

9 Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly for a variety of reasons. These may include unforseen events that affect the researchers capacity to complete the project



10 What happens when the research project ends?

If you give us your permission by providing your consent, we plan to publish the results in a peer reviewed journal, present at relevant conferences / seminars and to include this work within a doctoral thesis. In any publication, information will be provided in such a way that you cannot be identified. The purpose of the published information is to inform the development of measures and strategies to improve the quality of care provided to people with serious chronic illnesses, and their families / carers within the hospital setting. Results of the study will be provided to you, if you wish.

Part 2 How is the research project being conducted?

11 What will happen to information about me?

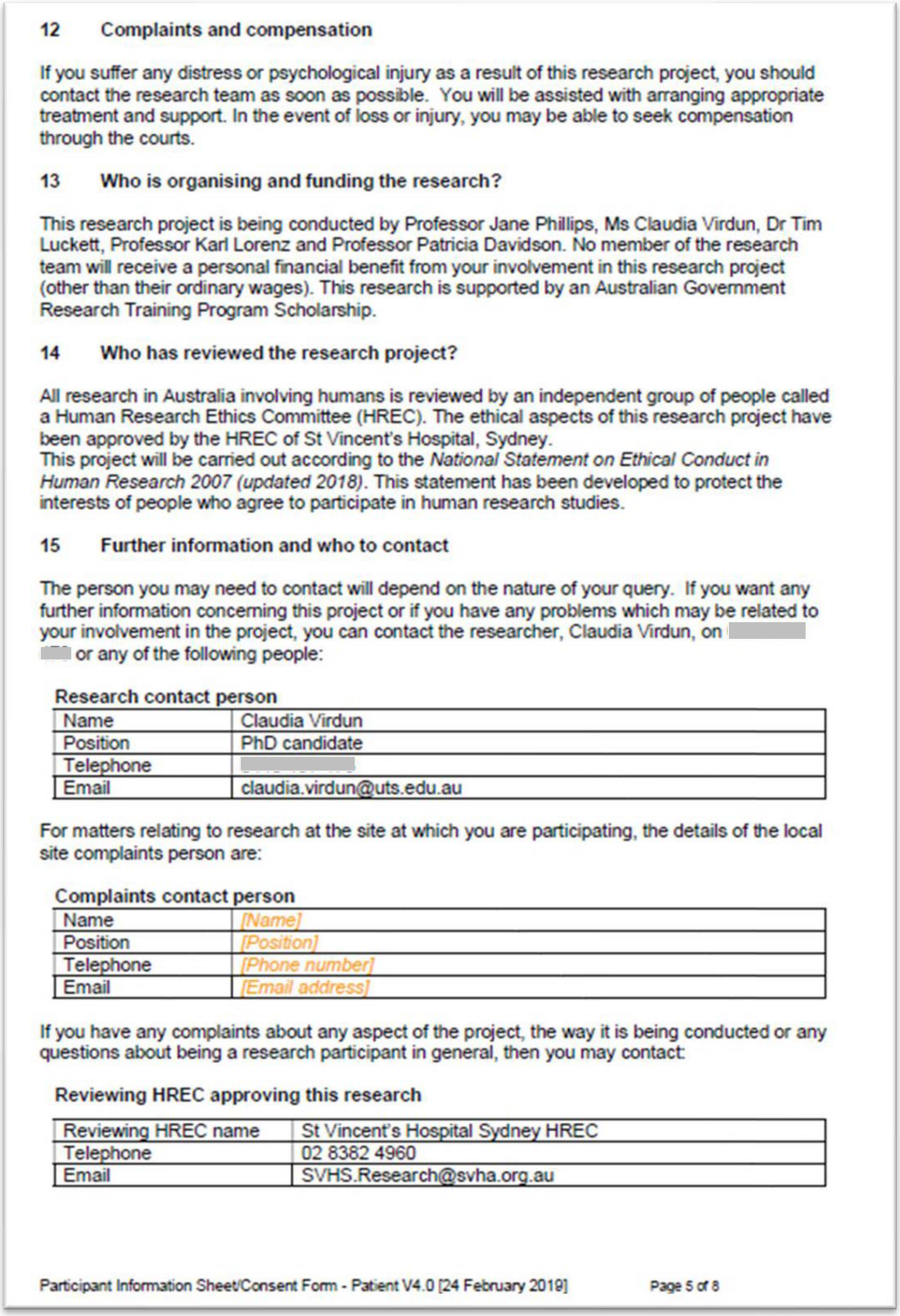
Verbal informed consent will be collected from all participants prior to study enrolment, documented by the researcher on a verbal consent form template and the audio-recording of such gaining of consent, filed for retrieval as needed. By providing verbal consent you agree to the research team collecting and using personal information about you for the research project.

Any information obtained in connection with this research project that can identify you will remain confidential. This will occur through a unique participant identifier being provided and all data from an individual coded to this identifier only. A mastercopy of participant details and their unique identifiers will be stored in UTS research software, be password protected and accessible to the research team only.

The personal information that the research team collect and use is information provided within the interview itself. No additional data will be collected. All interviews will be audio-recorded and written notes taken by researcher. Interviews will be transcribed verbatim. Audio-files and transcripts will be stored on a password protected UTS endorsed Cloud storage. Disposal of all data files will be managed in accordance with the University of Technology Sydney Records Management Policy and the policy The General retention and disposal authority: higher and further education records (GA47) as approved by the State Archives and Records Authority of NSW.

Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law. Only the researchers named above will have access to your identifiable details. Information you provide will be non-identifiable prior to data analysis and held securely at the University of Technology Sydney under password protection.

Your health records and any information obtained during the research project are subject to inspection (for the purpose of verifying the procedures and the data) by the relevant authorities and authorised representatives of the Sponsor, St Vincent's Hospital Sydney Limited, the institution relevant to this Participant Information Sheet, St Vincent's Hospital, Sydney Human Research Ethics Committee or as required by law. By providing verbal consent, you authorise release of, or access to, this confidential information to the relevant study personnel and regulatory authorities as noted above. It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified. Any reports or publications resulting from this study will not identify you.In accordance with relevant Australian and/or New South Wales privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.



12 Complaints and compensation

If you suffer any distress or psychological injury as a result of this research project, you should contact the research team as soon as possible. You will be assisted with arranging appropriate treatment and support. In the event of loss or injury, you may be able to seek compensation through the courts.

13 Who is organising and funding the research?

This research project is being conducted by Professor Jane Phillips, Ms Claudia Virdun, Dr Tim Luckett, Professor Karl Lorenz and Professor Patricia Davidson. No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages). This research is supported by an Australian Government Research Training Program Scholarship.

14 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of St Vincent's Hospital, Sydney.
This project will be carried out according to the *National Statement on Ethical Conduct in Human Research 2007 (updated 2018)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

15 Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact the researcher, Claudia Virdun, on [redacted] or any of the following people:

Research contact person

Name	Claudia Virdun
Position	PhD candidate
Telephone	[redacted]
Email	claudia.virdun@uts.edu.au

For matters relating to research at the site at which you are participating, the details of the local site complaints person are:

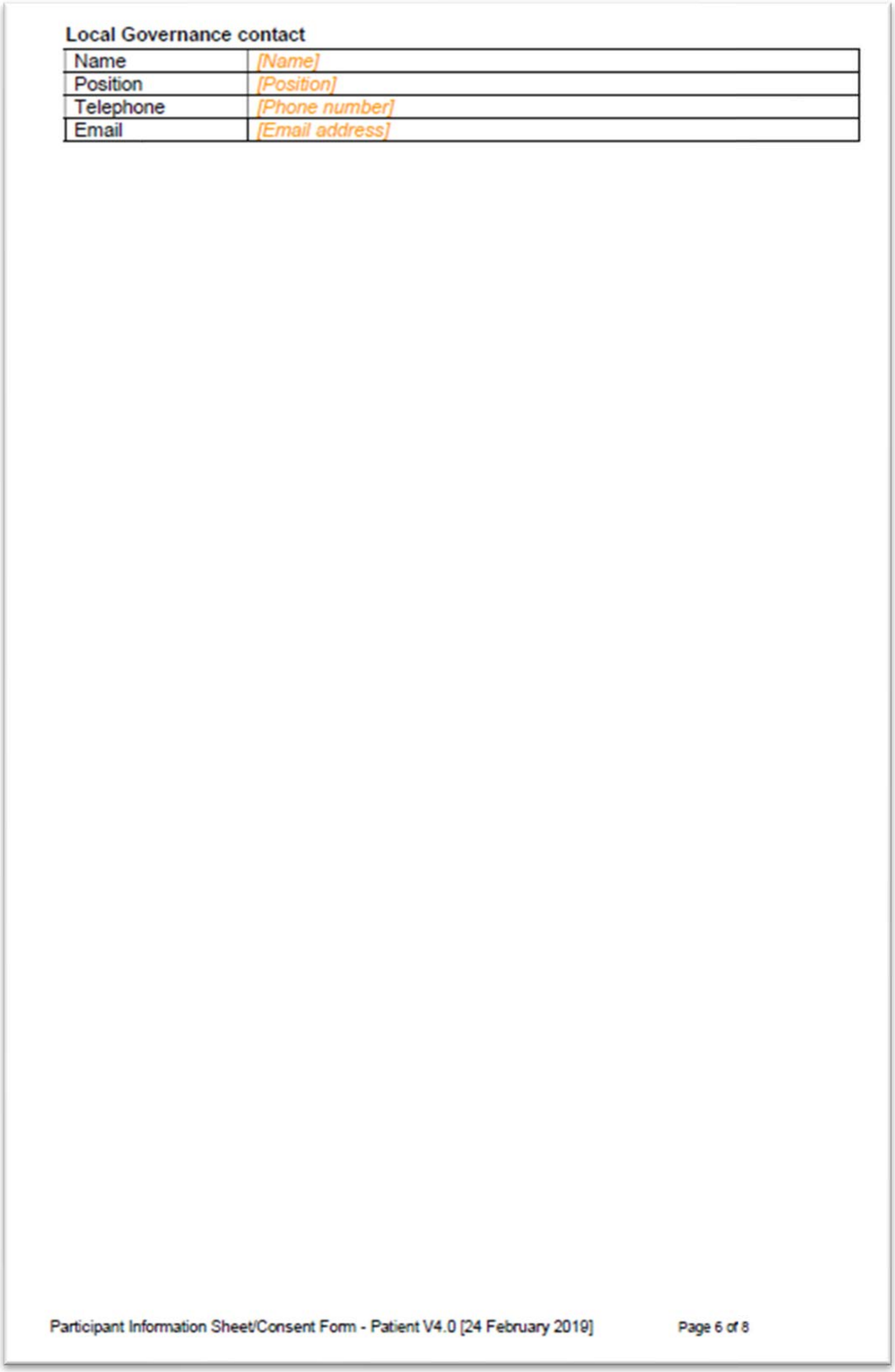
Complaints contact person

Name	*[Name]*
Position	*[Position]*
Telephone	*[Phone number]*
Email	*[Email address]*

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

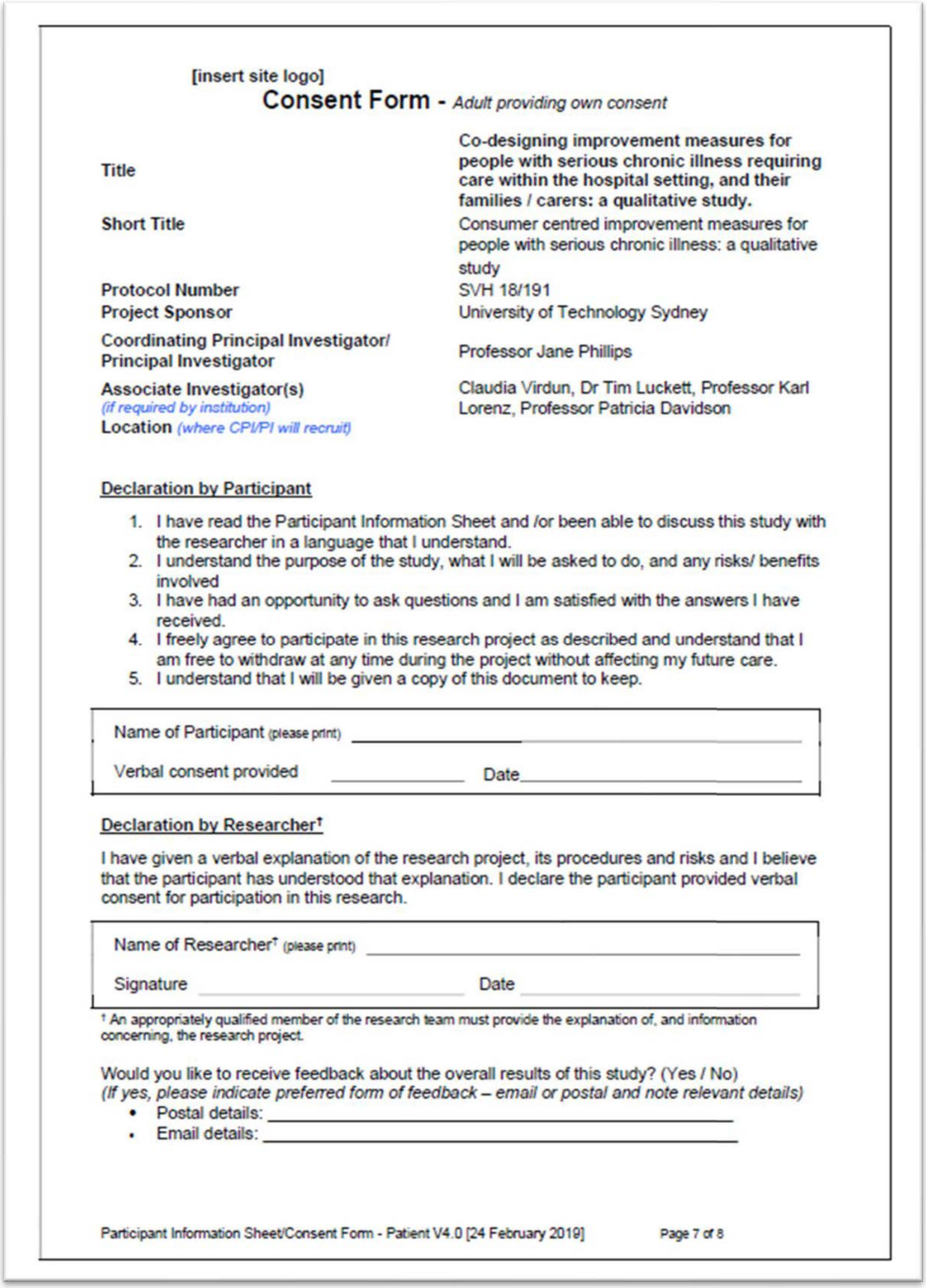
Reviewing HREC approving this research

Reviewing HREC name	St Vincent's Hospital Sydney HREC
Telephone	02 8382 4960
Email	SVHS.Research@svha.org.au



Local Governance contact

Name	*[Name]*
Position	*[Position]*
Telephone	*[Phone number]*
Email	*[Email address]*



[insert site logo]

Consent Form - *Adult providing own consent*

Title	**Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families / carers: a qualitative study.**
Short Title	Consumer centred improvement measures for people with serious chronic illness: a qualitative study
Protocol Number	SVH 18/191
Project Sponsor	University of Technology Sydney
Coordinating Principal Investigator/ Principal Investigator	Professor Jane Phillips
Associate Investigator(s) *(if required by institution)*	Claudia Virdun, Dr Tim Luckett, Professor Karl Lorenz, Professor Patricia Davidson
Location *(where CPI/PI will recruit)*	

Declaration by Participant

1. I have read the Participant Information Sheet and /or been able to discuss this study with the researcher in a language that I understand.
2. I understand the purpose of the study, what I will be asked to do, and any risks/ benefits involved
3. I have had an opportunity to ask questions and I am satisfied with the answers I have received.
4. I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future care.
5. I understand that I will be given a copy of this document to keep.

Name of Participant (please print) ______________________

Verbal consent provided ____________ Date______________________

Declaration by Researcher†

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation. I declare the participant provided verbal consent for participation in this research.

Name of Researcher† (please print) ______________________

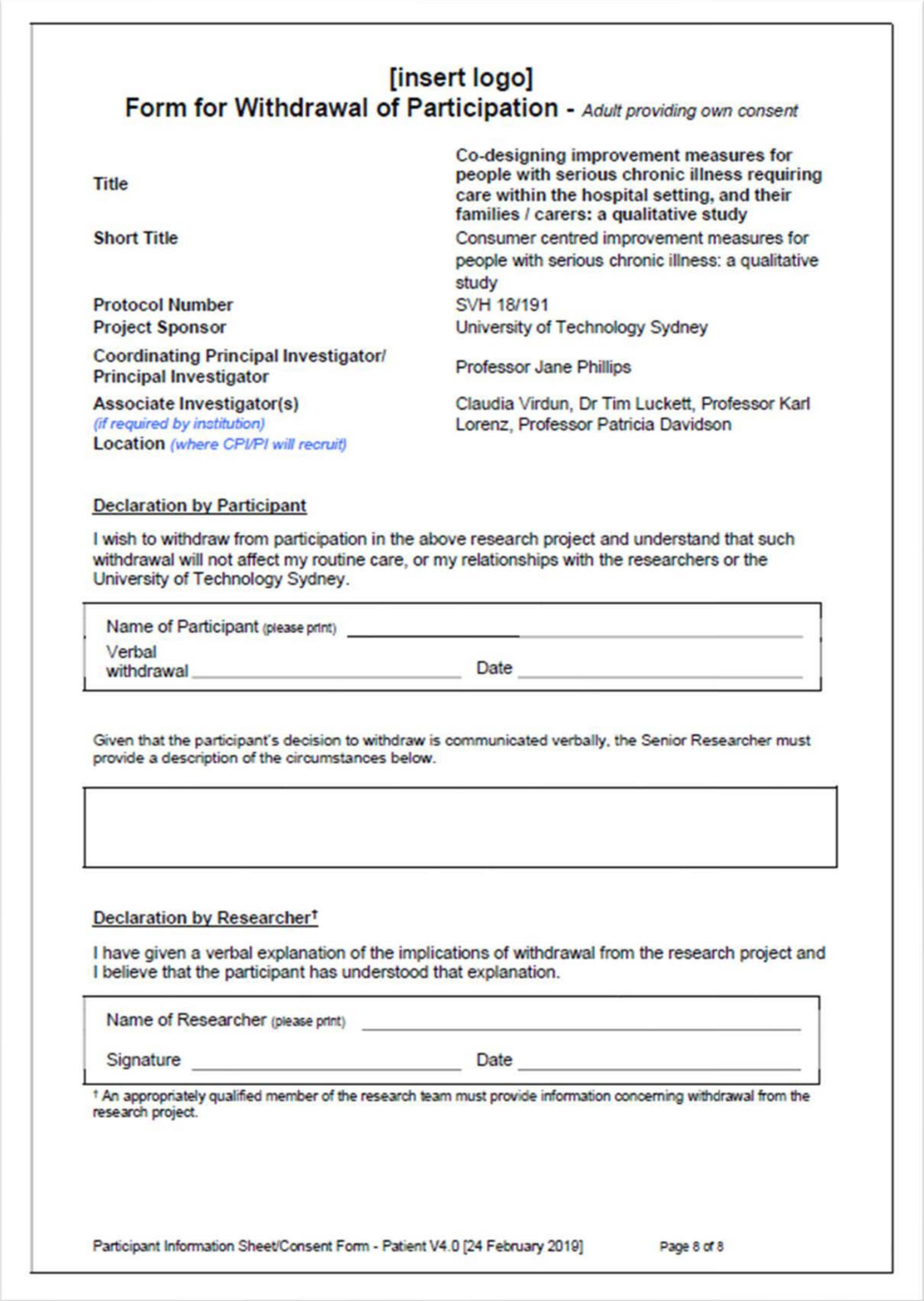
Signature ____________________ Date ____________________

† An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Would you like to receive feedback about the overall results of this study? (Yes / No)
(If yes, please indicate preferred form of feedback – email or postal and note relevant details)

- Postal details: ______________________
- Email details: ______________________

Participant Information Sheet/Consent Form - Patient V4.0 [24 February 2019] Page 7 of 8



[insert logo]

Form for Withdrawal of Participation - *Adult providing own consent*

Title	**Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families / carers: a qualitative study**
Short Title	Consumer centred improvement measures for people with serious chronic illness: a qualitative study
Protocol Number	SVH 18/191
Project Sponsor	University of Technology Sydney
Coordinating Principal Investigator/ Principal Investigator	Professor Jane Phillips
Associate Investigator(s) *(if required by institution)*	Claudia Virdun, Dr Tim Luckett, Professor Karl Lorenz, Professor Patricia Davidson
Location *(where CPI/PI will recruit)*	

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine care, or my relationships with the researchers or the University of Technology Sydney.

Name of Participant (please print) ______________________________

Verbal withdrawal ______________________ Date ______________________

Given that the participant's decision to withdraw is communicated verbally, the Senior Researcher must provide a description of the circumstances below.

Declaration by Researcher[†]

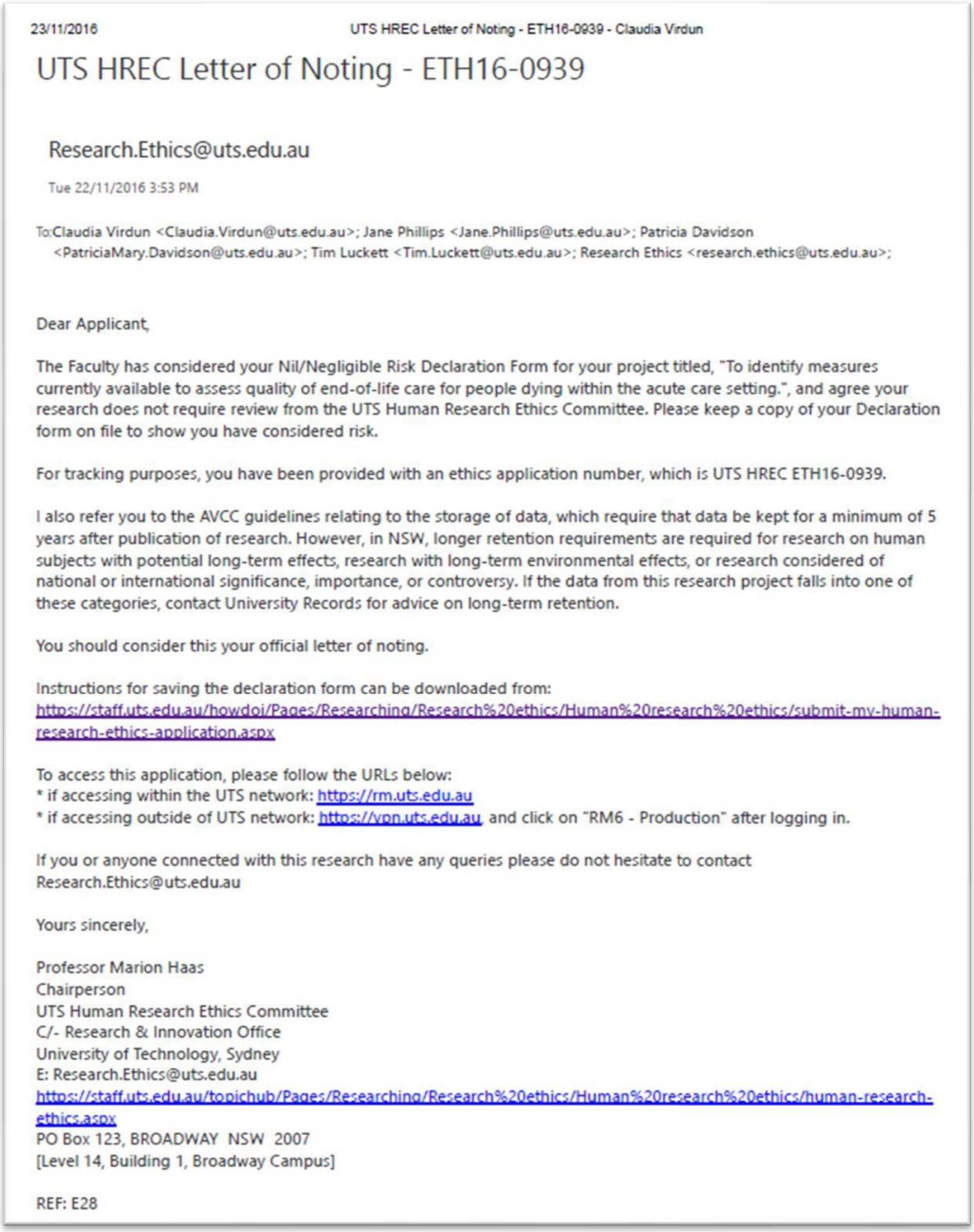
I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Researcher (please print) ______________________________

Signature ______________________ Date ______________________

[†] An appropriately qualified member of the research team must provide information concerning withdrawal from the research project.

Appendix 8: Study 3: Negligible risk ethics approval, November 2016



23/11/2016 UTS HREC Letter of Noting - ETH16-0939 - Claudia Virdun

UTS HREC Letter of Noting - ETH16-0939

Research.Ethics@uts.edu.au

Tue 22/11/2016 3:53 PM

To:Claudia Virdun <Claudia.Virdun@uts.edu.au>; Jane Phillips <Jane.Phillips@uts.edu.au>; Patricia Davidson <PatriciaMary.Davidson@uts.edu.au>; Tim Luckett <Tim.Luckett@uts.edu.au>; Research Ethics <research.ethics@uts.edu.au>;

Dear Applicant,

The Faculty has considered your Nil/Negligible Risk Declaration Form for your project titled, "To identify measures currently available to assess quality of end-of-life care for people dying within the acute care setting.", and agree your research does not require review from the UTS Human Research Ethics Committee. Please keep a copy of your Declaration form on file to show you have considered risk.

For tracking purposes, you have been provided with an ethics application number, which is UTS HREC ETH16-0939.

I also refer you to the AVCC guidelines relating to the storage of data, which require that data be kept for a minimum of 5 years after publication of research. However, in NSW, longer retention requirements are required for research on human subjects with potential long-term effects, research with long-term environmental effects, or research considered of national or international significance, importance, or controversy. If the data from this research project falls into one of these categories, contact University Records for advice on long-term retention.

You should consider this your official letter of noting.

Instructions for saving the declaration form can be downloaded from:
https://staff.uts.edu.au/howdoi/Pages/Researching/Research%20ethics/Human%20research%20ethics/submit-my-human-research-ethics-application.aspx

To access this application, please follow the URLs below:
* if accessing within the UTS network: https://rm.uts.edu.au
* if accessing outside of UTS network: https://vpn.uts.edu.au, and click on "RM6 - Production" after logging in.

If you or anyone connected with this research have any queries please do not hesitate to contact Research.Ethics@uts.edu.au

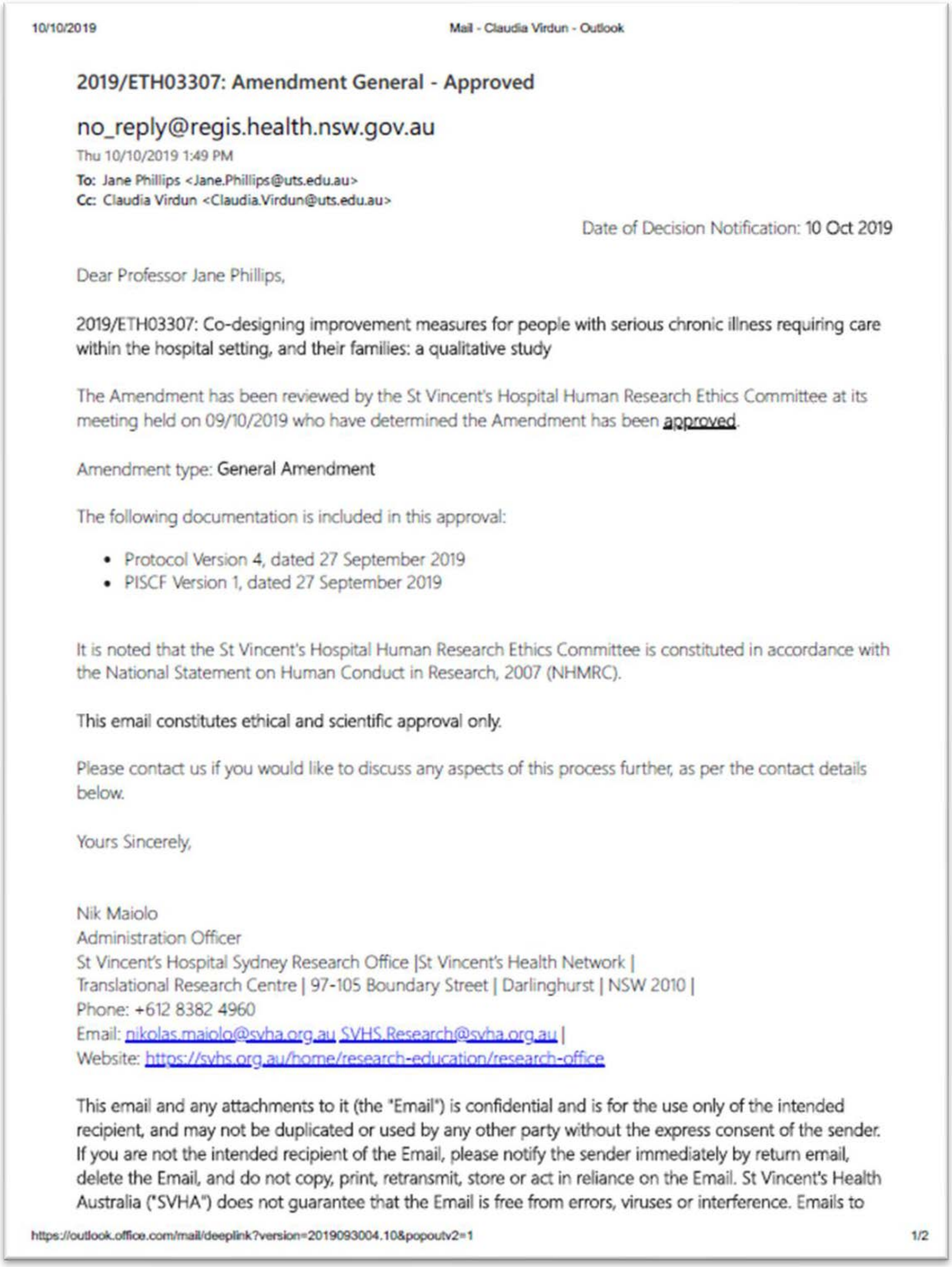
Yours sincerely,

Professor Marion Haas
Chairperson
UTS Human Research Ethics Committee
C/- Research & Innovation Office
University of Technology, Sydney
E: Research.Ethics@uts.edu.au
https://staff.uts.edu.au/topichub/Pages/Researching/Research%20ethics/Human%20research%20ethics/human-research-ethics.aspx
PO Box 123, BROADWAY NSW 2007
[Level 14, Building 1, Broadway Campus]

REF: E28

Appendix 9: Ethics approval for Study 4 – HREC amendment, UTS ratification and Participant information sheet and consent form

This was submitted as an amendment to the original approval for Study 2, October 2019



10/10/2019 Mail - Claudia Virdun - Outlook

2019/ETH03307: Amendment General - Approved

no_reply@regis.health.nsw.gov.au
Thu 10/10/2019 1:49 PM
To: Jane Phillips <Jane.Phillips@uts.edu.au>
Cc: Claudia Virdun <Claudia.Virdun@uts.edu.au>

Date of Decision Notification: 10 Oct 2019

Dear Professor Jane Phillips,

2019/ETH03307: Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families: a qualitative study

The Amendment has been reviewed by the St Vincent's Hospital Human Research Ethics Committee at its meeting held on 09/10/2019 who have determined the Amendment has been approved.

Amendment type: General Amendment

The following documentation is included in this approval:

- Protocol Version 4, dated 27 September 2019
- PISCF Version 1, dated 27 September 2019

It is noted that the St Vincent's Hospital Human Research Ethics Committee is constituted in accordance with the National Statement on Human Conduct in Research, 2007 (NHMRC).

This email constitutes ethical and scientific approval only.

Please contact us if you would like to discuss any aspects of this process further, as per the contact details below.

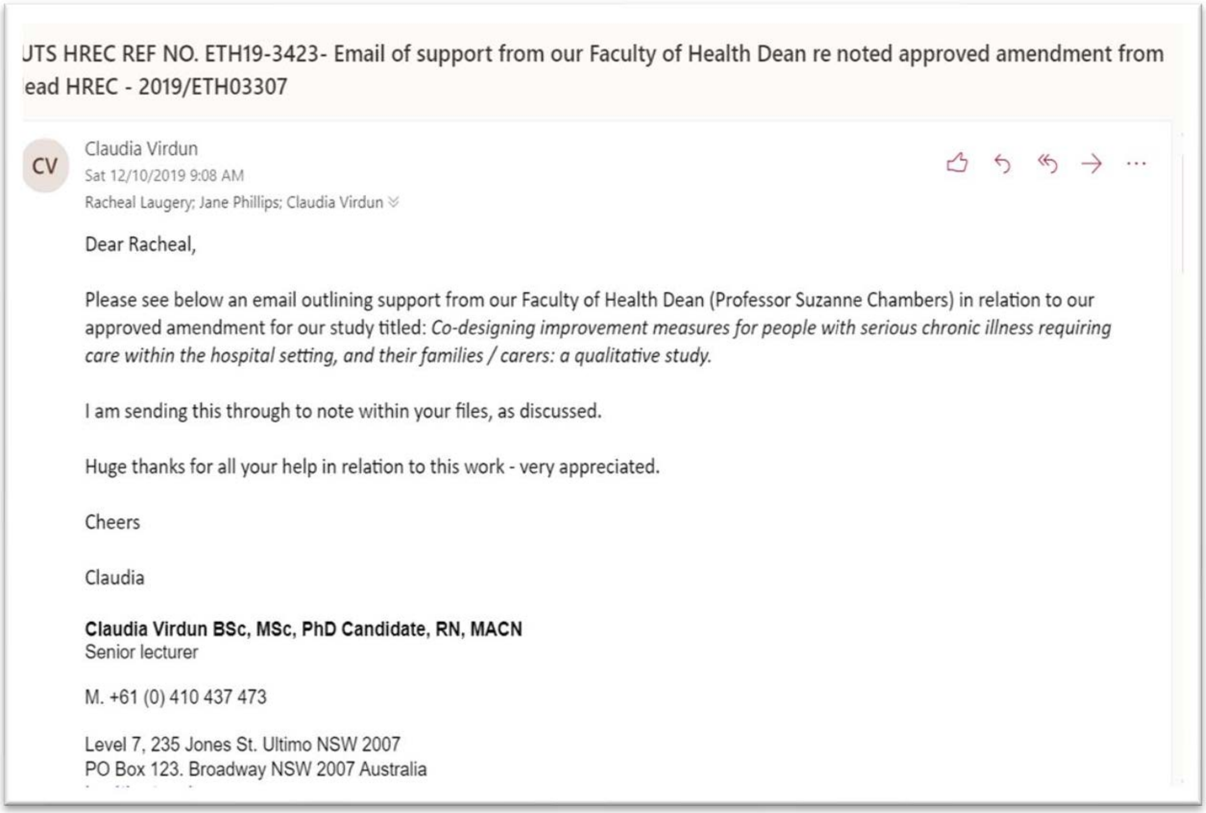
Yours Sincerely,

Nik Maiolo
Administration Officer
St Vincent's Hospital Sydney Research Office |St Vincent's Health Network |
Translational Research Centre | 97-105 Boundary Street | Darlinghurst | NSW 2010 |
Phone: +612 8382 4960
Email: nikolas.maiolo@svha.org.au SVHS.Research@svha.org.au |
Website: https://svhs.org.au/home/research-education/research-office

This email and any attachments to it (the "Email") is confidential and is for the use only of the intended recipient, and may not be duplicated or used by any other party without the express consent of the sender. If you are not the intended recipient of the Email, please notify the sender immediately by return email, delete the Email, and do not copy, print, retransmit, store or act in reliance on the Email. St Vincent's Health Australia ("SVHA") does not guarantee that the Email is free from errors, viruses or interference. Emails to

https://outlook.office.com/mail/deeplink?version=2019093004.10&popoutv2=1 1/2

UTS noting of amendment and approval to locate workshops onsite at UTS, Oct 2019



JTS HREC REF NO. ETH19-3423- Email of support from our Faculty of Health Dean re noted approved amendment from ead HREC - 2019/ETH03307

Claudia Virdun
Sat 12/10/2019 9:08 AM
Racheal Laugery; Jane Phillips; Claudia Virdun

Dear Racheal,

Please see below an email outlining support from our Faculty of Health Dean (Professor Suzanne Chambers) in relation to our approved amendment for our study titled: *Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families / carers: a qualitative study.*

I am sending this through to note within your files, as discussed.

Huge thanks for all your help in relation to this work - very appreciated.

Cheers

Claudia

Claudia Virdun BSc, MSc, PhD Candidate, RN, MACN
Senior lecturer

M. +61 (0) 410 437 473

Level 7, 235 Jones St. Ultimo NSW 2007
PO Box 123. Broadway NSW 2007 Australia

TS HREC REF NO. ETH19-3423- Email of support from our Faculty of Health Dean re noted approved amendment from
ead HREC - 2019/ETH03307

From: Suzanne Chambers <Suzanne.Chambers@uts.edu.au>
Sent: Friday, 11 October 2019 8:16 PM
To: Jane Phillips <Jane.Phillips@uts.edu.au>
Cc: Catherine Lambert <Catherine.Lambert@uts.edu.au>; Claudia Virdun <Claudia.Virdun@uts.edu.au>
Subject: Re: Seeking you acknowledgement of a study amendment involving UTS FOH Staff - as study (requested by UTS research office)

Jane this is important and thoughtful work and I am happy to approve.

Best wishes

Suzanne

Get Outlook for iOS

UTS HREC REF NO. ETH19-3423- Email of support from our Faculty of Health Dean re noted approved amendment from
lead HREC - 2019/ETH03307

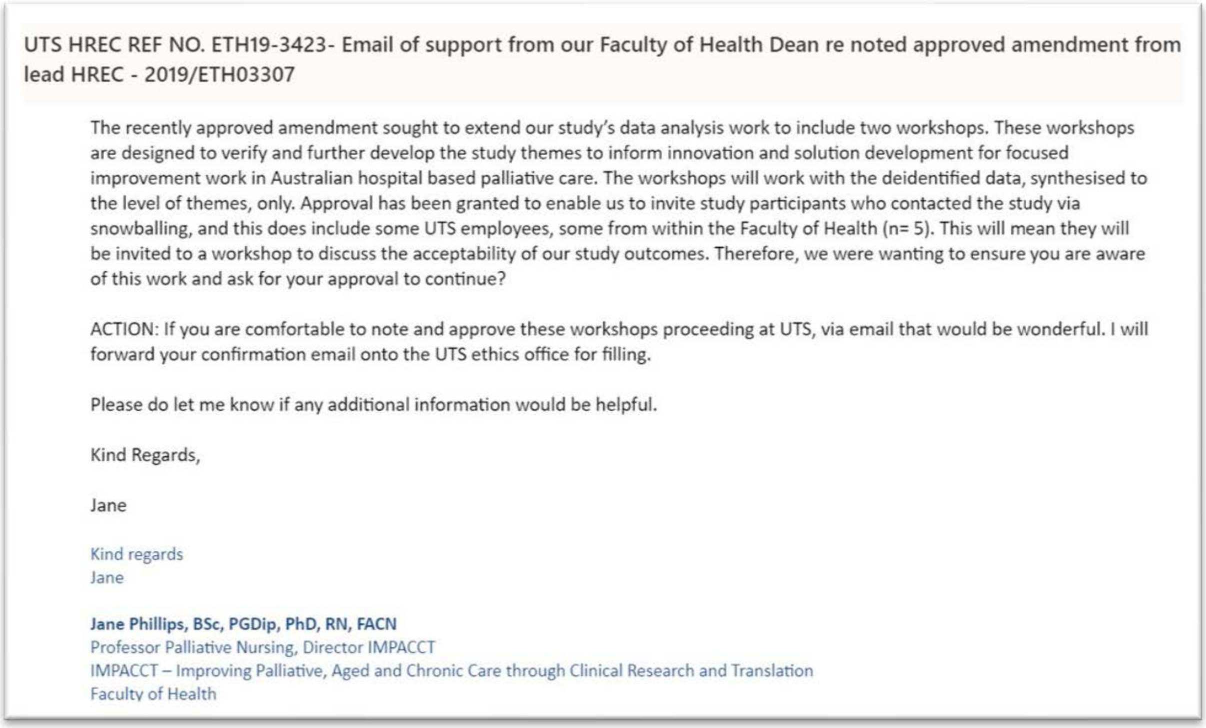
Get Outlook for iOS

From: Jane Phillips <Jane.Phillips@uts.edu.au>
Sent: Friday, October 11, 2019 8:38:33 AM
To: Suzanne Chambers <Suzanne.Chambers@uts.edu.au>
Cc: Catherine Lambert <Catherine.Lambert@uts.edu.au>; Claudia Virdun <Claudia.Virdun@uts.edu.au>
Subject: Seeking you acknowledgement of a study amendment involving UTS FOH Staff - as study (requested by UTS research office)

Dear Suzanne,

REQUEST: I am writing to you at the request of UTS Ethics about the study titled: 'Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families / carers: a qualitative study'. We have secured UTS ratification/noting for the ethics approval for a series of workshops with palliative care consumers (including five FOH UTS employees). UTS Ethics has asked we inform you about amendment and seek your email approval (to be held by UTS Ethics) before these workshops can proceed.

CONTEXT: One of my doctoral students Claudia Virdun (a UTS FOH employee – currently on leave) is leading this study. Ethics approval: 2019/ETH03307;
Sites involved (all with RGO approval) - St Vincent's Hospital, St George Hospital, Westmead Hospital, Blacktown Hospital, Broken Hill hospital and the University of Technology Sydney;
Design: Exploratory study using qualitative methods based on semi-structured interviews. This study has progressed well with 50 participants having participated thus far and data analysis is now underway.



UTS HREC REF NO. ETH19-3423- Email of support from our Faculty of Health Dean re noted approved amendment from lead HREC - 2019/ETH03307

The recently approved amendment sought to extend our study's data analysis work to include two workshops. These workshops are designed to verify and further develop the study themes to inform innovation and solution development for focused improvement work in Australian hospital based palliative care. The workshops will work with the deidentified data, synthesised to the level of themes, only. Approval has been granted to enable us to invite study participants who contacted the study via snowballing, and this does include some UTS employees, some from within the Faculty of Health (n= 5). This will mean they will be invited to a workshop to discuss the acceptability of our study outcomes. Therefore, we were wanting to ensure you are aware of this work and ask for your approval to continue?

ACTION: If you are comfortable to note and approve these workshops proceeding at UTS, via email that would be wonderful. I will forward your confirmation email onto the UTS ethics office for filling.

Please do let me know if any additional information would be helpful.

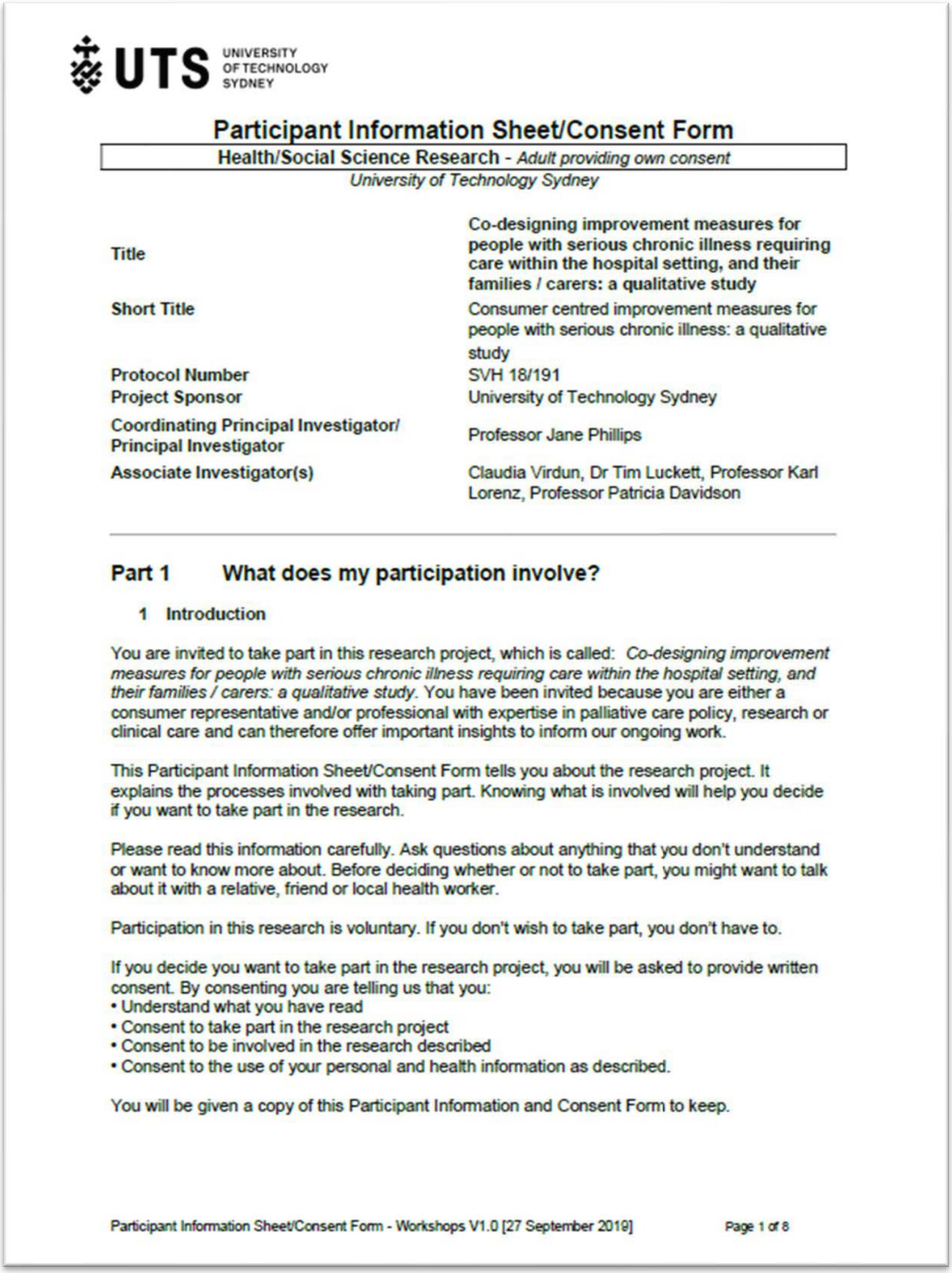
Kind Regards,

Jane

Kind regards
Jane

Jane Phillips, BSc, PGDip, PhD, RN, FACN
Professor Palliative Nursing, Director IMPACCT
IMPACCT – Improving Palliative, Aged and Chronic Care through Clinical Research and Translation
Faculty of Health

Participant Information Sheet and Consent Form_Co-design workshop



UTS UNIVERSITY OF TECHNOLOGY SYDNEY

Participant Information Sheet/Consent Form

Health/Social Science Research - *Adult providing own consent*

University of Technology Sydney

Title	**Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families / carers: a qualitative study**
Short Title	Consumer centred improvement measures for people with serious chronic illness: a qualitative study
Protocol Number	SVH 18/191
Project Sponsor	University of Technology Sydney
Coordinating Principal Investigator/ Principal Investigator	Professor Jane Phillips
Associate Investigator(s)	Claudia Virdun, Dr Tim Luckett, Professor Karl Lorenz, Professor Patricia Davidson

---

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project, which is called: *Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families / carers: a qualitative study*. You have been invited because you are either a consumer representative and/or professional with expertise in palliative care policy, research or clinical care and can therefore offer important insights to inform our ongoing work.

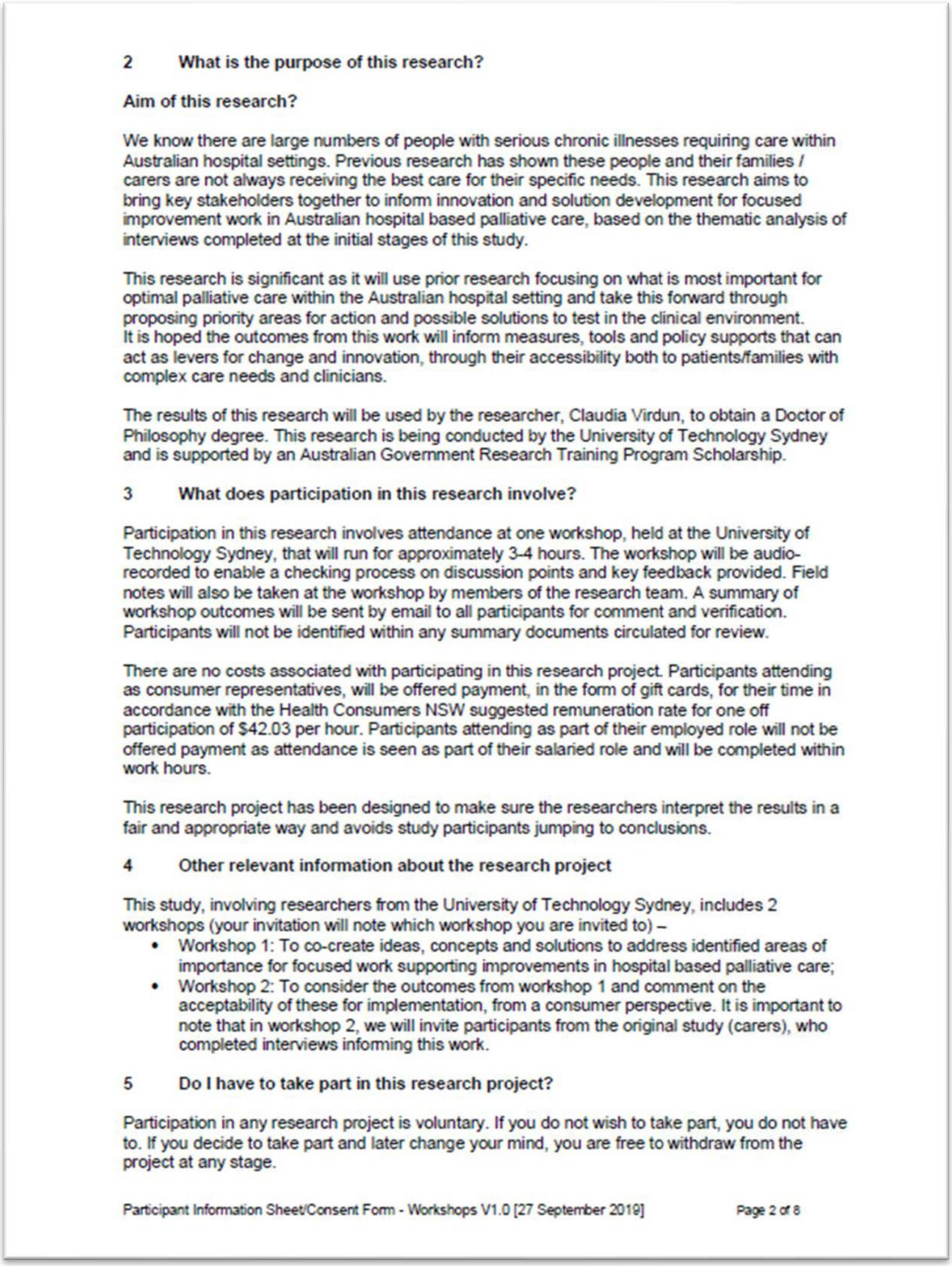
This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to provide written consent. By consenting you are telling us that you:
- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.



2 What is the purpose of this research?

Aim of this research?

We know there are large numbers of people with serious chronic illnesses requiring care within Australian hospital settings. Previous research has shown these people and their families / carers are not always receiving the best care for their specific needs. This research aims to bring key stakeholders together to inform innovation and solution development for focused improvement work in Australian hospital based palliative care, based on the thematic analysis of interviews completed at the initial stages of this study.

This research is significant as it will use prior research focusing on what is most important for optimal palliative care within the Australian hospital setting and take this forward through proposing priority areas for action and possible solutions to test in the clinical environment.
It is hoped the outcomes from this work will inform measures, tools and policy supports that can act as levers for change and innovation, through their accessibility both to patients/families with complex care needs and clinicians.

The results of this research will be used by the researcher, Claudia Virdun, to obtain a Doctor of Philosophy degree. This research is being conducted by the University of Technology Sydney and is supported by an Australian Government Research Training Program Scholarship.

3 What does participation in this research involve?

Participation in this research involves attendance at one workshop, held at the University of Technology Sydney, that will run for approximately 3-4 hours. The workshop will be audio-recorded to enable a checking process on discussion points and key feedback provided. Field notes will also be taken at the workshop by members of the research team. A summary of workshop outcomes will be sent by email to all participants for comment and verification. Participants will not be identified within any summary documents circulated for review.

There are no costs associated with participating in this research project. Participants attending as consumer representatives, will be offered payment, in the form of gift cards, for their time in accordance with the Health Consumers NSW suggested remuneration rate for one off participation of $42.03 per hour. Participants attending as part of their employed role will not be offered payment as attendance is seen as part of their salaried role and will be completed within work hours.

This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way and avoids study participants jumping to conclusions.

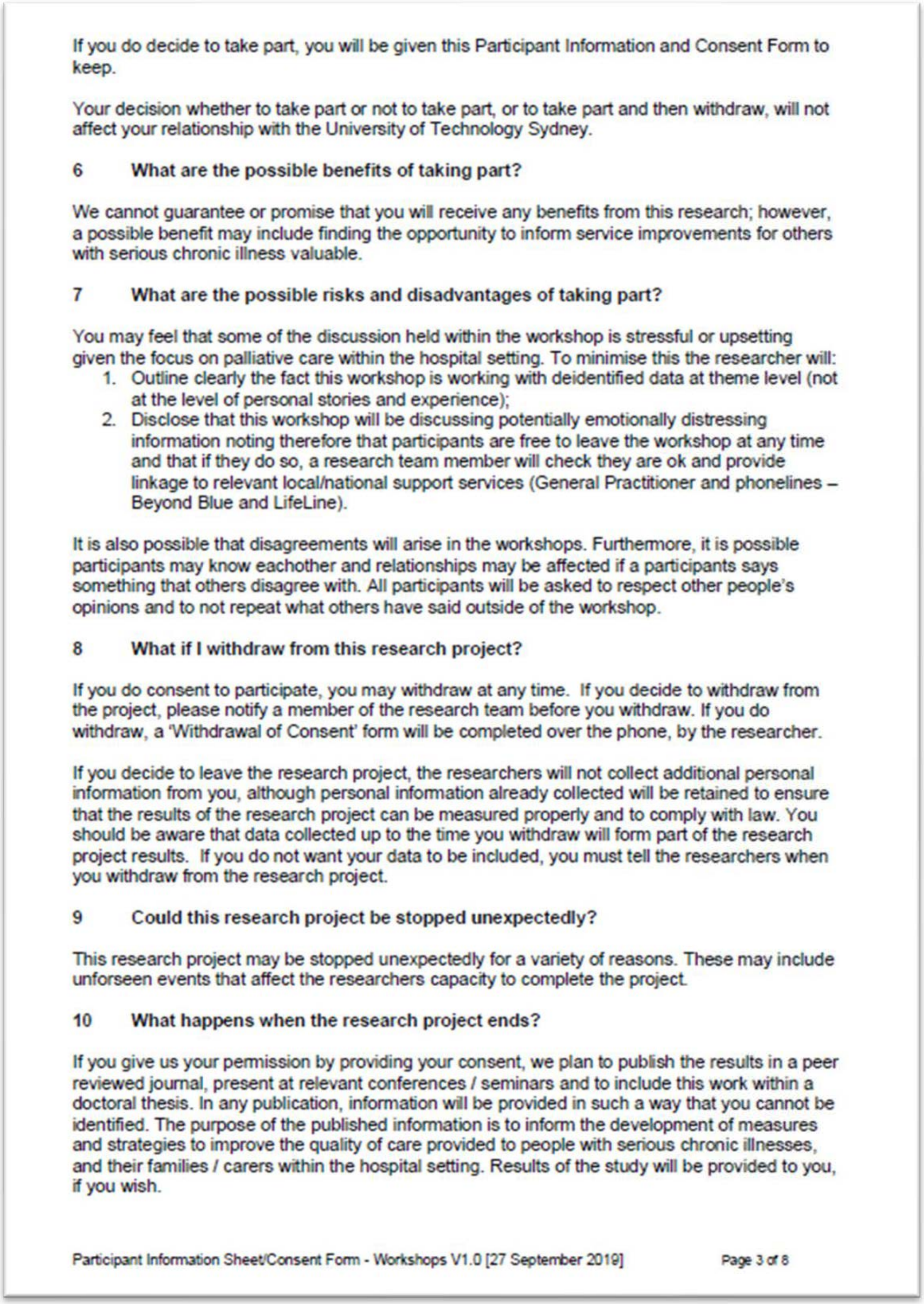
4 Other relevant information about the research project

This study, involving researchers from the University of Technology Sydney, includes 2 workshops (your invitation will note which workshop you are invited to) –

- Workshop 1: To co-create ideas, concepts and solutions to address identified areas of importance for focused work supporting improvements in hospital based palliative care;
- Workshop 2: To consider the outcomes from workshop 1 and comment on the acceptability of these for implementation, from a consumer perspective. It is important to note that in workshop 2, we will invite participants from the original study (carers), who completed interviews informing this work.

5 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.



If you do decide to take part, you will be given this Participant Information and Consent Form to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your relationship with the University of Technology Sydney.

6 What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, a possible benefit may include finding the opportunity to inform service improvements for others with serious chronic illness valuable.

7 What are the possible risks and disadvantages of taking part?

You may feel that some of the discussion held within the workshop is stressful or upsetting given the focus on palliative care within the hospital setting. To minimise this the researcher will:

1. Outline clearly the fact this workshop is working with deidentified data at theme level (not at the level of personal stories and experience);
2. Disclose that this workshop will be discussing potentially emotionally distressing information noting therefore that participants are free to leave the workshop at any time and that if they do so, a research team member will check they are ok and provide linkage to relevant local/national support services (General Practitioner and phonelines – Beyond Blue and LifeLine).

It is also possible that disagreements will arise in the workshops. Furthermore, it is possible participants may know eachother and relationships may be affected if a participants says something that others disagree with. All participants will be asked to respect other people's opinions and to not repeat what others have said outside of the workshop.

8 What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify a member of the research team before you withdraw. If you do withdraw, a 'Withdrawal of Consent' form will be completed over the phone, by the researcher.

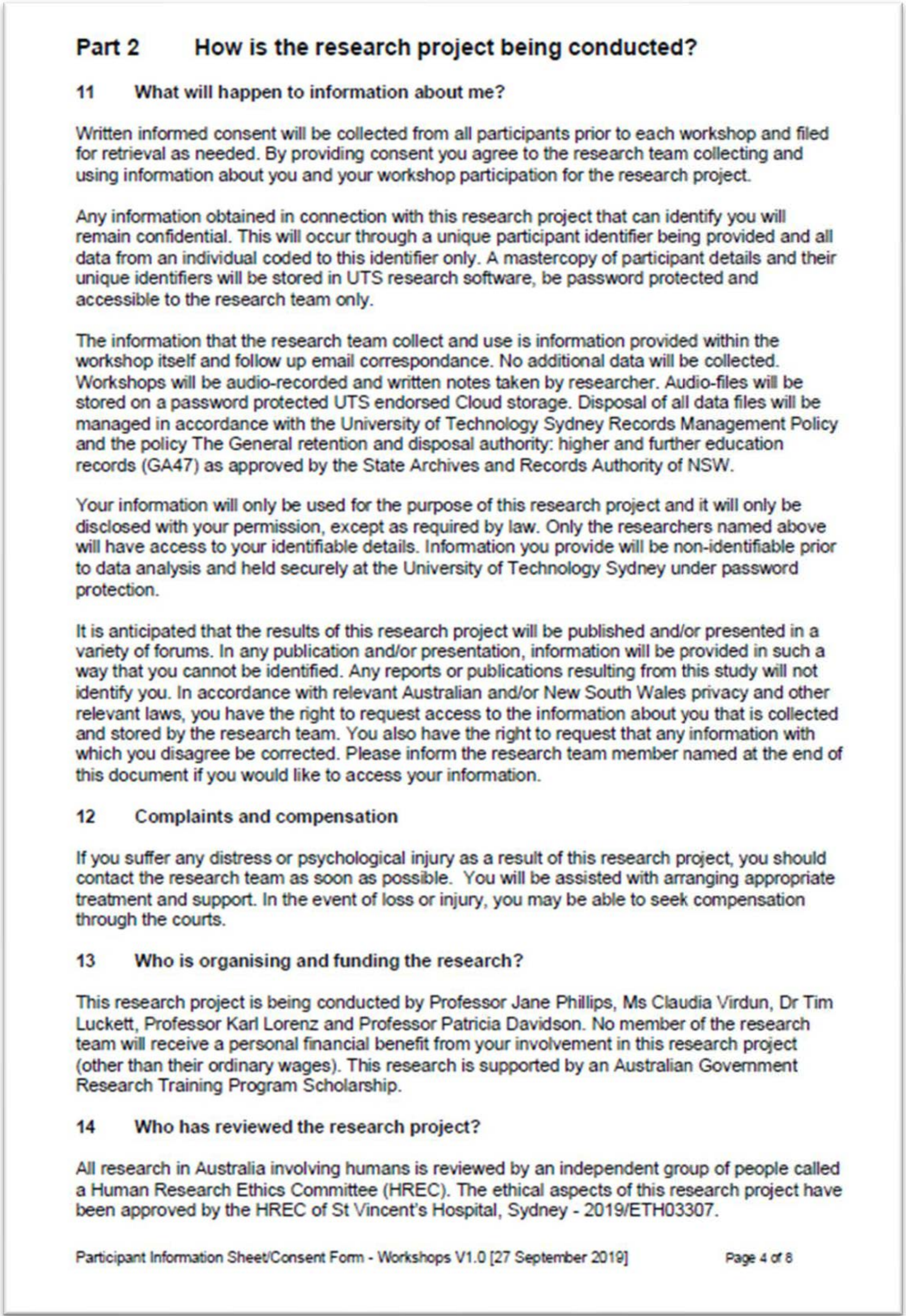
If you decide to leave the research project, the researchers will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want your data to be included, you must tell the researchers when you withdraw from the research project.

9 Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly for a variety of reasons. These may include unforseen events that affect the researchers capacity to complete the project.

10 What happens when the research project ends?

If you give us your permission by providing your consent, we plan to publish the results in a peer reviewed journal, present at relevant conferences / seminars and to include this work within a doctoral thesis. In any publication, information will be provided in such a way that you cannot be identified. The purpose of the published information is to inform the development of measures and strategies to improve the quality of care provided to people with serious chronic illnesses, and their families / carers within the hospital setting. Results of the study will be provided to you, if you wish.



Part 2 How is the research project being conducted?

11 What will happen to information about me?

Written informed consent will be collected from all participants prior to each workshop and filed for retrieval as needed. By providing consent you agree to the research team collecting and using information about you and your workshop participation for the research project.

Any information obtained in connection with this research project that can identify you will remain confidential. This will occur through a unique participant identifier being provided and all data from an individual coded to this identifier only. A mastercopy of participant details and their unique identifiers will be stored in UTS research software, be password protected and accessible to the research team only.

The information that the research team collect and use is information provided within the workshop itself and follow up email correspondance. No additional data will be collected. Workshops will be audio-recorded and written notes taken by researcher. Audio-files will be stored on a password protected UTS endorsed Cloud storage. Disposal of all data files will be managed in accordance with the University of Technology Sydney Records Management Policy and the policy The General retention and disposal authority: higher and further education records (GA47) as approved by the State Archives and Records Authority of NSW.

Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law. Only the researchers named above will have access to your identifiable details. Information you provide will be non-identifiable prior to data analysis and held securely at the University of Technology Sydney under password protection.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified. Any reports or publications resulting from this study will not identify you. In accordance with relevant Australian and/or New South Wales privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

12 Complaints and compensation

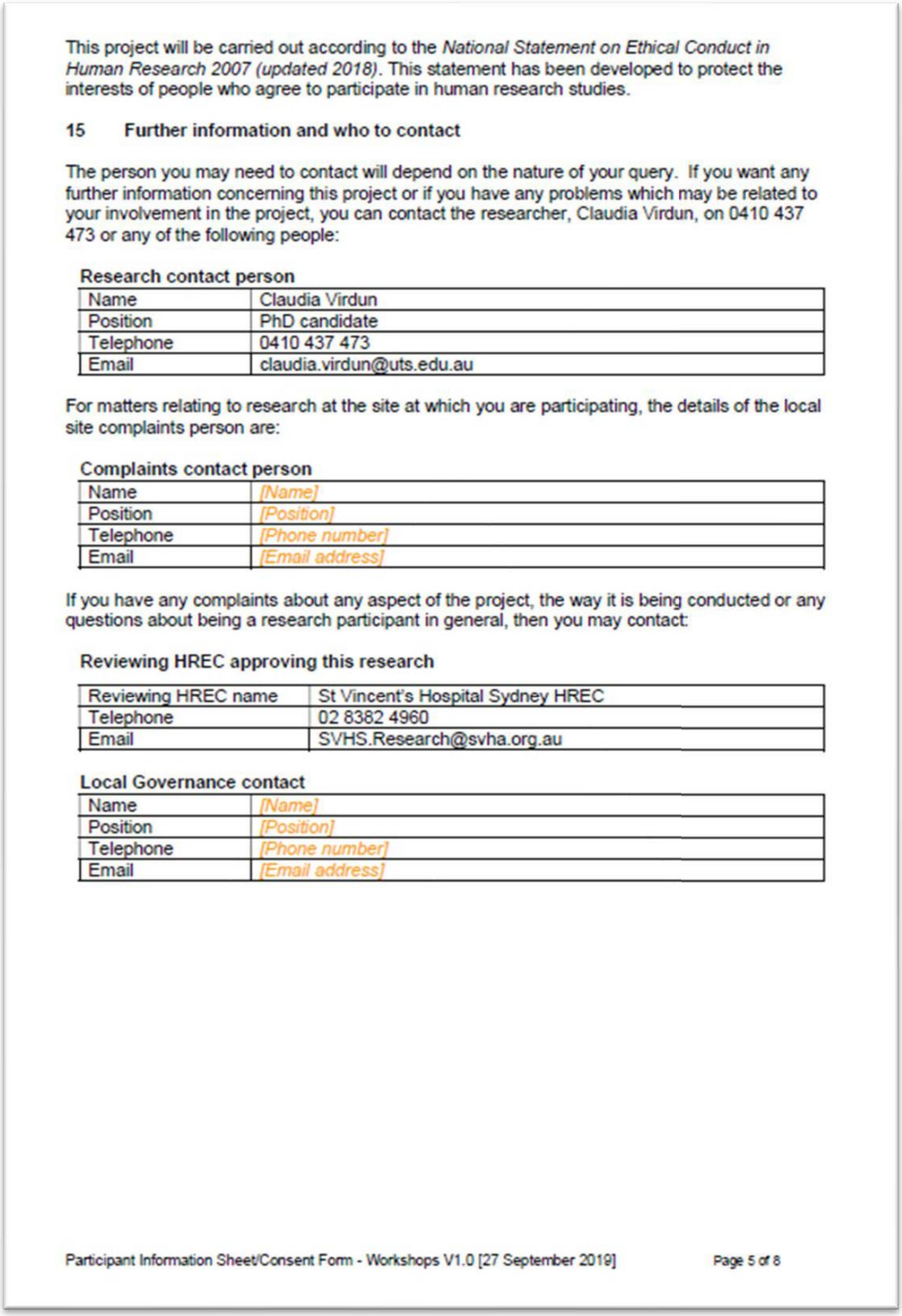
If you suffer any distress or psychological injury as a result of this research project, you should contact the research team as soon as possible. You will be assisted with arranging appropriate treatment and support. In the event of loss or injury, you may be able to seek compensation through the courts.

13 Who is organising and funding the research?

This research project is being conducted by Professor Jane Phillips, Ms Claudia Virdun, Dr Tim Luckett, Professor Karl Lorenz and Professor Patricia Davidson. No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages). This research is supported by an Australian Government Research Training Program Scholarship.

14 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of St Vincent's Hospital, Sydney - 2019/ETH03307.



This project will be carried out according to the *National Statement on Ethical Conduct in Human Research 2007 (updated 2018)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

15 Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact the researcher, Claudia Virdun, on 0410 437 473 or any of the following people:

Research contact person

Name	Claudia Virdun
Position	PhD candidate
Telephone	0410 437 473
Email	claudia.virdun@uts.edu.au

For matters relating to research at the site at which you are participating, the details of the local site complaints person are:

Complaints contact person

Name	*[Name]*
Position	*[Position]*
Telephone	*[Phone number]*
Email	*[Email address]*

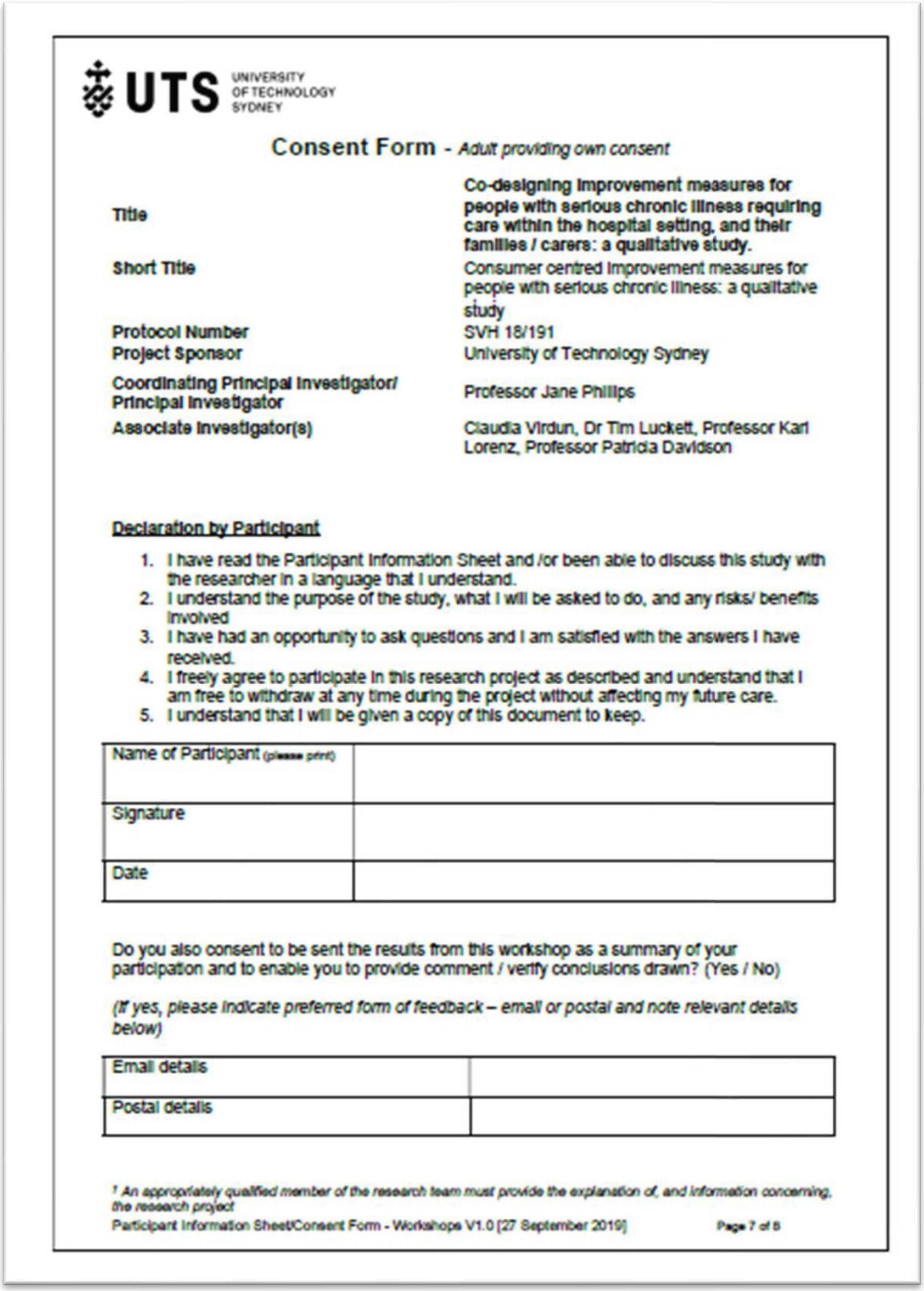
If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Reviewing HREC approving this research

Reviewing HREC name	St Vincent's Hospital Sydney HREC
Telephone	02 8382 4960
Email	SVHS.Research@svha.org.au

Local Governance contact

Name	*[Name]*
Position	*[Position]*
Telephone	*[Phone number]*
Email	*[Email address]*



UTS UNIVERSITY OF TECHNOLOGY SYDNEY

Consent Form - *Adult providing own consent*

Title	**Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families / carers: a qualitative study.**
Short Title	Consumer centred improvement measures for people with serious chronic illness: a qualitative study
Protocol Number	SVH 18/191
Project Sponsor	University of Technology Sydney
Coordinating Principal Investigator/ Principal Investigator	Professor Jane Phillips
Associate Investigator(s)	Claudia Virdun, Dr Tim Luckett, Professor Karl Lorenz, Professor Patricia Davidson

Declaration by Participant

1. I have read the Participant Information Sheet and /or been able to discuss this study with the researcher in a language that I understand.
2. I understand the purpose of the study, what I will be asked to do, and any risks/ benefits involved
3. I have had an opportunity to ask questions and I am satisfied with the answers I have received.
4. I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future care.
5. I understand that I will be given a copy of this document to keep.

Name of Participant (please print)	
Signature	
Date	

Do you also consent to be sent the results from this workshop as a summary of your participation and to enable you to provide comment / verify conclusions drawn? (Yes / No)

(If yes, please indicate preferred form of feedback – email or postal and note relevant details below)

Email details	
Postal details	

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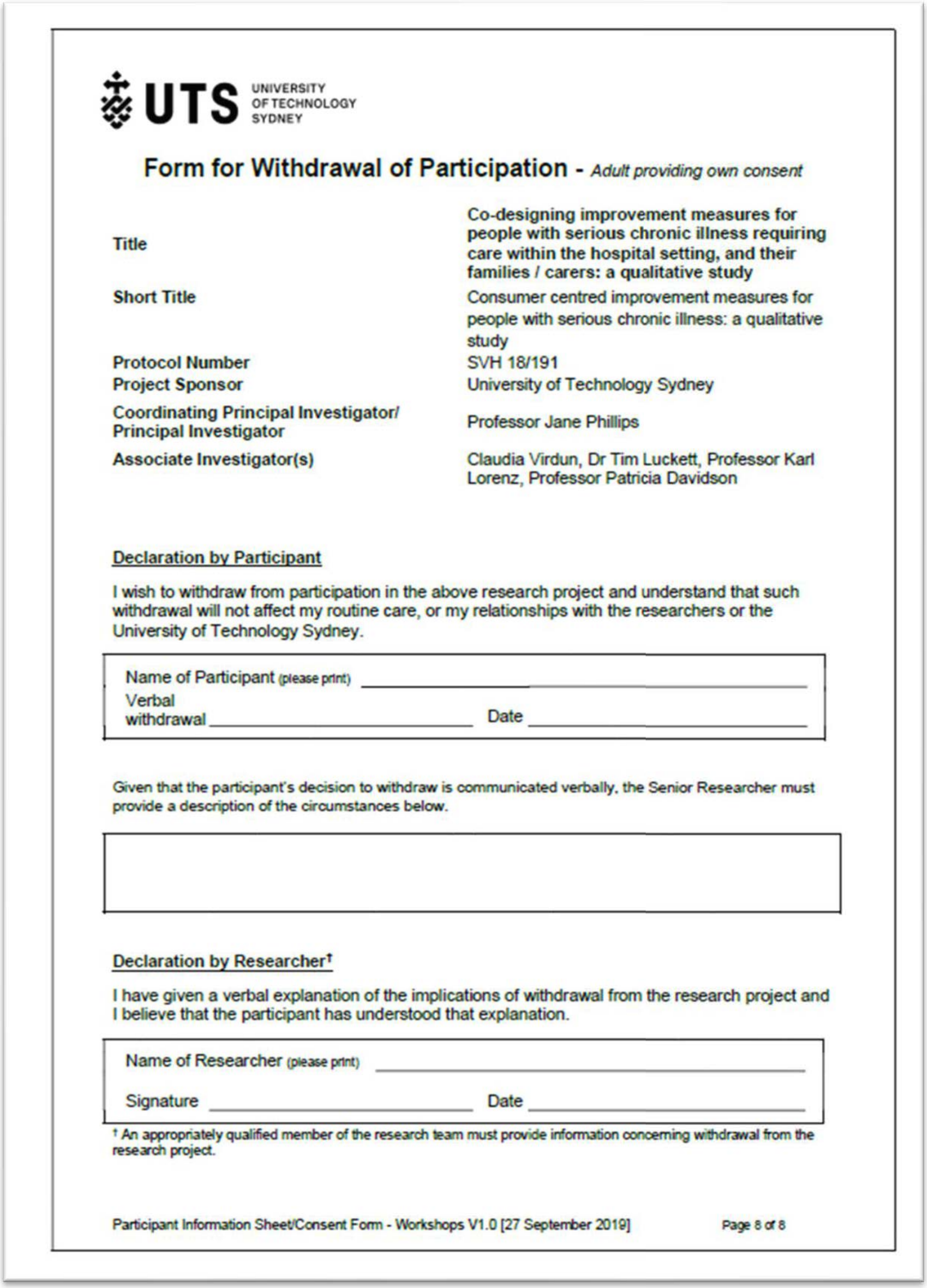
[1] An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project

Participant Information Sheet/Consent Form - Workshops V1.0 [27 September 2019] Page 7 of 8



UTS UNIVERSITY OF TECHNOLOGY SYDNEY

Form for Withdrawal of Participation - *Adult providing own consent*

Title	**Co-designing improvement measures for people with serious chronic illness requiring care within the hospital setting, and their families / carers: a qualitative study**
Short Title	Consumer centred improvement measures for people with serious chronic illness: a qualitative study
Protocol Number	SVH 18/191
Project Sponsor	University of Technology Sydney
Coordinating Principal Investigator/ Principal Investigator	Professor Jane Phillips
Associate Investigator(s)	Claudia Virdun, Dr Tim Luckett, Professor Karl Lorenz, Professor Patricia Davidson

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine care, or my relationships with the researchers or the University of Technology Sydney.

Name of Participant (please print) ______________________

Verbal withdrawal ______________________ Date ______________________

Given that the participant's decision to withdraw is communicated verbally, the Senior Researcher must provide a description of the circumstances below.

Declaration by Researcher†

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Researcher (please print) ______________________

Signature ______________________ Date ______________________

† An appropriately qualified member of the research team must provide information concerning withdrawal from the research project.

Participant Information Sheet/Consent Form - Workshops V1.0 [27 September 2019] Page 8 of 8

Appendix 10: Tabulated data for each domain with illustrative quotes

Key points from SR work	Key points additions from current study	Illustrative quotes
Domain: Effective communication and shared decision making		
1. Honest communication; 2. Ability to prepare for life's end; 3. Ensuring availability of someone to listen; 4. Being aware of what to expect about physical condition; 5. Appropriate treatment and tests; 6. Not being placed on life support with little hope for recovery; 7. Having the opportunity to nominate their preferred decision maker; 8. Honest and clear information to enable a shared understanding; 9. Need for layman's language; 10. Communication delivered with compassion; 11. Adequate information throughout a hospitalization, inclusive of family members, to support decision-making, decrease stress and prevent surprises;	13. Communication that is mindful at time of discussion 14. To connect with and listen to the patient 15. To link into the patient's own knowledge and expertise relating to their condition 16. To maintain positivity and hope within the context of their illness 17. Being well informed across an admission enables trust and assurance 18. Depth of information provided from medical team 19. Consistency of messaging across teams and departments 20. Accurate documentation 21. A lead clinician available to pull complex information together 22. To acknowledge and support the requirements for cross cultural communication to prevent misunderstanding and negativity across patient and staff population groups	**Confirmatory quotes:** Patient data *I mean, yeh, the attention was good, I can't say something was wrong in that, because the doctors immediately came and spoke to me and told me what they were going to do and they were bringing in the antibiotics, and immediately that happened and all that they explained to me, they did… and they said they might do some scans and all and get me soon transferred to the ward (Patient 5, 72yr male with malignancy)* *but I got good care there and if everybody came and explained everything then it was ok (Patient 5, 72yr male with malignancy)* *Oh, I was very happy with my oncologist at the XXX. She always was precise, on the ball, clear, not doubtful. She listened to me. We decided together how to go ahead. Yeah. So clarity, empathy, truth. I think those are qualities and firmness (Patient 11, 72yr female with malignancy)*

12. To be engaged in care planning, inclusive of advance care planning, to remove the burden for decisions from family members		*Yeah. That's exactly right. It's so important to be told right. They've spoken to the surgeon, right, and then they've made a call, right, and then they tell me (Patient 12, 65yr male with non-malignant illness)* *… there's a lot of stuff goes on behind the scenes….someone always tells me what is going on. Which is good. (Patient 12, 65yr male with non-malignant illness)* *I mean look, you know, everybody has their trade, right? You know I can talk to you in building language that you'd never understand. You've got to break it all down. The staff are very good at breaking stuff down. (Patient 12, 65yr male with non-malignant illness)* *I've asked certain questions and I've had it explained to me. What my life will be like. What can I expect, right? (Patient 12, 65yr male with non-malignant illness)* *I felt really like I wasn't being listened to at all. (Patient 13, 61yr female with non-malignant illness)* *I suppose that it's just open and clear. (Patient 14, 45yr male with malignancy)* *Yeah, I think I was pretty much kept up-to-date, and up-to-speed with things. (Patient 14, 45yr male with malignancy)*

		Now, the guy that gave me the bad news, delivered it very quietly. Just, he delivered it like it was like, "here's your ham and cheese sandwich." Right? (Patient 16, 60yr male with non-malignant illness) *And, well, we've done all the tests, looked up... sorry, there's nothing we can do. You've got motor neurone disease and you'll be dead in two and a half to three years…Yeah, pretty much like that. Boom, boom. (Patient 16, 60yr male with non-malignant illness)* *To get away from the brutal, clinical aspect of the servant of death that I'd just been delivered, you know? (Patient 16, 60yr male with non-malignant illness)* *The delivery of the death sentence from the mighty god in the white coat from upon high (Patient 16, 60yr male with non-malignant illness)* *Some empathy. This was a delivery that, the guy that did it, I don't think was... he probably had a big work load and he didn't seem to be very well trained in the whole empathy, compassionate... He was a clinical deliverer of bad news. (Patient 16, 60yr male with non-malignant illness)* *Language is very important. Kindness, communication, empathy, positivity, humor. (Patient 16, 60yr male with non-malignant illness)*

		Well I like the doctors, because they're very direct. I'd prefer that than people pussing footing around. (Patient 17, 66yr female with malignancy) *I don't want any bull, you know. Yeah I'd rather know what's what (Patient 17, 66yr female with malignancy)* *Yeah. I want you to explain in layman's terms really. (Patient 19, 69yr female with malignancy)* *Oh, I like to be, I'm a bit bossy, so I like to be, just know what they wanna do. And if I don't like it, well then I'd say something. (Patient 19, 69yr female with malignancy)* *The care is good. But not much information. (Patient 20, 75yr male with non-malignant illness)* *When explaining about my condition, she just like reading books, reading a story without emotion to me. (Patient 21, 50yr female with malignancy)* *Yeah, it's lack of compassion. She's just like a woman with answers- You know, you ask question and she going to answer it just like reading books (Patient 21, 50yr female with malignancy)* *Yeah. It's too mechanical. It's yes or no. And well, with a patient like me, I need more explanations and more compassions on what to do. (Patient 21, 50yr female with malignancy)*

		Yeah. Right away. Yes, I know the fact that she needs to be honest, but have more compassion when telling. (Patient 21, 50yr female with malignancy) *Oh, to be honest, to have good communication skills with them. Patient 7 (59yr male with non-malignant illness)* *To be able to understand, if I don't understand any medical terms or to be able to get my message across... or be able to get their message across to me that I can understand what the course of the treatment would be. (Patient 7, 59yr male with non-malignant illness)* *And be able to understand what the medical terminology means and to have a good understanding of what the road ahead was (Patient 7, 59yr male with non-malignant illness)* *A few of the medical terms, I had to say, "Oh please, in language I understood," but that was only once. Because the names of all the drugs and everything, that gets away from you. But yeah. (Patient 8, 77yr female with malignancy)* *And that I know the truth, yes. (Patient 8, 77yr female with malignancy)* *No, I prefer 50/50 there, love. Like I said, I asked when I first got diagnosed, how long, was it terminal, how long did I have to live? And they were forthwith, giving me that….But that's most important to me, to know what is going on. I also converse with my family.*

		They're happy with whatever decision I make, and so are the doctors. (Patient 8, 77yr female with malignancy) *Well Nurse XX sort of, subtely, informed me that I could go at any tick of the clock, so you've got to get your affairs in order. So she was quite helpful directing me in that area, which I did straight away actually. (Patient 9, 75yr male with non-malignant illness)* *Well yes. I mean it was... I had to get my act together. I didn't realize that... I mean I got to the point where I accepted the fact that I was dying, or I could have died at the time, and so that was helpful to get my affairs in order, you know. (Patient 9, 75yr male with non-malignant illness)* *And they didn't lie, they said "Look..." First they said I'd probably have five years and then I got down to the end of the year and stuff like that. No, they're just really good in everything and I like their honesty... mostly they just come straight out and let you know, they didn't sort of put something off, they just said "Look, this is the way it is." (Patient 1, 48yr male with malignancy)* *Yeah, just if there's something there, just let us know straight up. Don't sort of beat around the bush and just let me know so I know what's going on. (Patient 1, 48yr male with malignancy)* *But it's not like they explain to you. They just leave you in the dark. (Patient 18, 71yr male with non-malignant illness)*

		I suppose for me, communication of what was going to happen. Obviously, they'd done some x-rays and things to make sure there wasn't any obstructions, but just communicating what they were going to do so that obviously I could get out. (Patient 18, 71yr male with non-malignant illness) *So, I just wanted the communication to be upfront and honest and clear I suppose…But she was straight up communication. (Patient 18, 71yr male with non-malignant illness)* Family data *I'm not very good at remembering actual details of words used and things like that. I do know when she talks to mum, she gets right on mum's level and she has a gentle approach and is able to read mum and how to explain it to her. (Family 11, 61yr female carer for mother with malignancy)* *What did he do that was really helpful and supportive? Well, he spoke very kindly to mum. And he was explaining what he was doing and then he spoke to me and explained, and it was all very logical (Family 13, 56yr female carer for mother with non-malignant illness)* *I mean, I'm very fortunate. I've got a medical background, but my sister hasn't. So putting it in terms that people can really understand, and there were certain things, certain tests that happened, and they'd come back and they'd say, "Oh, this, this, this*

		and this," about the tests. And then the next thing, you're getting something from another team, another medical doctor that would come around on different rounds and say, "This, this, and this," and there was a fair bit of confusion of what was actually happening. And I thought that's another thing that we felt was really important, that talking to us at a level that we could understand, and it's not so confusing. Mind you, it was probably confusing for them as well, because they were really still trying to find out exactly what was actually happening in regards to where he was after doing the CT scan and things like that (Family 16, 59yr female carer for father with malignancy and non-malignant illness) *It's sort of not just about the knowledge, but having that care factor, that compassion, that they know how difficult it is for you to have someone in hospital, and that they can meet those needs in a way that, yeah, it's helpful, and can maybe have a bit of a joke, because dad's got a pretty good sense of humor, but same with us. You can tell us something serious, and don't have to make a joke about it. I'm not saying that, but you can sort of have a joke with the family and be serious as well (Family 16, 59yr female carer for father with malignancy and non-malignant illness)* *And not using layman's terms. She said to them, "Oh, you've got diffuse nodules in both lung spaces, and it's in the pleura, and we're going to look for a primary." And dad's like, "So what does that mean? She said, "Well that means cancer." Mom and dad's first thought, "Well, clearly she has cancer, so okay, we'll move on from*

		that, because that just means cancer. It doesn't mean..." They didn't understand that that mean that they were looking for a different cancer (Family 5, 50yr female carer for mother with malignancy) *How they explain themselves to what's wrong in a way that you'd understand. And even when dad was in a week or two ago, the doctors that come in there, happy, helpful and explain things really well (Family 1, 53yr male carer for brother with malignancy and parents with non-malignant illness)* *We're happy. We're happy to be led, because they get the solution. They know the problem. But I don't feel left behind, so it works out (Family 3, 52yr female carer for mother with malignancy)* *Really poor communicator, really poor bedside manner. Didn't listen to anything that was being said. And I pretty much went to town on him one day. Not rudely, but just called him on a few things. Then he still wouldn't listen, overrode what I was asking and suggesting, sent a little resident in to tell me that that's not what's going, and so the poor resident (Family 5, 50yr female carer for mother with malignancy)* *It's really important for the family, or from my perspective anyway, that the patient is listened to, and that any procedures are explained, and that the concerns of the patient are taken onboard….And I think that's vital, because then the patient can feel like they're given the dignity of being almost a part of the team. It's really very special to feel that you're not just an object but that*

		you're actually part of your own care so that you still have the dignity of a sense of autonomy even though it might be really taken away. It's just that there's an acknowledgment of the person's dignity and autonomy in all the processes (Family 8, 52yr female carer for father with malignancy and bereaved Family for daughter with non-malignant illness) *It's just listening to the patient, I think. I know they come across difficult people all the time but you've got to still listen (Family 14, 49yr male carer for wife with malignancy)* *Yes. And then Dr. XXX, when she'd come the next day to ask how that went, she gave us time. She talked to my brother and I outside of ... She talked in front of mum then she called us outside to talk further, which I really appreciated because it was all so confusing and frightening for my mum to hear all this information that to protect her from some of the more detailed end result possibility scenarios, my brother and I had already decided that we were going to protect her from hearing some of those things. So, we hadn't even conveyed that to Dr. XXX yet, but she wisely called us outside just to let me know. Seeing I am the primary Family at home by myself with mum. We said, "What is there that I can expect that could occur? And when will I know when to call ambulances and things like that?" So, it was detailed and a bit hard to hear, but good in that it prepares me for what could occur and how to find the strength to be able to care for her (Family 11, 61yr female carer for mother with malignancy)*

		In and out, in and out for 55 of 58 days she was in hospital, so from end of April to 58 days later last year. She was incredibly sick. It was some kind of encephalopathy. They didn't know what was happening with her, so they were doing umpteen tests and quite invasive procedures. It was really looking for things that probably weren't there, when it was probably just the reactivation of the myeloma, so it was really frustrating that she was having so many invasive tests checking for more and more things without actually beginning treatment (Family 5, 50yr female carer for mother with malignancy) *The first time mom was in, she was a really sick woman, and I thought, "All right, she's probably not going to be here at Christmas time. Why are you doing all of these invasive tests, and really, it's the myeloma. Just leave her alone. And give her the option of choosing treatment or not choosing treatment." But it was always about the next thing, the next thing, the next thing. "No, you can't go home," even though mom was saying every day, "I just want to go home." "No, we have to do this test, this test, this test," getting all different consultants, like neurologists, to come in and do the basic mental screening tests, and then, "Well we might do lumbar puncture again. We might do this, we might do this." I did say to one reg, "What value you think that's going to add to her care? Do you think that's going to improve her care? No? Then why are you suggesting doing it?" And mom and dad both looking at me like,*

		"What do you mean?" (Family 5, 50yr female carer for mother with malignancy) *What I wanted from that was, first of all, that his dignity would be upheld. I was very worried that he would be over investigated and would go through a million procedures that may, in the long run, have been not useful to his quality of life and just been more trauma for the man, because he was in such an awful state when he went in. So it was more my concern that he was heard, that people didn't go over the top for his individual situation.And that he, hopefully, felt better for actually being in there (Family 9, 64yr female carer for father with non-malignant illness)* *Well, I think that they listen to you, number one and that they look you in the eye and they have the body language of being present is all. Yeah. And that they're looking to you and they might relay back what you said that you can hear that they've heard you, and be caring to the patient (Family 13, 56yr female carer for mother with non-malignant illness)* *My confidence in the consultants is when they listen to questions and answer the questions, whether that's matter of factly or however, but they actually take the time to listen, and don't just say, "Oh, you don't need to worry about that." I respect the hematology oncology guy and the lung physician, because of the way that they listen. Different bedside manners, but they both listen (Family 5, 50yr female carer for mother with malignancy)*

		Confidence, preparedness to listen. Preparedness to take questions. A sense that they're not being defensive when questioned and queried about something. And primarily again as the observer, to see that they will listen and speak to the patient first. Not to me or to the other staff (Family 9, 64yr female carer for father with non-malignant illness) *He stayed for about 40 minutes with another team member of his and just talked us through. Because it was important to us to know what's this mean, what's going to happen down the track, or what sort of treatments do you offer and would they be any good to access. So, he spent all that time with us to go through all those options (Family 11, 61yr female carer for mother with malignancy)* *she wisely called us outside just to let me know. Seeing I am the primary Family at home by myself with mum. We said, "What is there that I can expect that could occur? And when will I know when to call ambulances and things like that?" So, it was detailed and a bit hard to hear, but good in that it prepares me for what could occur and how to find the strength to be able to care for her (Family 11, 61yr female carer for mother with malignancy)* *I'm not very good at remembering actual details of words used and things like that. I do know when she talks to mum, she gets right on mum's level and she has a gentle approach and is able to read mum and how to explain it to her. And I think she probably did that with me too when I was asking sort of how I ... She said, "Oh, she could have a bleed." And I said, "Well, what would a bleed look*

		like?" And that's when she realized I wanted more details, so she said she could cough up coffee granules which would be old blood or she could just have a massive bleed which could be bright red. She said, "I'd suggest dark green towels, things like that, just have them around the room, ready for anything like that." And so I've done all that and I use those towels too for them to bathe mum so that she's used to seeing those towels around. And it could be that she'll stay conscious and I can call for help or it could be that something like that takes her out. So, they're hard things to hear, but I'm sort of aware of them now, but I'm also aware that anything could be something that suddenly appears and could be a virus of some sort or pneumonia or anything (Family 11, 61yr female carer for mother with malignancy) *She kind of had an air about her that sort of made me feel at ease that he was being looked after, and then she proceeded to talk to me about a medication that they wanted to put dad on, a blood thinner, and she had this really great way of telling me, and then saying, "Well, these are the risks. These are the things that we've got to think about. Now, which would your dad like?" (Family 16, 59yr female carer for father with malignancy and non-malignant illness)* *I think for dad it's the comfort factor that's allowed him to start to ask questions. He feels like, at that level, that he's probably a little bit more involved in decision-making. But when they forget about that and they don't say, "Oh husband/Family, by the way, we've found*

		this and we're going to get this person involved in the care," when it just kind of happens, then he's back to feeling like, "I just don't understand what's going on." Does that make sense? (Family 5, 50yr female carer for mother with malignancy) *I also don't think that there's much shared decision-making that happens in hematology oncology. I feel like you're not given a whole lot of choices. You're just told, "This is what we've found, and this is what we're going to do." (Family 5, 50yr female carer for mother with malignancy)* *It's really very special to feel that you're not just an object but that you're actually part of your own care so that you still have the dignity of a sense of autonomy even though it might be really taken away. It's just that there's an acknowledgment of the person's dignity and autonomy in all the processes (Family 8, 52yr female carer for father with malignancy and bereaved family for daughter with non-malignant illness)* *He was given the dignity of making the wrong decision, I suppose that's what I'm trying to say, making a bad decision. And I was on the phone saying, "Dad, you can't do this. You've got to stay there, and it's really not safe to be going home when you've got an infection." But he wanted to feel like he still had autonomy, and so that's all part of it to, that you're given the freedom to make unwise choices and not comply, and then to come back and there's no sort of consequences. He didn't get the rap overthe knuckles or anything like that, it was just, "Okay. Well, this is what we're dealing*

		with now. Let's just move forward with what's happening." And he then settled down quite nicely after that. (Family 8, 52yr female carer for father with malignancy and bereaved family for daughter with non-malignant illness) *It is, but we've never been given an option I don't think, like I remember mom saying, "They want to maybe change me off Tamoxifen and put me on this other drug", mom gave me the list of the side effects of that other drug, but I don't think she was explained to the reasons she should have been changing over is because she was now post-menopausal and not pre-menopausal, and we if we'd have known all of that, we would have said yeah, we would change to it. So I feel like yeah, we don't have options, it's just this is what we want to do... it's not like there's this option or there's this option, it's this is the only one… So, it feels like for mom, if mom was for example, like her back is really bad, so if they ... mom's pretty straight, like frank with stuff like this ... so I think if they had said to mom, "You're not going to get quality of life, we're going to pump you full of these drugs, and you're just going to end up in bed, tired for six months", or "Let's just not treat it, and you have three months of quality", she would pick the three months, 100%.... So it's like, there's no discussions around that kind of thing, like her treatment plan's been picked, and we don't know what is going to be her life during that period (Family 6, 30yr female carer for mother with malignancy)*

		Yeah, the advance care plan. So, the emergency Doctor said, "Oh is she for resus? What's on your advance care plan?" I'm thinking, "Oh God." I had to review her statement, her will and to just double check that and talk to my brother who is power of attorney. And I mean, I don't know what I'd do about that, that's our personal thing isn't it? That's the answer we should have (Family 13, 56yr female carer for mother with non-malignant illness) *Yeah. The doctor, with your wishes, Dr. XX who is a palliative care doctor, he gave us the forms to have a chat about when we first saw him and then when we were in the ward, in the heart ward, was a doctor who, she said, "What are you wishes? If anything happens, if Patient 15's heart stops or anything like that?" I said, well give us some time to have a chat about it. She literally walked out of the curtain, washed a cup out and she came back and said, "Okay, what is it?" Yeah. That wasn't good (Family 14, 49yr male carer for wife with malignancy)* *You know, where the nurses sort of go, "Oh yeah. Yeah. Right-o. Yep." That's it. They don't ever say, "What would you like me to do?"..From what I gather, they sort of like to tell you what they are doing. They don't ask you (Family 17, 69yr male carer for wife with non-malignant illness)* *Yes. I think, any observation I had with him in the emergency department was extremely positive. They were superb. They treated him and spoke to him in terms he could understand. They repeated things for him. I thought... he was only there for, what, 12*

		hours? But my experience of that was very positive. Some of the nursing staff up on the wards I found excellent, really good, would be very cheery with him. Come in, ask him things, et cetera. I thought the bulk of the nursing staff I saw up in the wards, although I felt they were very overworked and overstretched, I can tell you. But whenever they did come in, I thought they really gave him great respect. It was wonderful (Family 9, 64yr female carer for father with non-malignant illness) Bereaved Family data *Definitely. You know, I think they read that from you as well. I can't speak highly enough, you'll probably just see this as a complete praise to Hospital XX hospital and their nurses and doctors of level seven because you know, honestly they just read you so well. They know what to say and do at the right time. They know when to pull it back and when to just push it forward. But, in that situation, in that quickness, you can't have dishonesty, you have to have the honesty, you can't sort of have the... You have to have it blunt so to speak (Bereaved family 10, 43yr female carer for mother with malignancy)* *And they did it with such kind and careness, like one of the doctors almost started crying when she was telling me, but not in a way to make me feel bad for her, but just in a way to make me feel like she could feel my pain, so to speak. You know? Beautiful people (Bereaved family 10, 43yr female carer for mother with malignancy)*

		This is where nurses and doctors would need to read the situation and the people to know whether to provide detailed information or not…but I think what it is important regardless of the level of information that's given is that doctors and nurses show that, communicate that they are aware of the situation, they know what's going on, and then I suppose offer that information if it's needed (Bereaved family 11, 33yr female carer for father-in-law with malignancy) *..talked in a caring, compassionate manner about the options. Really, it couldn't have been better textbook stuff. Absolutely, it was an extraordinary conversation. You got to take your hat off to him. It couldn't have been better (Bereaved family 13, 54yr male carer for both parents with non-malignant illness)* *Oh, absolutely. We don't want dishonest communication. You don't want them gilding the lily (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)* *Once you get good communication established even the worst problems don't seem as bad, if you know what I mean? Because you know what you're facing, but when you're not sure what you're facing and you can't get answers to your questions, it just seems a thousand times worse. So communication is so important (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness)*

		Then finally he rang me at home and told me that my husband had been diagnosed with ... "I've just told your husband he's got stage IV bowel cancer. He probably won't live, but we'll see what we can do." Kind of thing, it was very offhand. He said, "Are you sitting down?" I went, "No, I'm not sitting down, because I'm racing out the door to come and visit my husband to make sure he's all right, because you should not have told him on his own that this is what his situation is." … Yeah, so things like that, it just really, really frustrating. Sad for the patient that they're being told in that manner. But sad for us as a family as well, because this wasn't our style (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness) *They were good communicating. They kept us up to date with what was happening. They didn't hesitate if we had questions to ask. They didn't balk at any of that. They were realistic in their appraisal of mom's situation. But, they still had a really caring, nurturing approach to that (Bereaved family 5, 56yr female carer for mother with malignancy)* *And of course, one of the first things that Patient asked when he was diagnosed was his prognosis. And the doctor would consistently not give it. And his response was "How long's a piece of string?". And I really don't think that was helpful because he genuinely wanted to know (Bereaved family 6, 68yr female carer for brother-in-law with malignancy)*

		And that was probably the first time, I think, that anyone had had an honest conversation with him (Bereaved family 6, 68yr female carer for brother-in-law with malignancy) *There was just something about him, he spoke softly, he was kind, he was ... because I also asked him some questions and he was responsive to me as well (Bereaved family 6, 68yr female carer for brother-in-law with malignancy)* *An amazing way of communicating that's very sort of grounded and thoughtful and kind but objective at the same time. Just amazing. Amazing people. Quite a careful way. She sort of was almost a little bit preoccupied as she was talking to you like she was thinking it through but she was very carefully laying out, this is what will happen and blah blah blah (Bereaved family 7, 56yr female carer for husband with malignancy)* *Again, she was kind and empathetic without being emotive. It's that kind of calm, authoritative, but gentle, firm but gentle kind of calm, authoritative, but kind. I mean, she was kind about it, because she was ... I had no idea and I said to her, I can't believe it. How can it be? I was completely stunned and then you ask, well, how long? They say, well, we don't know. That's the one thing I was probably unsatisfied with. So, then when she'd gone, I was really talking to the nurses and they said ... again, I don't know if that's true but they said we can't tell, it could be two days, two weeks, two months. They just reckoned they couldn't tell. In fact it was a few hours and he was gone. So, it's that ... they have a great empathy but it's not*

		emotive. If that makes sense. It's kind and it's gentle but it's quite firm and authoritative as well (Bereaved family 7, 56yr female carer for husband with malignancy) *He went through the options. He went through the likelihood of the outcomes of those options, and he did it in a really time, unpressured way. The conversation wasn't long, but it wasn't pressured by time if you know what I mean… So although it was a relatively short conversation, it was the right conversation. It was the right length. It had understanding and compassion, and it was about a person, It wasn't about a scan. The scan was there, it was discussed. But it was absolutely about a person... So that was wonderfully reassuring and very special (Bereaved family 13, 54yr male carer for both parents with non-malignant illness)* *I think it's always always around communication. With communication, comes understanding…I think that's my main beef with everything, is information, communication, understanding information (Bereaved family 9, 57yr female carer for father with malignancy)* *that just helped enormously, even though it didn't really change anything, but I just felt like I had been consulted and talked to and that they did have it under control. It's just really all I needed to know. It wasn't going to change much, but after being ... I felt like I was dangling on a string all day after him being in ICU all night and dangling on a string. So, the tension was just so high and then to have that sort of happen and get so upset and then the interview*

		and then she did that, it just made it ... well, I was able to carry on after that (Bereaved family 7, 56yr female carer for husband with malignancy) *No. I guess just ... I've said that many times I think, but I now regret that we didn't sort of ... maybe that I didn't ask more questions of the palliative care people. That was very much focused and when I talked to them, it was very much about how he was feeling at the time and how to help him feel better. It was about ... there was so many other things probably we should have been talking about. You can't go back and change it, so I do feel like we had ... I do feel like we were a bit robbed but people die in car accidents and then they're robbed as well, so it's ... but it does feel hard that it's like I never got to say goodbye to him when he could actually respond and I have no idea what the last thing he said to me was. It would have been something completely banal about what he was trying to drink or his breathing or something. Nothing meaningful. I'm sure it's tricky but I think ... I don't know. I would have liked to have known more about palliative care and more about the realities of ... well, not the realities but the possibilities of what may or may not happen and I don't know how you do that (Bereaved family 7, 56yr female carer for husband with malignancy)* *I suppose I was concerned about him having what he needed all the time. Generally speaking, I think they were very good. I know that after what I've said ... I think the standard was good, but I'm never sure, I'm never confident that they really get the detail, and*

		that they really listen (Bereaved family 9, 57yr female carer for father with malignancy) *He really wanted to make his own, so if I got too involved, he'd sort of tell me to shut up, basically. He wanted to make his own decisions with his health (Bereaved family 9, 57yr female carer for father with malignancy)* *And I wasn't there. I came home to feed the dogs and she rang me and told me she had a visit with this doctor. And she said, "She was really great because she actually listened to what I was saying." (Bereaved family 1, 66yr male carer for wife with malignancy)* *They were ... well, one they were able to listen. Many people don't listen, they just talk, and talk, and talk, and talk and they don't listen, you know? The thing is, people don't ... I've explained it to people before, there is a world of difference between hearing and listening. Hearing is something you have no control over as long as you are not deaf, you can't help but hear. Listening requires active participation because you're listening to what the person says and then you go to say what you're going to do in relation to what they said to you. And people just are not prepared to listen, they just go, "Well, I'm right and I know it all, and there you go. My way or the highway," which I think is profoundly stupid. And I find it a bit of a paradox, you have people so clever and so stupid at the same time (Bereaved family 1, 66yr male carer for wife with malignancy)*

		Just them listening to the Familys, because often the patient is quite out of it on pain medication or whatever, they become very institutionalized. So you know, their big obsession is what time is morning tea coming, and what time is lunches coming? You know, they don't actually ... My husband was such a beautiful, gentle man, I'd get there and I'd say, "Have you had your tablets today?" "Oh, I don't really know." Kind of thing (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness) *Listening. So, when you talk to them about something, and they respond. It's that thing of reiteration, and saying, "Yeah, we can do that," rather than, "I'll look into that," or, "Maybe." Because, I think that's something that sometimes happens is because they're under pressure, you don't always feel it's definitive. Like the nappy thing was a classic, because I'd ask, and then on the next day on a new shift, new people, there still weren't the nappies. I'd say, "Look, I asked yesterday. I don't mean to bother you. I don't mean to be a pain, but could we please have a regular supply?" In other words, can someone actually look and see that there's one nappy left. That sort of thing. Yeah, it's about listening. I think it's the way, when you communicate, you look someone in the eye. Looking people in the eye, and actually acknowledging and having a sincerity. I don't know. It's just we're all human, and you can usually tell if someone's listening or not, or they're just jumping off to the next thing (Bereaved family 9, 57yr female carer for father with malignancy)*

		And so that was really the start of it going wrong. There was very little communication about what to expect (Bereaved family 6, 68yr female carer for brother-in-law with malignancy) *he didn't give Patient options as to what might happen if he did stop and not have the immunotherapy. He didn't tell him what could he expect from the next round of immunotherapy. It was like "This is what we're doing if your bloods are okay, you go out and have it", end of consultation (Bereaved family 6, 68yr female carer for brother-in-law with malignancy)* *I had no idea and I said to her, I can't believe it. How can it be? I was completely stunned and then you ask, well, how long? They say, well, we don't know. That's the one thing I was probably unsatisfied with. So, then when she'd gone, I was really talking to the nurses and they said ... again, I don't know if that's true but they said we can't tell, it could be two days, two weeks, two months. They just reckoned they couldn't tell. In fact it was a few hours and he was gone (Bereaved family 7, 56yr female carer for husband with malignancy)* *No one in this busy general hospital asked, what do you want? Everyone of them framed it in, what would your mother or your father want in this circumstance? They did a superb job, an unbelievable job (Bereaved family 13, 54yr male carer for both parents with non-malignant illness)*

		he had what I thought was a brilliant way of dealing with things where when you have options as to what you can do about something, what he would do is, he would outline the option. He's say, "Number one, we could do this. Number two, we could do that. Number three, we could do that." And at the end of it, he would say, "My recommendation is ..." and then he would say the option that he favored. And I thought that he was brilliant because you're not telling the person and you're not asking them. You're putting the options in front of them, which means that she has the choice to choose, but with the benefit of his expertise he was able to say, "Personally, if it was me, I would pick number two." And that's the sort of thing that I'm talking about that you can be authoritative without being overbearing. And you can ask questions or get answers without telling people what to do (Bereaved family 1, 66yr male carer for wife with malignancy) *I think for the admission, the actual admission, we were fully included in decision making. They knew that I had enduring guardianship and power of attorney, and that sort of thing, and they would acknowledge that. Yes, and you know, care directives. We were included in that. In decision making in the hospital setting was okay (Bereaved family 5, 56yr female carer for mother with malignancy)* *And the doctor did not, in that communication, ask him what his goals were or what he wanted. It was as if doctor wanted him to have immunotherapy but Patient wanted to be able to eat, to enjoy*

		food and to not have this dreadful nausea and vomiting (Bereaved family 6, 68yr female carer for brother-in-law with malignancy) *Yeah, I did and probably a lot of it was because I was there all the time pretty much and I kind of insisted on being included. I mean, I didn't really have to but I was there asking questions and if they said, oh, we're going to do this, I would say, why? And question things if I didn't think they'd explained it. Mostly they did explain things reasonably well (Bereaved family 7, 56yr female carer for husband with malignancy)* *So we had all talked through all of the options. We'd engage mum in the conversation. She again had been very clear about her wishes over the years. I'm not sure she fully understood that day just how sick she was. But she certainly was clear about how symptomatic she was (Bereaved family 13, 54yr male carer for both parents with non-malignant illness)* *That was the kind of stuff, she was dying and I wanted her to have what she wanted (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)* *So, I mean, one of the things that we did was, I was my wife's medical decision maker. So, we had a power of attorney drawn up, so I had control if she couldn't decide for herself. And I made sure that what she wanted was carried out (Bereaved family 1, 66yr male carer for wife with malignancy)*

		New data to support additions: Patient data *Well, I think it's somebody looking at you, speaking to you. Not appearing thinking about something else or thinking about the next thing they have to do. But, they're absolutely focused on what we're talking about. They're mindful. In the moment, and that they had done their homework and know what they're talking about. (Patient 3, 80yr female with non-malignant illness)* *Well it is to be nice to the patients, be human, and explain to me everything that is happening and also to be there to help me…. Listen to me… (Patient 5, 72yr male with malignancy)* *I get angry with ... I yell because nobody listened the first time, the second time, or the third time. (Patient 10, 82yr female with non-malignant illness)* *They think well they've done the training, they know what they're talking about and whatnot. They don't ask the patient "How are you managing and what you're doing yourself". (Patient 22, 75yr female with non-malignant illness)* *So, the other thing was that the guy didn't spend much time on doing anything... having any sort of positive conversation with me. (Patient 16, 60yr male with non-malignant illness)* *If they had given us some confidence first. I know it can be terminal or whatever. But I think firstly to give confidence to the patient and*

		say that we are having these types of treatments and we will try our best and try to get you out of it. They just said this is the situation and this is what we are going to do. It was sort of cut and dry….So, we would have preferred to have some positive words from the doctors. And wait and see how it works. We don't expect all of that to be told to you, you don't need to know all that detail – too much, and then immediately told to go to palliative care and then we had a phonecall about palliative care the next week…. So the path is laid out which is not expected…. But thank God, I mean I am ok. (Patient 5, 72yr male with malignancy) *I know the fact that she needs to be honest, but have more compassion when telling. (Patient 21, 50yr female with malignancy)* *The delivery of the death sentence from the mighty god in the white coat from up on high. (Patient 16, 60yr male with non-malignant illness)* *To get away from the brutal, clinical aspect of the servant of death that I'd just been delivered, you know? (Patient 16, 60yr male with non-malignant illness)* *So just her talking to me and telling me what we were going to do, and that I needed to be in a hospital, even though I didn't really like the concept, what she was going to do. I think that that changed for me that I went right, okay, I trust her so I'll go into this as long as it's her, I'll be okay. (Patient 4, 54yr female with malignancy)*

		The transmission of information. So that you are not given... so that there is consistency everywhere. And you feel assured about that. If you get one info from the oncologist and then you go to the chemo, then maybe slightly different there, then you have to go to the blood tests and then they tell you to go back to the oncologist, or they say to go back to the chemo. I mean all of that could be streamlined better (Patient 11, 72yr female with malignancy) *I think that the main problem everywhere in communication are the notes. When you are not under exactly the same department or the same the notes are very important and because there is a huge exchange of personnel, I don't know how that can be solved but with computers and so on maybe, but the problem is that the patient sometimes doesn't feel reassured because he gets a different information from the different notes or if not necessarily different information but not streamlined information (Patient 11, 72yr female with malignancy)* *They walk in, they give you what they need to know, they give you a tablet and walk straight back out. There's no time to answer a question. You just really feel like a robot. Like a chicken in there in one of those chicken hatches. (Patient 13, 61yr female with non-malignant illness)* *It would have been better if they could have stood still and explained what they were trying to do because they're all ... everybody's always in a rush, so you don't get that extra ... It's not even a long conversation that you need with everybody. It's just a*

		bit more information. (Patient 13, 61yr female with non-malignant illness) *Well, I need to ask question. Whether she's not approachable, and my doctor is like that. She's not approachable. You need to chase her, and once you are in front of her, she's always in a hurry (Patient 21, 50yr female with malignancy)* *With answers. So it's like that. Our relationship is like that. You know it's just like a strict teacher to the student, and I'm not, I mean I do not deserve that kind of doctor with my situation (Patient 21, 50yr female with malignancy)* *Well, whenever I do get the chance to speak to the doctors, they come to see you, and there again, they're always in a rush, by the way. They walk in with five other people, mainly students, interns, or whatever they are called, and they're just very quick and do the basic, and okay, bum, bum, bum, and that's it. Off they go. Sometimes I can stop them in time and try and get some information, and you get a little bit of information, and then, well, you feel like you've got that information, that's fine, but after they leave, within in two minutes, you think of sort of something else to ask and too late. You can't ask it now. They're gone. (Patient 18, 71yr male with non-malignant illness)* *everybody was there with their bit but there wasn't anybody to pull all the bits together, if you know what I mean. That would be helpful. (Patient 13, 61yr female with non-malignant illness)*

		Well, don't just give me the bad news, now I'll give you the good news about what I can do that is positive… So, a much better conversation would have been, "Look, sorry to have to tell you this, but look, you do have motor neurone disease, and as yet there is no known cure for this. It's a chronic degenerative disease that eventually leads to death." Then I'd go, "Well, okay, that makes sense. I mean, we're all going to die, I understand that" We don't know exactly how long that's going to take. The rate that we can assess from your body indicates that it might be as soon as two and a half to three years. But, we don't know for sure. It could be five or six years. We really don't know. So, what we can do, in the meantime, is make sure that you live in the best possible manner to reduce... to keep this at the slowest rate of progression possible, and enjoy as much quality of life as you can. Does that sound like a good idea? And I would have gone, "That sounds like a fucking, bloody good idea." (Patient 16, 60yr male with non-malignant illness) *….in many cases the language doesn't transfer well, in other cases then that creates confusion and possibly I think a cross cultural component, just making people aware that cultures are very different and people react very differently in different cultures, not necessarily meaning offense, which could be taken by offence. And that it definitely, that triggers a reaction, which is a negative reaction and that creates its own another negative reaction. So very, very*

		important a cross cultural awareness. (Patient 11, 72yr female with malignancy) Family data *And so that was just all part of the patient care, just making sure that the patient feels a sense of that they're in control of ... They've heard the spiel from the clinical team and they've made a decision, "Yes, that's what I would like for my care." And then they have a sense of ownership, so it's not like a learnt helplessness where you're just passively accepting everything. You're part of the decision-making and you have ownership, and you're more likely then to notice if things aren't quite right (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness)* *And I'll just say, one day Consultant X, who runs the department, we only saw Consultant X once, but he charged in with all his crew at one stage and he was really good, he speaks very fast, but he sat on the edge of the bed, and absolutely directly, spoke to Dad for about five minutes. It was a pretty confronting conversation about the fact that you know this was terminal, and Dad said "This means I'm not going to get better?" Yes, that's right. And then turned to me and asked me what I thought, et cetera, et cetera. And I thought, because often you don't see consultants that will do that. They often send their 2IC in. Or they talk over the patient, to either relatives or*

		to their team. And I was very impressed when I saw that (Family 9, 64yr female carer for father with non-malignant illness) *They haven't really sat us down and said...And said, this is what... We know what's going to happen, but when, or how long or how long... They did it once... Well, just Patient X asked the question. She said, "Well how much time do you think that we've got?" And they said, "6 to 12 months." But after that, there's nothing they've said about that or anything else like that. And they haven't sat us down to sort of...It's always been about Patient X's condition and treatment, and what medication she was going to get and all that sort of thing…Well, I think that I'd like to know... and assess what it's going to be like for Patient 8. Because I know it's going to get bad, in the long run. And I want to know... Because, being her husband and her Family, you don't want to see the person that you love in that sort of pain and all that sort of thing, and you want to be a bit prepared for what's going to happen, you know?.. And we can, like, we will accept it. But at least, if you know what's going to happen and you're a little bit prepared for it, it's not such a big shock I think, you know what I mean? (Family 10, 73yr male carer for wife with malignancy)* *The only thing probably, maybe I could say would be a problem is, because she gets very breathless and talking and that, every time someone different comes in, she's got to go through the whole spiel of it all again instead of them getting the notes and reading the notes.. Same questions over and over again every time a different*

		one comes into the room. Whereas if they read her notes, they would know…. It just seems to happen the whole time she's in the hospital. So whether, I don't know, I know they're busy, whether they that don't have time to read the notes before they see to the patients, because the staff changes. You know, the nurses are changing so regularly. I don't know (Family 18, 59yr female carer for mother-in-law with non-malignant illness) *What tends to happen is someone will come in and say something to her, and she won't remember or she'll get it completely wrong, and then she'll pass that on to dad or myself, and then it's a process of having to try and get that person back or get somebody to actually clarify was that actually really what was said, or this really what's going to happen? And then having whoever you ask have absolutely no idea because nothing's really written in the notes and they don't know who was on the ward, haven't got time to go back to it, so you maybe just wait until they come back next time and ask them again (Family 5, 50yr female carer for mother with malignancy)* *and then when we went in to see doctor, it was a very young doctor, very young doctor, assistant, who first spoke to us – and the way he spoke to us was very negative – and he told us we have realized that for lung cancer pts it is better to see a palliative care nurse early than waiting to later and he wanted us to see a palliative care nurse the same day – which was very distressing for us, we didn't even want to think of palliative care. From the first day I think they*

		should not have done that. And then the doctor then told us the prognosis, after we went to the specialist and the specialist told us the prognosis of three months to a couple of years. Because she said just a few months, that caused so much distress, I didn't know whether we only had 2 or 3 months – I was so upset…because she said it might only be a few months…. Yeh… I don't know whether you have to tell patients that information, because it caused so much distress… and now he is 8 months later and we are ok. So much stress and tension was created for us (Family 4, 53yr female carer for husband with malignancy) *Yeah. Quite important. At the same time, you don't want pity, pity you, tone. You don't want to enable all the self pity thoughts, right? You want just positive and encourage (Family 3, 52yr female carer for mother with malignancy)* *But to speak because the patient is central. And that gives me confidence. Even if they're medical treatment's not good, if they'd actually centred the patient, where I think the patient is central to what we do. If they'd centre the patient, then there's always going to be good... for me there's always going to be a better feel about things (Family 9, 64yr female carer for father with non-malignant illness)* *Just the communication, being told, CT scan being read to us, giving us updates on her changes in her body. So yeah, even when they were checking the liquid in the lungs, I was informed. And so I would also tell her and then they would also reassure her. We felt*

		that they were in charge.I noticed a change in ….wait a minute…how to improve communication. There was a time when I had her go to the palliative care doctor alone, because I thought maybe she would like to tell her something that I'm not present and just give her space and freedom to share whatever. So, I thought I wonder if that's a good thing, that the Family doesn't always have to be present, or if the Family should have a chat without the patient. That is just a thought in my head. Because we go see the doctors together, but that one time I wanted her to freely discuss her feelings or her needs, because of course, as a daughter and if I'm a little bit controlling or she doesn't want to reveal things when I'm around, something like that. At the same time, I have thoughts and I have observations about her that I wish I could share, and I'll consult the doctors about (Family 3, 52yr female carer for mother with malignancy) *Not talking down to a 91 year old. And also Dad's a little bit deaf and being prepared to know that and take the time to repeat something and to enunciate clearly. Because I've seen so often when that hasn't occurred, Dad looks vaguely at people, says inappropriate answers and no one questions it. So I was very concerned that he wasn't talked down to, and that people were sure that he understood what was actually going on. And I didn't talk over the top of him, because I'm his daughter, and he tends to look for me to do things for him, that it wasn't all just my decisions, it was his decisions, but provided I was able liase and be his advocate so*

		he was informed (Family 9, 64yr female carer for father with non-malignant illness) *First of all, he sat very close to Dad. He didn't quite touch him, but he sat very close to him. He had all his team on the other side of the room, not all charging around Dad. And he looked at him in the eye directly and spoke very loudly and clearly at him, because I said "Dad's a little bit deaf." (Family 9, 64yr female carer for father with non-malignant illness)* *If you're in the ward, you might see two or three different doctors. You do get to know the better ones, just with the bedside manner. That is a big one if they've got a good bedside manner. If they just come walking in, give you a mouthful of information and then walk away. That makes it very difficult. Just taking the time to explain in better detail whatever they're trying to get across. We're not all doctors and nurses that have had hours and years of medical training. The more detail the better (Family 14, 49yr male carer for wife with malignancy)* *Well, we haven't come across many that aren't friendly. They're very friendly. You get the odd one here and there but that's just human nature. With the doctors, they're always in a rush. They give you a mouth full of long difficult words to understand and then they leave. Where the nurses will actually explain it down to layman's terms (Family 14, 49yr male carer for wife with malignancy)*

		One of those people that doesn't rush your answers. You know when the... I'm putting my fingers up, you can't see them, like inverted commas speech marks, "the good clinician", is he... I was there for one of his visits. So not rushed at all. Speaking to mom, so looking at mom, listening for mom's response, which is usually blank and, "I've got no idea what's going on with me, you'll have to ask, husband X," and then saying, "Thank you, patient X," and then looking at dad, saying, "husband X, what's going on? Have you got questions?" Introducing himself first of all, shaking hands with dad, shaking hands with mom, and I was there, so introduced himself to me, said, "Who are you?" and then shook my hand. A person that looks at the person that's talking to them, so includes the patient, then includes the Family and acknowledges whoever else is in the room, and does a bit of the head nodding. Those really good non-verbal communication skills as well. And leaves the room with the people feeling like, "Oh, this is somebody that's going to help me." (Family 5, 50yr female carer for mother with malignancy) *It was great, except for the don't talk down on me, and use a tone that is ... So, the senior doctor went to talk to her and make jokes with her, she appreciated that, she bristled when the younger doctor was not as she felt not as as professional. The tone. The tone, speaking so fast as if ... Yes, I noticed that also that that younger doctor spoke slower towards the other patients while he was as if deliberately confusing her. So, she did feel, you kind of feel when someone is not kind to you. It's a human thing. It's not a cultural thing, you know? Yes, yes. Professionalism, more the tone. Yeah,*

		more the tone. She's not able to process the science of it. Yeah, but she responds to the tone (Family 3, 52yr female carer for mother with malignancy) *I mean, I'm very fortunate. I've got a medical background, but my sister hasn't. So putting it in terms that people can really understand, and there were certain things, certain tests that happened, and they'd come back and they'd say, "Oh, this, this, this and this," about the tests. And then the next thing, you're getting something from another team, another medical doctor that would come around on different rounds and say, "This, this, and this," and there was a fair bit of confusion of what was actually happening. And I thought that's another thing that we felt was really important, that talking to us at a level that we could understand, and it's not so confusing. Mind you, it was probably confusing for them as well, because they were really still trying to find out exactly what was actually happening in regards to where he was after doing the CT scan and things like that (Family 16, 59yr female carer for father with malignancy and non-malignant illness)* *It was just that sense of being confident enough as a clinician to disarm slightly, disarm enough for the conversations to feel human, to feel warm, to just feel safe. And that's still within those professional and clinical parameters, so there are boundaries you don't cross but there's still enough room within those boundaries to enable patients to feel human and to feel that they're talking to someone at their level, if you know what I mean (Family 8, 52yr*

		female carer for father with malignancy and bereaved carer for daughter with non-malignant illness) *he was brash, and his bedside manner was a little bit brash…. Yes, very patient, impatient with my mother, spoke very fast. So, she was a little bit disoriented. She was wondering why are you asking me where I am? She didn't know the protocol. He would ask her, "Do you know where you are. Do you know what's happening?" Just to check out her mental state, and my mother got offended and they had a few words. But I told my mom not to be testy because it's the rigor and I pointed out that it's not racist, it's something that the doctors do. They need to know your mental, if you're feeling confused (Family 3, 52yr female carer for mother with malignancy)* *No care planning. Yeah just to understand, "Okay well this is her condition this normally takes this many days we will make a plan. There is no Geriatrician here so, maybe we can make it more comfortable. Well, we can go to the private hospital if you want, or you know", there was no I don't know whether that's a good option for, her condition and then I don't know just, you're just sort of left in the dark. Basically, "Oh she's an emergency lets give her oxygen, CPAPs. Let her have some Lasix. Okay, we'll talk to Dr XXX, this is the alternate we'll talk to Dr XXX see what he thinks. We'll administer this protocol and this Doctor is allied with Dr XXX, he'll be able to talk to him." (Family 13, 56yr female carer for mother with non-malignant illness)*

		When I think about care, it's all around who says what and who doesn't say what to mom, to dad, to the rest of us. When mom's in hospital, it leaves her really anxious about what's happening because she doesn't know what's happening. What tends to happen is someone will come in and say something to her, and she won't remember or she'll get it completely wrong, and then she'll pass that on to dad or myself, and then it's a process of having to try and get that person back or get somebody to actually clarify was that actually really what was said, or this really what's going to happen? (Family 5, 50yr female carer for mother with malignancy) *The biggest thing is just the communication. Just day to day stuff. It doesn't get to the clinical stuff of what's happening next. It's just a conversation. That would make a big difference, for them to actually feel like they were being well looked after, not just task looked after. Like I said, even just the very basics of dad having to check mom's arms to see if she's had blood taken through the night... For the nurse not to... Even if the nurse has been in a couple of times, to not say, "Oh, by the way, in handover this is what they said, this is what happened. Have you got any questions?" Or, "I just want to let you know that we've had a blood taken last night, because her temp was 39.6." (Family 5, 50yr female carer for mother with malignancy)* *Knowing what's going on. Like even now, there's a lot of things that probably haven't been really answered. I know there's some questions they can't answer, but yeah (Family 6, 30yr female carer for mother with malignancy)*

		Basically if you need to know anything, what's going on with your treatment, the doctors, they don't actually come forward and tell you straight away. You have to actually ask the nurse and then when the doctor comes around again, she asks what's going on and then the doctor tells you limited amounts of the information that you want…And not knowing is probably half the problem of being in hospital (Family 14, 49yr male carer for wife with malignancy) Bereaved Family data *What was bad about it was there was a minimizing of the symptoms, no acknowledgement of the ascites, the discussion about whether he would have an extra round of immunotherapy, the fact that it was clear that Patient was very ill and yet it seemed as if he had this plan and no matter what he was going to proceed with the plan, "If your bloods are okay, we're going to have the immunotherapy". The fact that Patient challenged him twice about what were his chances, I think were an opportunity to open the conversation that perhaps this isn't working and he didn't take that opportunity. The fact that he then started reeling off all these success cases, I don't think was particularly helpful for the man sitting in front of him, he was obviously very ill. The conversation about the bloods and the fact that the bloods hadn't come in and that he needed to come earlier if he expected him, "If you expect me to be able to interpret your blood tests, you need to come earlier to have them". I didn't feel that that was particularly sensitive. He didn't want to know about his nausea and how distressing that was.*

		He didn't ask about his current quality of life, the fact that Patient was spending 80% or more of the day in bed, he didn't inquire about that. I was very conscious that this was the first time I'd been invited in, I could have given him so much information. So to some extent, perhaps you couldn't blame him, I would have told him so much more and perhaps he would have made a different decision. But he didn't probe, he didn't ask for information, he asked nothing about the palliative care consultation, he didn't give Patient options as to what might happen if he did stop and not have the immunotherapy. He didn't tell him what could he expect from the next round of immunotherapy. It was like "This is what we're doing if your bloods are okay, you go out and have it", end of consultation (Bereaved family 6, 68yr female carer for brother-in-law with malignancy) *I think that they had time for you. It seemed that things... It wasn't a burden to ask an extra question or two... For someone to come back and say, "Hey, look I thought about this" or "here's a reference to this" or "why don't you try that?" It was sort of just, it could be just even little things. That would help (Bereaved family 5, 56yr female carer for mother with malignancy)* *I think the surgeon, for one, if they came in and maybe even sat down. They never sit down, because they don't have time… I think they're brilliant. But I think they could just sit down and just say, "patient X, okay, look. You will have a bit of bleeding for a while. Look, if you have any severe pain, here's my card again. You*

		contact my secretary. We'll get a nurse to see you." I don't know. Just a little bit more ... They really, they do their job, and then it's somebody else's problem. That's how it feels with them. Basically, "If you've got any problems after this, pardon me, either call an ambulance, or call the nurse, or call the dietician. I've done my bit. That's what I'm good at, and I've done it. See you later." I just don't think it's their ... Maybe it depends on the type of surgeon. So sometimes I feel like in everything it's about communication, and connecting with people (Bereaved family 9, 57yr female carer for father with malignancy) *But, I must say, accents, people have to ... With all people, my father, because of his bad hearing, and because of the stress I think when they're sick, they find it very difficult to understand (Bereaved family 9, 57yr female carer for father with malignancy)* *To be honest, like we had a few, like the social workers sort of sought us out a few times and the nurses and doctors and always made sure that they kept us informed, after they spotted me, they always spoke to me. So that to me, made me feel quite good (Bereaved family 10, 43yr female carer for mother with malignancy)* *So you know, I guess I would have liked to have been updated a little bit more regularly during that period because I kept having to ask, is she going to come back to being normal? And they, yeah, I don't know (Bereaved family 10, 43yr female carer for mother with malignancy)*

		No, I think we felt that, he communicated really well, and he kept coming back and saying what he was doing. And every time he'd talk to somebody else, he'd come and say what they said. He was getting a bit frustrated that they couldn't agree with eachother. But I think that we felt that he was really doing his level best to try and sort it out (Bereaved family 4, 69yr female carer for friend with malignancy) *I guess if you ask a question, they knew the answer to that, and if they didn't know, they said they'd go and find out about it. They didn't try and make some crap up. The ones that actually came in and asked about how we were going, how's patient X going, when they came in and did things, actually explaining what they'd done, and what the outcome of what they'd done was. Yeah, I guess that (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)* *And then you're telling my mom who at that time the brain cancer was really affecting her and all she wanted to do was get home and they sort of kept telling her different things and that was hard for me to handle on that side as well. But yeah, that was a bit difficult (Bereaved family 10, 43yr female carer for mother with malignancy)* *They talked to my father as I talk to unconscious patients, and that was beautiful. In eliciting my mother's preferences for her care in the next 15 minutes because it was 15 minutes by 15 minutes for her. She was profoundly physically unsettled understandably. They listened to that beautifully. It wasn't in a patronizing way. They*

		weren't talking down to her, nor were they assuming that she was well. So getting that pitch right, I was just blown away with how good it was. It was really beautiful to watch (Bereaved family 13, 54yr male carer for both parents with non-malignant illness)
Domain: Expert care (good physical care, symptom management and integrated care)		
Physical care • Being kept clean; • Receiving good care when family members were not present; • Maintaining hygiene; • Maintaining independence; Symptom management • Symptom relief; • Regular, person-centred pain assessment and management; • Enabling a rapid response when analgesia is required; • Effective pain management; • Clinicians demonstrating they cared about a patient's symptoms; • Sufficient pain assessment and management for a person with a known opioid dependency; • Management of vomiting; • Management of restless legs; Integrated care • Effective discharge planning;	Physical care • Providing physical care in a compassionate, empathetic and willing way; • Being informed if a delay in care will occur; Symptom management • Effective communication in relation to symptom assessment and management • Staff to be mindful of clarity of message with symptom management, as multiple drug names can be confusing for this population of patients who are unwell and may have some cognitive effects from illness or related pharmacology; • Need for patients to understand that asking for medication, assists the clinical team to understand analgesic requirements; • Importance of exploring why patients may be reluctant to take analgesia and the impact of their prior life experience with opioids;	**Confirmatory quotes:** Physical care Patient data *They're there to help you, to help you butter your bread, to make you a cup of coffee, or to give you a shower or brush your teeth or something. It's just there's a lot more personal care. (Patient 13, 61yr female with non-malignant illness)* *Oh, because when I tell them I need my nappy changed for instance...It's no problem. (Patient 17, 66yr female with malignancy)* *Well, the fact that the medications was given in a timely manner. (Patient 7, 59yr male with non-malignant illness)* *Well, I don't know, everything was pretty much done for me. just everything was... most important I suppose is just the last day at Hospital XXX I couldn't get shower or I couldn't get in the toilet or anything and that was hard for me because I've never done anything like that before. (Patient 1, 48yr male with malignancy)* *Good, really good. It's... because I'm really independent so most of the things like I'd do myself and when I couldn't do it, I'd hit the*

• Clinicians need to be knowledgeable about the specific condition of the patient; • Clinicians working together as a team in relation to their care; • Staff working as a team	• Need for managing breathlessness in the acute care setting and the difficulty in managing this when fans, fresh air or cooling may not be easy to access; Integrated care • Complex care needs to be handed over between shifts to enable good care and prevent continual repeating of needs by patients; • Clinicians working as a team between and across departments; • Able to access advice from departments outside of their admitted location; • Availability of medical history and care plan within the Emergency Department. Other: 1. Importance of an expert to insert an intravenous cannula; 2. Appropriate management of intravenous cannula; 3. Importance of pleural effusions being drained by an expert; 4. To work with senior staff given complexity of needs; 5. Managing issues with rotational intern programs in rural and remote setting for this population 6. To accurately assess a person with palliative care need's current situation and related requirements	*buzzer and the nurse would come and help me do it whatever, to get out of bed or whatever. When I was in recovery after my operation, I couldn't move for four weeks. I couldn't get out of bed, so I had to go in the toilet in the bed and all that sort of stuff and I couldn't shower and they had to wash me with a cloth. So yeah, they were just really good. They were just there every day and they'd always come in and they'd change the sheets and they'd have someone come in and help me roll over and yeah, they were just... I can't knock them. (Patient 1, 48yr male with malignancy)* Family data *Interviewer: When she's in hospital and your dad was doing that, was that because he wanted to or because the staff weren't available to help? Family 5: Bit of both. It started off that it's because there wasn't anybody to help, and then he just... Mom felt more comfortable with dad doing it, because it was more comfortable because it's like what they do at home (Family 5, 50yr female carer for mother with malignancy)* *I haven't really had any issues, like I haven't been there the whole time, mom hasn't had any issues, and if she had any, she's one to pretty well voice them. I think she's a bit on edge with that because there is a lady next to her who's literally been left in shitty nappies all day, and she's meant to be getting help feeding, and they'll leave her for hours before they feed her and stuff…So I think in terms of the way they deal with mom, yes, they are, because mom's alert,*

	7. Clinical competence of the nursing staff 8. Timely response to requests for care, especially for people with breathlessness	*but this lady that's literally next to her who can't even talk, or feed herself, and it can be a completely different story (Family 6, 30yr female carer for mother with malignancy)* *the Friday night…So, I asked the nurse to take her into the shower. … I mean with not being washed for a day and a half, it is pretty bad, you know? (Family 9, 64yr female carer for father with non-malignant illness)* *Yeah. Yeah. I mean they're good as far as that goes and hygiene and everything like that they're really good there and she seems comfortable in there (Family 18, 59yr female carer for mother-in-law with non-malignant illness)* *Yeah. When she's in she's that sick that she does, and dad was doing that too, so doing her showers and taking her to the bathroom. The only time he didn't was the times where she really couldn't walk, when they actually needed to put her on a commode to take her into the bathroom. But he does that at home too. She can shower herself, but he's always there just in case she slips or does something. She can dress herself, she can feed herself, she can do all of those things. But there are times when she's actually really sick that she needs help with those things (Family 5, 50yr female carer for mother with malignancy)* *And the nurses changed the sheets all the time. Just little things like that where you're being looked after. Like, they got clean sheets*

		and being looked after (Family 1, 53yr male carer for brother with malignancy and parents with non-malignant illness) *Well, I arrived there on Sunday morning at about 9:30 am and I said, "Oh, mum, what's going on?" And you know, she hadn't had a wash for a day not since she'd arrived on (Family 13, 56yr female carer for mother with non-malignant illness)* *So basically, when he started getting better seven days, he wanted to have a shower. Couldn't get anybody to give him a shower. He did not have a shower until the last day of him being in hospital, no one had the time to give him a shower, they kept on telling me, 'You go and give him a shower.' And I said, 'There is no way I'm going to go into a wet bathroom and give him a shower, I don't want to fall myself, I've got a bad knee,' and for 13 days I could not get anybody to give him a shower until the last day when he was going home. That's terrible…And I tried chasing them, and they're too busy. The nursing stations, there are little desks, are unmanned most of the time. And heaven only help anybody if they need a bedpan, because you could bust, you could throw your bed 33 times, nobody would come. I don't blame them, they don't have any time. These nurses work like slaves, it's not right (Family 12, 78yr female carer for husband with non-malignant illness)* Bereaved Family data

		She was never messy. She has never left dirty. She has never left untidy. She was always 100% looked after in that way (Bereaved family 10, 43yr female carer for mother with malignancy) *My father was incredibly comfortable. His face was relaxed. His breathing was relaxed. The nursing care was exemplary. It was just beautiful. On a busy general medical ward, it was superb (Bereaved family 13, 54yr male carer for both parents with non-malignant illness)* *Not enough. Like, they did what they had to, but I don't think it was adequate. As I say, you can make somebody very comfortable by, patient X's had a lot of ulcers in her mouth, well nobody offered her mouth care. I had to go and get all the stuff, I had to ask for Bonjela, I had to ... If I hadn't been there, she would have just been lying there, and that's painful. You just don't need that additional pain. ..It was just little things like that that were getting missed, basic care that makes people comfortable (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)* *Well, I've got a jaded view of that. I think that's the case generally across nursing. I think people, they go, "Oh, we've got to wash them once a day and that's it." I don't think that they're taught the importance of those little things for people who are on bedrest. That's what I think. It's not an expectation anymore (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)*

		It's the personal hygiene stuff. I think more of that. If not done by the nurses, at least enabling family to do it, and giving them some ideas of things they can do, because I think a lot of people are scared to touch the person (Bereaved family 8, 56yr female carer for mother-in-law with malignancy) *Especially when you're dealing with high-care kind of patients. Just to shower them and whatever. We've been there and there's been piles of towels lying piled up in the bathroom. The next patient's going in there, and things like that really shouldn't be happening (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness)* *The other thing was that, and again I don't know whether it was because I was there or not, but the whole week that she was there, nobody ever came in to offer to help her to have a shower. Or to check whether she could manage in the shower on her own. Nobody offered to see if she wanted any help to clean her teeth, or anything like that. There was no personal care was offered at all. Whether that was because I was there or not, I don't know (Bereaved family 4, 69yr female carer for friend with malignancy)* *"They can't provide any personal care, we're doing the mouthwashes, we're turning him, we're doing all of it because there just aren't the staff" (Bereaved family 6, 68yr female carer for brother-in-law with malignancy)*

		The physio was good, but they ... the nurses seemed to be ... I don't think they were that good really. They didn't look after his back properly and he didn't tell me, but the wound opened up and started seeping from the back surgery (Bereaved family 7, 56yr female carer for husband with malignancy) *I mean, again, I think the fact that they didn't pay enough attention to the wound opening up and then that ... that might not have been where the sepsis came from, but it wasn't good and it was ... as soon as I knew ... he didn't tell me either and as soon as I knew that that wound was leaking, I was beside myself. I thought, well, that's no good, something's got to happen. They were in ... that's another reason they sent him back to neurosurgery, because they were really good at wound care and really keeping an eye on the wound. So, that was awful (Bereaved family 7, 56yr female carer for husband with malignancy)* Symptom management Patient data *The doctor was very good. I think, they're trying to do their best. Since I don't have any, really any solution. They talk to me, they ask me, they readjust the dosage and things like that. Very good. (Patient 11, 72yr female with malignancy)* *And the quickest thing for me was that I get relieved of the pain (Patient 14, 45yr male with malignancy)*

		... the attention to your problem, the attention to your wounds. I had one nurse just by visualizing and looking at me and noticing me, could identify if I needed pain relief. (Patient 14, 45yr male with malignancy) *Oh, pain. Yes. Nerve pain, but there, it's under control. (Patient 19, 69yr female with malignancy)* *My palliative care doctor is fantastic. (Patient 19, 69yr female with malignancy)* *The comfort I got from all the doctors. What was most important to me? Oh probably, love, pain free. (Patient 8, 77yr female with malignancy)* *Oh yeah, well, I went in with severe pain and bloating, love. And I think it was the Tuesday night, they started me on new medication, which was morphine. And I woke up at 2:00 in the morning and I was pain free. Can you believe that? (Patient 8, 77yr female with malignancy)* *They had it pretty much downpat, they had me on all the right medication. And they'd bring it in... every like they'd bring in the morning and lunchtime and night. I still have little bits of pain here and now and then they might give you an extra Panadol or something like that through the day. But to be honest with you, the doctors, they nailed it, they pretty much knew exactly what was*

		happening. And the pain management lady at... (Patient 1, 48yr male with malignancy) Family data *Well, for the symptom management for my dad, it's been wonderful. He came into accident and emergency in agony with bone metastases flaring, and it was quickly managed (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness)* *It's sort of, come to the stage where it's all about managing the pain and making her comfortable, that's what I think it's all about. And that's what she got (Family 10, 73yr male carer for wife with malignancy)* Bereaved Family data *For me, it was about making sure that they maintained her dignity, gave the family some space to be around her, and gave her adequate pain relief (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)* *Oh, absolutely. I think when she was conscious, it would have been really important for her to be involved in actually spending time, saying, "How much pain you in?" Rather than, "Oh, if you had much pain, would it be 1 out of 10? What would it be?" That to me, is not actually when you're talking to someone of that generation, she's*

		not going to make a fuss. She's always going to go, "Oh no, I'm okay, dear." Because nobody's actually delving into the personality or the background of the person to understand the way they engage with those pain scales, so its just this kind of, they know they've got to tick a box, so when they do a medication round, they'll tick a box. "What's your pain score out of 10?" (Bereaved family 8, 56yr female carer for mother-in-law with malignancy) *Well, there was no connection. It was literally, "I'm just taking your temperature, I'm taking your blood pressure, and now out of 1 to 10." There was no thought in it, no critical thinking behind why am I doing this and does this scale actually mean anything to this person? How do I engage with them to actually get them to give me an honest, a deeper answer and an answer that's actually a real answer, rather than trying to please the nurses so that they don't make a fuss? That kind of thing (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)* *And what was important to me was about her care was that she was treated with respect, which she was, that her pain was managed wherever possible, which I'll give them 5/10 for that (Bereaved family 1, 66yr male carer for wife with malignancy)* *But you know, two days prior to that, my father is complaining of stomach, not two days a week before that he's complaining about stomach pain, abdomen pain. And it's in the file, it's all in the file, abdomen pain, abdomen pain. And it says next day, still complaining about abdomen pain. They're giving him laxatives*

		'cause they thought it was his bowel. The machine that actually measures, that scans his bladder, takes two minutes to use, and it's sitting outside in the hallway. Two days before they actually find it...my Dad's...I get a call from the nurse in the middle of the night saying, "your Father is hitting himself in the head with the remote, T.V. remote, saying that he wants to die. Can you please come down?" And the reason he is doing that is because he's been in pain for those three days, because his bladder. He had so much pain that he couldn't take it anymore... (Bereaved family 12, 54yr male carer for father with malignancy) *Let me think. I guess what would've made a lot of difference to my friend's care was people actually checking on her, and doing proper pain assessments and I suppose the general attention to care that seemed not to be a priority. I think that would've made a big difference. It's actually the caring part of it that really stands out for me (Bereaved family 4, 69yr female carer for friend with malignancy)* *I suppose the most important thing was responsiveness. You know when we wanted, for me I wanted to know that when things were getting bad or if he needed something that a nurse or a doctor was, you know, was able to respond straightaway (Bereaved family 11, 33yr female carer for father-in-law with malignancy)* *Well, everyone goes on about dignity in the end but the reality but the reality is there is nothing dignified about dying. So, you know, I think for me what we all found was the thing that we needed was*

		nurses and doctors that were available to respond when he needed it, when Patient X needed (Bereaved family 11, 33yr female carer for father-in-law with malignancy) *It was actually really traumatic watching him pass away to be honest. He was, you know they eventually gave him enough meds that his body wasn't stressed. Even though, whether he was there or not, doesn't really matter but his body looked like it was so stressed because they didn't give him enough meds. So they, I don't think they weighed him when he was admitted, so they kind of guesstimated his weight and he was a big man, like he was very overweight, and I don't think they actually, you know we all at the time were like, "They haven't-" even the nurses, a couple of these nurses said they hadn't given him enough drugs. So at one point in that final day I actually had, I went up to the nurse because I was I suppose the most distant from the situation being an in-law, not a daughter, and basically demanded that a doctor come down and give him more drugs straightaway because he was just, you know, almost hyperventilating with his breathing. His whole body was shaking. It was just awful. So responsiveness would be my number one (Bereaved family 11, 33yr female carer for father-in-law with malignancy)* *And I suppose the other frustrating thing is, and I know they have to do it because it's too open to abuse otherwise, but the having to wait for second nurse or a doctor to go and sign off to give meds. I mean, but having to do that even to just Panadol and nurofen is just*

		a bit much (Bereaved family 11, 33yr female carer for father-in-law with malignancy) *Actually one thing that would've made a big difference for us - the doctors prescribed the medication and the max limits and that was a thing where we needed that changed and we couldn't actually get a doctor for almost an hour and a half to have that changed. But once those pre-approval or pre-authorizations are in place from the doctor for the nurses, you know, the nurses can more easily hand out that medication. If that whole process was somehow improved- I don't know if that's that they need more doctors around or whatever but..it took a long time to get the doctor back down to reassess that (Bereaved family 11, 33yr female carer for father-in-law with malignancy)* *And how frustrating and it is actually quite traumatizing because it's the pain levels. So someone who's actually dying and having to wait for that, whether they're consciously aware of it or not, cause that was one of the things that, you know, a lot of the time the doctors and nurses said, "Oh, he's not conscious, he's not aware of the pain, it's just that it looks discomfiting to you." That was actually something that was, I suppose, for me having had that experience I'm like, "Well, yeah, you might say that he's not consciously aware but you don't know that for sure."..That was incredibly stressful thing for, like me, for XXX and for the rest of the family that were there with ..So it would be, if there was some way to still have adequate assurance levels on the administering of drugs, but*

		without having such, you know, significant delays in getting drugs to patients, I think that would be a great improvement (Bereaved family 11, 33yr female carer for father-in-law with malignancy) *So she went back to coronary care, and so then started two very different paths of palliation. So my colleague said to me, "Bereaved Family 13, you're the palliative care doctor, what would you do for your mother?" The irony of that was I suggested that he write her up for some regular low-dose morphine for her breathlessness. He kind of did that with a bit of trepidation, which was interesting to watch at a cerebral level. This is what I spent my last 20 years working on. Here's a colleague who was absolutely my best mate at University kind of going – you really mean that bereaved Family 13., But he did it. And, the difference was absolutely amazing…There's no doubt that she'd blown a valve and was in extremist, but her breathlessness settled. She was able to get some sleep at night, and she was able to actually spend longer time with us because she was so much more comfortable and so much less breathless. Really, that was her physical palliation. And it worked phenomenally well (Bereaved family 13, 54yr male carer for both parents with non-malignant illness)* *And I wasn't there. I came home to feed the dogs and she rang me and told me she had a visit with this doctor. And she said, "She was really great because she actually listened to what I was saying." And so she relayed the whole story and then at the end of the story, the doctor said to her, "Well, I can see one problem right off the bat,*

		and that is that Oxycontin's designed to be absorbed into your jejunum and you don't have one." So it was backing up and she was being poisoned by it. So, that was probably the worst part of the whole thing (Bereaved family 1, 66yr male carer for wife with malignancy) *What was a problem though, the day the tube was put in, I was there during the day, and I had left probably about six o' clock in the evening. I was a little bit concerned because the lady was quite uncomfortable, but I thought well the chest tube is uncomfortable and I knew she written up for analgesia and so I thought she would probably be okay." So I went home. When I came back early the next morning, I really only took one look at her and I was really quite alarmed I suppose would be the word. But she looked really really sick. She was a terrible colour, she was very distressed sitting up on the side of the bed. Said she'd been in really dreadful pain all night, that she'd rang the bell and it took a long time for anyone to come. When they did come, they gave her some minimal analgesa and went again, and never came back to check whether it had worked or not. She said, that she'd just been up on the side of the bed in agony all night. This was sort of early you know, when the medical teams were gathered around the desk, I suppose getting hand over and the registrar happened to be there and so I went and spoke with him and asked him to come and have a look at her. I said she had an absolutely dreadful night, and has a degree of pain that's far beyond what should be for that procedure. And he came and looked at her and agreed and obviously thought that something*

		needed to be done. … However having been there, coming that morning. I was upset that my friend was so distressed and had spent a terrible night in pain. But the thing that really got me, was that nobody had noticed that there was anything wrong. I thought these people have been here all night and nobody had noticed that that this person looks absolutely dreadful this morning, and that there's obviously something wrong. I took one step inside the room and thought there's something very wrong here (Bereaved family 4, 69yr female carer for friend with malignancy) *Yeah, I think that the medical team seemed to be more aware of what was happening with her as a person. They were concerned about the pain, they were concerned that there was obviously some reason for it, that they had to get to the bottom of, and they were concerned that they needed to make a plan to fix it. So I think we both felt that the medical team had her interests at heart (Bereaved family 4, 69yr female carer for friend with malignancy)* *Yeah. I think that maybe competency is the word, or incompetency I think. The fact that my friend was in a lot of pain after the first procedure and she's not someone that's got a low pain threshold or complains about anything. She's really quite a stoic sort of person. But she said she had to ring three times with some time in between each, before anybody came at all. And then when they came they just gave her 1 endone or ½ and endone I think and then went away and never came back again to check whether it had worked or not, and it obviously didn't work. So that didn't seem to be a*

		priority, they weren't really anticipating pain or assessing it well at all I didn't think (Bereaved family 4, 69yr female carer for friend with malignancy) *Oh, no, no, no. That was brilliant. In the admission... That was so, so, thoughtfully managed. She was never in pain, pain relief was always very forthcoming and they managed that really, really well. And that's the one thing, the whole blessing of what she went through with it. There was no point she was ever in pain. That's I think, a really important thing, in that sort of palliative... you know that last end stage, is that you just don't want to see anybody suffer (Bereaved family 5, 56yr female carer for mother with malignancy)* *For me the most important was for them to get the history. To really understand the continuity of care because the first time when he went into emergency, they were quite shocked seeing him, with his ascites, with him on oxygen, with this uncontrolled nausea. And I thought this has been going on for six weeks. They brought in the senior consultant in emergency who immediately did an ultrasound of his heart to see if there was fluid around the heart. And the care in emergency was extraordinary, it was absolutely extraordinary. They immediately put him on IV fluids, because he was dehydrated. So I would say the care once he got there was better than what he was certainly getting from the medical oncologist and, well, there was none from the palliative care team at that stage (Bereaved family 6, 68yr female carer for brother-in-law with malignancy)*

		They weren't just looking at his nausea. They were looking at his ascites, they were looking at his immunotherapy. And then I think it was on the Sunday, they did the ultrasound and then, I forget how many mls they said were there, they said "Look, this is a weekend at a hospital. We're not that experienced. It would be far better for the palliative care people to drain this. We don't feel it needs to be drained yet, there's not enough there to warrant it but when it does need it, it's better that the palliative care people do it because they're more experienced" (Bereaved family 6, 68yr female carer for brother-in-law with malignancy) *It was just instant in came the machine, they did the chest x-ray while he was there, they did the ultrasound, they had bloods, they had the first round of bloods back within, I think, the first hour and a half that we were there. And that was appropriate. I think up on the ward, getting a full history and a good picture of him was appropriate (Bereaved family 6, 68yr female carer for brother-in-law with malignancy)* *So, some of them were amazing and really they were efficient, effective, kind and attentive and some of them were a little bit vague or too busy or didn't ... you didn't feel like you really got the sort of ... when I say attention, I don't mean attention, seeking attention, I mean the looking at Patient X, taking into account what was happening and doing whatever needed doing next or should be happening, that kind of attention is what I mean (Bereaved family 7, 56yr female carer for husband with malignancy)*

		Yes, I think that there wasn't attention being paid to what was actually happening with the people. That it was more, it seemed to me they were just there doing what they had to do, without actually assessing and looking at the person (Bereaved family 4, 69yr female carer for friend with malignancy) *But the time that this person turned up and it was like a great relief by the time they turned up. When they did finally turn up, they walked into the room and it was starting that process right from scratch. So Mrs X, what's wrong with you? What's brought you into hospital? It was that oh... It was probably a little bit down the line, to be starting that off, but I understand. That's how some of the, taking the history taking process goes. I get that. But then it became really evident pretty soon on that, this person hadn't even read a single note. That they had come in totally cold… she was asking mom about, "Oh, you know... See even the things like that. Maybe you've got an infection." At which my sister and I, said, "Oh, yes, she's actually been diagnosed with aspiration pneumonia." To which they said, "Oh, has she?" Then they left the room for probably 10 or 15 minutes to presumably read the notes, that they probably should have done, before they entered the room (Bereaved family 5, 56yr female carer for mother with malignancy)* <u>Integrated care</u> Patient data

		They will not give you any specific time. They will going to give you broad answer, this afternoon. And that afternoon will going to last up to eight o'clock in the evening. Waiting for them to release you with just two pieces of paper. I do not know what the kind of system like that. It always does that. ... And you waiting starting one o'clock to 8:30 in the evening. Waiting for the two pieces to be released….We cancer patients are always in the seventh floor, and it's very hard for us if we are being sent home and walk from seventh floor down to the parking area, so we need a wheelchair. And waiting for a wheelchair takes you one to one and half hour. (Patient 21, 50yr female with malignancy) *The only thing is, when you're discharged from hospital, only once have I had a sheet given to me on the discharge summary. And, my GP has never got summaries from them. She's always complaining. I have to take my list of medication in and explain what medication I'm on. (Patient 3, 80yr female with non-malignant illness)* *Yeah, they work in conjunction with each other. Yes. Except, as I pointed out earlier, except the fact that they somehow got the medications situation... my personal medications went awry somewhere along the line. (Patient 7, 59yr male with non-malignant illness)* *Apart from that, everything was fine. (Patient 7, 59yr male with non-malignant illness)*

		They all worked like a team like unbelievable, yeah. (Patient 1, 48yr male with malignancy) *During the first couple of days, no. They didn't communication to each other very well, and that's why I had the problems with the opioids. (Patient 18, 71yr male with non-malignant illness)* *They were pretty apologetic about it. So, in the private situation, because you have private doctors and you're a private patient, it does have to communicate. In the public hospital, it's more a team. (Patient 3, 80yr female with non-malignant illness)* *She always let the nurses know - The nurses knew what the plan was (Patient 4, 54yr female with malignancy)* *Well, I had also the oncology team as well. I was admitted under oncology because of my cancer, but the directive was pain because I went in with a lot of pain and weight loss issues and they were very good as well. So they knew what Professor XXXX was doing as her treatment, and the oncology team were checking in with that. So they all knew. Everybody was talking to each other. Which was great. If you don't have your staff talking to each other, you can get a gap in the hole. (Patient 4, 54yr female with malignancy)* *Well, yes it is, because it's very hard, because they've got to coordinate. And there's usually ... You've got the nurses and they change over, and suddenly you see somebody you've never seen before. They don't know you, they don't know the ward. They've got*

		a whole ... It's not just your ward, it's the whole ward. (Patient 10, 82yr female with non-malignant illness) Family data *…nurse doesn't know what's going on either, and it is just that task. "I'll just do my tasks, and I don't really know anything about you. Then I'll go home at the end of the day." (Family 5, 50yr female carer for mother with malignancy)* *..they sort of don't seem to know what the other part's doing. You know, the doctors don't seem to know what the nurses are doing, or the nurses don't seem to know what the OH safety people are doing, and they don't seem to communicate very well with each other (Family 18, 59yr female carer for mother-in-law with non-malignant illness)* *They are two incredible teams that work together and look after him, and basically speaking, considering that we are in our ninth year of all this - No one thought that he would be around after the first year…So full credit goes to those two teams, and of course let's be quite honest, without the hospitals, it would not have been possible (Family 12, 78yr female carer for husband with non-malignant illness)* *Well, basically, the doctors working together too. As I said, I'd mentioned to the medical and surgical staff, even though dad came in with a medical problem, then it became more so a surgical*

		problem, and that they're able to sort of work together and say, "Well, okay. We've done all we can do on the medical side of things, so now we can get the surgeons to have a look," and that type of thing, like that holistic approach (Family 16, 59yr female carer for father with malignancy and non-malignant illness) *Yeah, and my sister was sort of saying, "Look, what? This is just totally wrong." The surgeon would ring me, the surgical registrar, and talk to me, and then I would speak to the medical registrar. So one day, I said to the medical registrar, "Look, I'm just wondering would it be all right if you could talk to the surgical registrar and talk to each other and see if we can get our heads around this because," I said, "I'm sort of getting so many different things that are happening here. We're just totally flabbergasted. It's overwhelming," was the word really. And so Dr XX went and spoke to the surgical registrar, and that's where it seemed then that, okay, this is what we're looking at on the surgical side of things, medically we've done everything that we can possibly do for dad in giving him the blood and the iron infusion. So, "Now, we've sorted that out. We can hand you over to the surgeon. ..So I think they did a good job once they started talking to each other (Family 16, 59yr female carer for father with malignancy and non-malignant illness)* *I was really pleased to see that they were picking up on changes in her. She's very clear-thinking and then I got there one morning and she's like someone with dementia, like twiddling her thumbs and trying to work out why she's there, what's happened to me, does*

		her family know. And I said, "Yes." And she said, "So, they're in on this?" She's totally unaware of ... And I called the nursing staff and I said, "That's not mum. She's not like that." They go, "Oh, we read her notes and saw that yesterday she wasn't like that." Basically, this is new staff that haven't met her before, but obviously the notes were clear enough for them to understand there was a change in state. And so they had the doctor coming to change the medication. And another morning, I went there and she had these jerking movements and I called them again. I said, "She's got a like a tick, like a little electric shock that comes over." And they go, "Oh, yes. We noticed that so that medication's already been stopped." So, to me, being that aware and their note-taking must be very, very good for new staff to be able to pick up where the old staff left off (Family 11, 61yr female carer for mother with malignancy) *And she just sort of looked at me and I said, "Well, it is in his history there in his notes." And it didn't appear that it had been in that. She said it hadn't passed on, and I thought, "Well, this is..." And I am a nurse myself, so I would have been through all of that before on a work level, but when it's the personal side of things, it's very, very different…. So it was just sort of that knowing. I know people get very busy, but it's about knowing that that's an issue when they come into hospital (Family 16, 59yr female carer for father with malignancy and non-malignant illness)* *It was kind of, "Oh, we're really sorry about that, but we're looking at these other things." And, yeah, it was kind of like, well, they didn't*

		really seem to have that depth of understanding there, and often, it was like the consultant would do the rounds, and then you'd have the resident or registrar who would be doing the rest of the work, which I mean, I know that happens, but the consultant would come around and say, "I'm really sorry, and blah, blah, blah." (Family 16, 59yr female carer for father with malignancy and non-malignant illness) *Yeah. Yeah. They sort of don't seem to know what the other part's doing. You know, the doctors don't seem to know what the nurses are doing, or the nurses don't seem to know what the OH safety people are doing, and they don't seem to communicate very well with each other (Family 18, 59yr female carer for mother-in-law with non-malignant illness)* *What I've found is that it doesn't matter that she's a private patient under a private hematologist. That's just how it happened three years ago when she went in, she was in a health fund. They admitted her under a hematologist and he's kind of followed through, but all her care goes through the public system. So it's extremely fragmented care. There's not great communication between any of the care professionals that she has, and that's right from nursing staff through to the consultants that she sees (Family 5, 50yr female carer for mother with malignancy)* *One of the biggest things and problems was he was admitted under... so he finally went up to the ward under a surgical team. Yet it became very obvious within 24 hours that they really weren't*

		going to be managing him, once they'd got this catheter in. Because he had a urethral stricture, and so they needed the urology team to, with a guide wire, put a very fine bore catheter, which, we then elected to leave in until he actually dies. And once that was in, he was left admitted under the urology team. Lovely people but I think they were out of their depth in management of his renal state, so they referred him to the renal department, but the renal department were coming in more just on an on-call and an extra add on feature. And yet, he was still being managed by the urologist. And they were really not playing a role at that stage. And so he was put on medication to try to treat his prostate enlargement, and stuff like that, which I actually had to request the medication was ceased. Because they weren't, I think and felt the communication between the two teams, as much as they are both good teams, was actually not great (Family 9, 64yr female carer for father with non-malignant illness) *Because it's not just one person, it's a team of people. And they really put all their ideas together, what would work best. So, you're looking at more than one person's knowledge. So, to pool people's knowledge and get the best of care I think is a great approach. I was pleased to see that there because it's my first experience in the hospitals with cancer, so to see so many different teams of people working together is really good (Family 11, 61yr female carer for mother with malignancy)* Bereaved Family data

		I think the NUM on the ward really sets the scene for a ward as well. Yeah, the one in the stroke ward was particularly caring and compassionate, and very open door with her staff and that. So that was a real team, you could tell it was a team. You can tell the wards that have got a team, or you can tell the wards that are a ward. Yeah, there is a difference…You just them engaging with one another in a pleasant manner, talking to one another. It just seems organized. You see them working together often in pairs more than just one on one, kind of thing. You see them consulting. You see doctors and nurses consulting on equal terms, kind of thing. Not barking down at them, that's all (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness) *So we called an ambulance and they took him into emergency and they kept him on the medical ward for the Saturday, Sunday, and then referred him back to presumably the palliative care team or medical oncology. And that was the other issue, that it seemed as if the different disciplines weren't talking to one another. The thoracic fellow wasn't talking to the medical oncologist wasn't talking to the radiation oncologist weren't talking to the palliative care team….Yeah. It was very piecemeal. It was very "This is my discipline, this is what I look at. This is my discipline, this is what I look at" (Bereaved family 6, 68yr female carer for brother-in-law with malignancy)*

		It was as if everyone stuck to their disciplines…So there was no combined discussion of goals of care, of a treatment plan. Everybody in their little silo did their own thing and focused on their little bit of it (Bereaved family 6, 68yr female carer for brother-in-law with malignancy) *I think to be honest with the social working department, like when we organized to get mom home, and it was on palliative care. We knew she had very little time but we did try to get her home. There was a lot of miscommunication between when she was going to be discharged and what day. And I was told one day and then I'm getting phone calls about another day and about picking up equipment. So that was the only experience in the whole thing that I have something negative to say about because I just think it was very stressful. I even ended up having words with one of the social workers saying like, "This is the third phone call I've had today and every phone call has been different information." And then you're telling my mom who at that time the brain cancer was really affecting her and all she wanted to do was get home and they sort of kept telling her different things and that was hard for me to handle on that side as well. But yeah, that was a bit difficult. Maybe if they had a little more communication between the social worker side and the nurse and doctor side to make sure that the information that the family and the patient is getting is sort of 100% correct across the board (Bereaved family 10, 43yr female carer for mother with malignancy)*

		The other thing that happened, she'd been there for a week and the day that she was gonna be discharged. She's pretty I suppose over being in there. It was really hard to get out of the place. We had to wait hours for the medication to be sorted out even though the discharge had been anticipated. And then the registrar wasn't able to sign off on the discharge, said she had to wait for the oncologist to sign it off (Bereaved family 4, 69yr female carer for friend with malignancy) **New data to support additions:** Physical care Patient data *When I, like, I had trouble with my bowels also, because I'm on special medication and I get embarrassed. They said, "Patient 8, don't worry about it," you know? They're very, yes, they made me feel at ease. (Patient 8, 77yr female with malignancy)* *And in those situations, you can't be independent, then you need the help and assistance. And you realize you lose your independence, so you've got to be, you are just another person. I understand that, but no, I think it's empathy. I think nurses have to have empathy. (Patient 18, 71yr male with non-malignant illness)* *As I say, they're more than willing to help you (Patient 17, 66yr female with malignancy)*

		I really do. I agree whole heartedly. There's nothing too much for them (Patient 17, 66yr female with malignancy) *I understood if I needed my diaper changed they couldn't come immediately because they were doing other things, so that was the reason. Like they'd say "We'll be back in five minutes," or something like that, and they were. (Patient 17, 66yr female with malignancy)* Family data *And he's had a couple of accidents in the bed and on the ward, and again, just very gently approached it. Rather than being roused on, you didn't get that sense of "I haven't got time for this"…It was like, you're the focus here, It's all right and often nurses would try to make a bed and when he was sitting on the toilet, and their running in and out all the time, just making sure he's okay, while they're trying to do their job. I just sensed there was great empathy and compassion (Family 9, 64yr female carer for father with non-malignant illness)* Bereaved Family data *They were very good at coming in every two hours and doing the turns, if I requested extra medication for patient X, they were very good at being on time to do that. But, there wasn't much more in it than that. And they were kind, when they turned him, they treated him respectfully. But certainly, beyond that, it was very much just to*

		tick the box, come in, do the turn, do a wash , make sure he's clean, and come back then two hours later (Bereaved family 3, 43yr female carer for brother with non-malignant illness) *Oh everything. Her physical care was fantastic. They were making sure... They'd roll her. Make sure there was no bed sores and just really meticulous with their administration of medication. But, even more than that, the care in terms of their spiritual care. The emotional care. The way they treated her with respect and dignity. Apart from that last, when she had actually passed away. That last one was just really good. So, I couldn't... the complaints I have, don't relate to the care process from the nurses (Bereaved family 5, 56yr female carer for mother with malignancy)* *they sent us out of the room and they washed him and made him comfortable and whatever. I can't remember when that was. But, that was quite a strange process because they actually said, go out of the room because it'll be distressing and come back. But they did that very respectfully too… . I was a bit shitty about it. I thought, okay , all right, I will (Bereaved family 7, 56yr female carer for husband with malignancy)* *Sorry. And this is really basic stuff. It's like the nappies. Well the guy's got colorectal cancer, with crap permanently coming out of his anus. Really? Can't you put a decent supply of nappies in to someone that's getting up every 20 minutes before or after a prep. that's what I meant. This is the thing that I suppose you go through, and you tell them, and they write it down, but they're busy, and*

		they've got lots of people coming in, and lots of people getting ready for surgery for the next morning. So, I feel always like I didn't write any negative complaints at the end of the day to the Hospital XX, but if you're asking me for details in this sort of questionnaire, I definitely think there is room for improvement (Bereaved family 9, 57yr female carer for father with malignancy) Symptom management Patient data *they ask you for example, comfort giving your medicine and they ask you, you're taking this, they shouldn't really ask you because they give you different names of the medicines and you are very confused from their morphine and all of that. So they should be self-assured they what they come to give you. They say it's antinausea that's fine. It's for the pain, that's fine. But if they say always MS-contin and then they say oxytocin and then they say, I don't know all these different names, then you get confused… One form, one function. The function is pain, you're giving a pain killer. The function is stomach, you give whatever. (Patient 11, 72yr female with malignancy)* *At first, I thought asking for more pain relief it seemed a little bit wussy on my part, but that was my head space. And they just kept reassuring me and saying, “Don't be afraid to ask. You need to ask because that's how we're going to measure your dosage. So, don't just lay there in pain and wait for the four hour gap when you're getting something else, asks for it.” So I thought that was really*

		good. They kept saying to me, "Ask for it. Don't be afraid to do that. It's okay to do that." (Patient 4, 54yr female with malignancy) *When I was younger I had two really good mates and they started taking tablets and pills and stuff like that, and then their lives just changed and they ended up getting all the over drugs and one of them died and the other one, I don't know what happened to him. And it was through just taking... I just hate taking tablets (Patient 1, 48yr male with malignancy)* *Because what happens when you can't breathe, everything ... You sort of hit a panic button. And you get all hot, very very hot and flustered. You want cooling blowing on you. You start to wheeze because you've got no control because you're panicking (Patient 23, 69yr female with non-malignant illness)* *And they can't always find a fan for me (Patient 23, 69yr female with non-malignant illness)* Family data - Nil illustrative quotes Bereaved Family data *But the thing about pain relief for me is they focus on the drugs, which is really important, but what they didn't focus on was on the other stuff that relieves pain. I was doing things like getting bowls of warm water and soaking Patient X's hands and feet in those bowls of water, which she just thought was fantastic. They don't have the numbers to do that, and I get that, but the pain relief certainly*

		seems to focus very heavily on just drugs. It took a little while for them to put a butterfly in, so when she was on the ward, she didn't have a butterfly cannula in, so it was kind of like just intermittent medication and they hadn't thought about how much to give her or what to give her. She was in a lot of pain, intermittently, so that was not good. I think probably they need the pain team in more quickly (Bereaved family 8, 56yr female carer for mother-in-law with malignancy) <u>Integrated care</u> Patient data *Or, they say, "It's changeover time." I always forget what ... I pretend I don't want to listen to that, because it's hard. Because they've got to change over, and then they don't know who you are. And then we're back to square one, because they don't know who the lady across the road is, who can never find her button, who falls out of the bed, and things like that (Patient 10, 82yr female with non-malignant illness)* *You've got the nurses and they change over, and suddenly you see somebody you've never seen before. They don't know you, they don't know the ward. They've got a whole ... It's not just your ward, it's the whole ward. (Patient 10, 82yr female with non-malignant illness)* *And as the shift changes, so the old nurse will walk around with the new nurses and say, "We've got this guy in this bed and he needs*

		this and this and this." And, "You've got this guy in this bed," and they go through, but they're only giving the basics. (Patient 18, 71yr male with non-malignant illness) *I just thought, well, "I'm doing all the things, they're communicating on all things, so I'm going to get out of here. I'm going to get out of here soon." (Patient 4, 54yr female with malignancy)* *Communication between departments is nil. It is absolutely off the tree, and that is very important, because you need that communication between departments. (Patient 10, 82yr female with non-malignant illness)* *And that's got nothing to do with the patients. That's the department. If the departments cannot communicate, god help the bloody patients (Patient 10, 82yr female with non-malignant illness)* *The doctors don't communicate. I mean, in private patients. I think in public patients they get a better integration with doctors... with the team of doctors. But, when you're a private patient, you have various doctors. I've got an endocrinologist now because of my parathyroidectomy. I've got a gut guy because I had gut problems as a result, and I've got XXX who's my renal specialist. And while they will communicate – they do communicate- they are fine.. I've had one problem because of medication that was understood by one of them. So, I've actually seen when it's fallen down and they've got good communication. They were pretty apologetic about it. So, in the private situation, because you have private doctors and*

		you're a private patient, it does have to communicate. In the public hospital, it's more a team. (Patient 3, 80yr female with non-malignant illness) *Once you're in hospital, getting anybody in another department is ... forget it. It's impossible. Communication between departments is not on. It is one of the worst things to try in the hospital. If you don't know somebody ... I tried to get somebody ... Who was it, the other day I tried to get on the phone, and they said, "You can't ring that person, because it's a human being. And you're not allowed to ring them." I said, "Why?" I know the ... "No, because you're in hospital you can't ring them." I thought, "God, help me." Yes, thank you. You know, that's annoying because you can't get hold of the people you want to get hold of. (Patient 10, 82yr female with non-malignant illness)* *...one thing more, in the emergency, they... Isn't it, our profile, is in the system already, in the computer? So, why is it that they need to repeat all over and over again- ... the interview before they go in to cure you? Patient 21 (50yr female with malignancy)* Family data *Well, also that she's got dementia so, she's not really understanding that there might be a specialist nurse or practitioner that understands... You know, there's looking after the medical condition of the person obviously, but understanding how to take care of a person with that condition (Family 13, 56yr female carer for mother*

		with non-malignant illness) *So they all come together and they have a meeting every morning and discuss the patients of the day, and so they do discuss all that sort of stuff, but there didn't seem to be anybody that was solely for that role, the dementia sort of things (Family 16, 59yr female carer for father with malignancy and non-malignant illness)* *Because when we met the palliative care nurse it wasn't really palliative care. So, we were in shock – what is this? At that time for me palliative care was end of life care. But later, they explained it to us, that palliative care means supportive care – it is palliative and supportive care. They didn't tell us that on that day. They just said we know for lung cancer patients it is better to meet the palliative care nurses at the beginning….. But that was really bad on the first day – really bad (Family 4, 53yr female carer for husband with malignancy)* *I did say, "Can you talk about other options like home care, Hospice care, versus hospital care, for all of these things that you're doing to mom?" And he said, "Well, I don't think we're there yet." And I said, "Well it's still worth a conversation happening." He said, "Well do you want to talk about end of life stuff now?" And mom and dad looked completely horrified. And I said, "Well I guess it's a family conversation for us to have, but mom and dad do need to know that there are other things that they can choose." And that was the end point of that conversation. That was last year, so that conversation*

		hasn't happened (Family 5, 50yr female carer for mother with malignancy) *I just feel like there are things that they just go along with because that's what they're told. It feels like... You know you hear about people saying that the only reason they nail coffins shut is to keep the oncologists out because they'll want to just keep treating them? That's kind of where mom's path is headed. Even the palliative care doctor, and that's her term, palliative care doctor, when they go and have a visit, she just talks about her pain management, which is managed well. She doesn't really have to change her medication, but there's no other talk about anything else at all. I know mom's big thing is she's terrified of hospitals, absolutely hates them with a passion, and the worst thing for her would be intubated in ICU, and she doesn't have her advance care orders in place, and so that's what they would do. I've also had that conversation. "If that's not what you want... Is there a point where you say, if you get to this point, you go home or you go to Calvary, or whatever you want, rather than being here in the hospital." But there's no direction from her about anything. From my perspective, that role is being... You're the lead Family then in palliative care, to not have given any options yet or given them anything to think about for later on, only just talk about what your pain tablets are doing, that doesn't seem like it's great care (Family 5, 50yr female carer for mother with malignancy)* Bereaved Family data

		These different specialist ... So, the ENT sees there is a problem with my father's blood pressure and heart rhythms after the operation. He doesn't do anything with it. He just goes to a cardiac guy and says, I need you to look at him. So, he comes and looks at him. Then, they find he has another problem and they get another doctor to come have a look, a specialist doctor. They are all specialized in their field right? But no one knows what the other guy is doing (Bereaved family 12, 54yr male carer for father with malignancy) *I would change. In the wards, because you have one doctor to do this and he has a urine problem there is another doctor. He has some kind of infection so he has an infection doctor or whatever. No one ... One doctor does not know what the other one is doing (Bereaved family 12, 54yr male carer for father with malignancy)* *So then you've got the medical team, and the medical team clearly things kind of fell between the slats when my father's cardiologist kind of got involved but wasn't at the head of the... his name wasn't on the bed card, and the general physician kind of stepped back, and the neurologist had one encounter. So, no one was steering that ship particularly well (Bereaved family 13, 54yr male carer for both parents with non-malignant illness)* *Obviously the neuro team was involved because of the seizures. The gastro team was involved from a liver perspective. He had a lot of issues with foot drop and nerve supply. Different teams were*

		involved with that…He became quite anti-coagulated, 'cause we had a INR of about 2, so suddenly the heamatology teams involved to teams would come in and put their two cents for us in, but no one pulled the picture together for us. We even, at that point, that was on a Friday afternoon, even at that point, we're told that he would recover from this, and he died on the Sunday ... He died on the Sunday morning. We were not ... I don't feel like anyone really saw Patient for what the situation truly was. I feel like it was a situation where everyone just saw their specialty, but no one actually saw Patient (Bereaved family 3, 43yr female carer for brother with non-malignant illness) *It's interesting, 'cause I see it a lot in my acute care nursing that I do, is often when someone comes to hospital, we start from the beginning again. I know we often have family, so I work in a big tertiary hospital in Sydney, and we have families coming in, and it's like what happened at the hospital before they arrived with us is disregarded. We often go and do the blood test again, we often do the X-rays again, and we often think that we do it a little bit better than the person before us did it. And we start again. When really, I think what should be happening is we should actually be working with the team that have previously cared for the patient, and bringing what they've done into the picture. And I think with my brother, that's what didn't happen, so we had been working with a community palliative care team. We had a community gastroenterologist. We had teams involved in Patient's care, but when he presented to a tertiary facility…I think that's the first thing,*

		is often there isn't that linking of services of what's happened before the person arrived at the hospital, in the hospital (Bereaved family 3, 43yr female carer for brother with non-malignant illness) *I think the initial communication both with the local palliative care team here and the oncology team in Sydney, couldn't have complained about that at all. We rang up, the right phone calls were made, everybody in the chain of things acted in trying to help the situation. The fact that we got a bed that afternoon was really quite amazing (Bereaved family 4, 69yr female carer for friend with malignancy)* *Yes, it was between the hospital and ourselves. It was between the public and the private. It was between the nurse practitioner and the clinician. It was between oncology and palliative care. I think it was between the lack of information flow between the GP and the provider, the health system (Bereaved family 5, 56yr female carer for mother with malignancy)* *Really, what I sort of look at it and I know region X have a much better involvement with the gerontologist and aged care team, in the process of intake for oncology and palliative care. None of that was offered …You know, such integration. That wasn't our experience at all. It was horribly fragmented (Bereaved family 5, 56yr female carer for mother with malignancy)* *You don't have to... And I would say it. But the nurse would be fine, they'd go, "Okay." But then they'd change roster. So the next day*

		it's a different nurse…And it's the same thing, and again he would say, "I had trouble breathing, and I couldn't breathe and no one came." And I would say to the nurse that's on, I'd say the same thing. Again, they would change roster. And it's just like I'm getting nowhere (Bereaved family 12, 54yr male carer for father with malignancy) *The pathway to his care, it became difficult for us to advocate for him, because, what the hospital was seeing, and what we were seeing was quite different. There wasn't much interaction between the community based palliative care teams, and the hospital, so once he went to hospital he was admitted under an ED consultant initially, and then obviously under the relevant team based on what he's care needs were, but it was difficult to get palliative care involved, because from what the hospital was seeing, they weren't seeing a palliative care patient, they were seeing someone in liver failure who was having seizures, so there was very different focuses on the care (Bereaved family 3, 43yr female carer for brother with non-malignant illness)* *None of that was offered in Cancer Unit X and that's disappointing, because they promote themselves as such a special unit .. You know, such integration. That wasn't our experience at all. It was horribly fragmented (Bereaved family 5, 56yr female carer for mother with malignancy)* *Or when at shift change over time when they would actually come and say, "Right, this person's going home now. This is your new*

		person," you know, those kinds of things (Bereaved family 11, 33yr female carer for father-in-law with malignancy) *And it's the same thing, and again he would say, "I had trouble breathing, and I couldn't breathe and no one came." And I would say to the nurse that's on, I'd say the same thing. Again, they would change roster. And it's just like I'm getting nowhere (Bereaved family 12, 54yr male carer for father with malignancy)* *You don't want to just have to make a whole another series of appointments for this and that. Like, why can't they, while you're in there ... I'm not sure (Bereaved family 9, 57yr female carer for father with malignancy)* *And it was only when Patient got involved with palliative care that we really began to find out what it was all about. There's this enormous ignorance everywhere about what palliative care is all about (Bereaved family 1, 66yr male carer for wife with malignancy)* *None of that was offered in Cancer Unit X and that's disappointing, because they promote themselves as such a special unit .. You know, such integration. That wasn't our experience at all. It was horribly fragmented (Bereaved family 5, 56yr female carer for mother with malignancy)* *I was horrified when they said the palliative care team should come and speak to him, but the other side of that was they were absolutely amazing and wonderful, and so professional and so*

		good to be around (Bereaved family 7, 56yr female carer for husband with malignancy) *The pathway to his care, it became difficult for us to advocate for him, because, what the hospital was seeing, and what we were seeing was quite different... Once I think people worked out what was happening, things changed. Once we, I think it was the Saturday afternoon, we got the palliative care team, actually in to see us, someone actually turned up, and we looked at the palliative care consultant, and we said to him, "Can you tell us what you can see?" And he looked at us and said, "Your brother is dying." It was that moment that I think when someone from their team saw what we saw, that things changed. At that point, a midazolam infusion was put up, my brother was given the medications, and the drugs that he needed to give him comfort, and we didn't have to fight for him to be comforted. And that was the turning point for us…I wish that there was a way that he could have been flagged as a palliative care patient straight off the bat, so when people looked at his blood results, and saw that he was coagulopathic, and that he was in liver failure, that it raised the right alarm bells not the wrong ones. What happened, it raised the wrong alarm bells. They were more worried about the fact that he's INR was 2 and therefore wouldn't be suitable for intubation. And then his liver function was abnormal and therefore couldn't have benzos, rather than the fact that he was needing comfort measures to assist him in the dying process…Because the decisions that were made, and all the right decisions were eventually made, but they were just slow to be*

		made that he could have suffered in the interim. And that's probably what, as a family we talk about the most. Did he suffer... And we don't know, we'll never know (Bereaved family 3, 43yr female carer for brother with non-malignant illness) *I wish that there was a way that he could have been flagged as a palliative care patient straight off the bat, so when people looked at his blood results, and saw that he was coagulopathic, and that he was in liver failure, that it raised the right alarm bells not the wrong ones. What happened, it raised the wrong alarm bells. They were more worried about the fact that he's INR was 2and therefore wouldn't be suitable for intubation. And then his liver's function was abnormal and therefore couldn't have benzos, rather than the fact that he was needing comfort measures to assist him in the dying process… That for us, looked at these things, if we didn't have to ... What's the word? If there was a way to, I don't know, flag him as a palliative care patient, or ... It's so difficult tho I understand we were the only people who could do that for him, because as his family, and ... you can’t just assume everyone who turns up with abnormal liver function is palliative..Yeh some way to ... Because I think that's what provides the family with some comfort. I think, for us, when he died, we blamed ourselves that maybe he didn't get the right care. We didn't feel comfortable ... While the care that he got wasn't bad care, we were sad that maybe the decisions could have been made differently for him, and we would be devastated to think that he could have suffered, because he was at a point where he could no longer communicate to us, we would have been devastated to think*

		that he could have suffered. Because the decisions that were made, and all the right decisions were eventually made, but they were just slow to be made that he could have suffered in the interim. And that's probably what, as a family we talk about the most. Did he suffer... And we don't know, we'll never know (Bereaved family 3, 43yr female carer for brother with non-malignant illness) *The palliative care specialist in charge, was very concerned about the disconnect between the oncology team and her team. …I think the fact that probably, by the time that we, that mom was diagnosed in the third week of January. We asked for palliation, we raised that as a possibility, we wereput down straight away. No, that wasn't an option. The palliative care specialist said, "Absolutely, that should have been an option. In hindsight, your mom was probably way too sick to have chemo her liver functionality meant that she was never going to be able to sustain even one round of chemo. Your mom would have been an ideal candidate", but this particular doctor didn't want to go down that route (Bereaved family 5, 56yr female carer for mother with malignancy)* *So I suppose I thought at that initial consultation, if we were to have a gerontologist, they would have been saying, "Ooh, maybe palliative care is a better option." This is a woman who's 86 with metastatic cholangiocarcinoma, what really is chemo going to achieve. It was just, I suppose, that I thought we'd moved on... I'm probably naive, I thought we've moved on a lot. Thinking of the palliative care being more ingrained in our care process, but that*

		certainly wasn't what we experienced. It was still like it was the alternative, out of the box sort of... The oncologist was set on the outcome, but processes are a big part of care. It seemed to be really missing in the oncology team (Bereaved family 5, 56yr female carer for mother with malignancy) *Having the oncology services and palliative care service working as one. Working in unison. Working together. It would have made a massive difference for mom. From day one, she would have, yes... Mom still would have passed away, I know that, but we might have had a little bit longer. Yes (Bereaved family 5, 56yr female carer for mother with malignancy)* *…*interdisciplinary rivalry, which I think was very real, particularly with the medical oncologist and palliative care (Bereaved family 6, 68yr female *carer* for brother-in-law with malignancy) Other Patient data *I think the most (important) thing is the competency of the people that are looking after you. I mean that's obviously number one. And then that probably breaks it into two areas; the nursing staff, and the professional staff with the doctors. (Patient 9, 75yr male with non-malignant illness)*

		And also, if I need an IV or anything, not to cause me too much pain on my nerves, by giving me people who will do it in one shot – this is what I expect (Patient 5, 72yr male with malignancy) *Well, first of all, if you go into ED ... I mean the first thing is, I've got very bad veins. I've got to have one of the doctors who really know what they're doing (Patient 10, 82yr female with non-malignant illness)* *Because I know that the first attempt was done by a nurse and a novice. Right. So I could tell by the way that they were interacting. So yes, definitely you need a senior person. I had, first of all, I had two nurses and then I had two doctors, so the second doctor got it, got the cannula in (Patient 19, 69yr female with malignancy)* *The cannulization. Took them six prick. Six, yeah, because they are all juniors. They are all practicing. And I was like a mannequin who, yeah, you know? No, it's so unfair. (Patient 21, 50yr female with malignancy)* *how come it had fallen out and no one had checked it, cause if they regularly checked it they would have found it. That was the only thing but was not serious anyway because only a little bit of blood had come out so immediately they called and got the person to come and do the IV properly, from the chemotherapy section, 1 of the nurses from there came and did it. But if it was identified earlier, I don't know why but they didn't… I assume that they might not*

		have come and checked on me regularly…. (Patient 5, 72yr male with malignancy) *and nobody writes the date on it either. Actually, you should write that down. This is the third time I've been in ED, and they don't write the date of the cannula down. You've got to write it down, because after three days it has to come out. (Patient 10, 82yr female with non-malignant illness)* *….and I had to tell her that she was doing the wrong thing when she was giving me my antibiotics and whatnot through the cannula. And she said, "I am the nurse, I know what I'm doing." And I said, "Well, you're going to bust the cannula." And I've got terrible veins, I know that. And she said, "No." And I said, "Yes, you're supposed to be putting that first of all saline through and then the antibiotic very slowly," but then I said, "You do not just come along with the injection and just jam it straight in." And because the cannula just burst, it just stopped. (Patient 22, 75yr female with non-malignant illness)* *That you're going through with this process. I mean, please have some consideration. I'm having a pain. Do it right away and give me the best doctor that you can do it….Not the junior doctors (Patient 21, 50yr female with malignancy)* *I don't want any bloody interns coming around especially ones that come from City X and what not. They come for about 3-4 weeks and they walk on the wards as if their the king Doctor and well they*

		use me for a guinea pig. Because there's not that many kidney patients that end up in hospital and they don't get the training of people with kidney trouble in their City X hospitals when they're doing their rounds and what not. But they do, they use me as a guinea pig and they decide all the time to start me on a different medication and what not. And I end up in hospital instead of being there for 2 or 3 days, I could be there for a fortnight. It's bloody awful, I'm telling you. (Patient 22, 75yr female with non-malignant illness) *And I want good nurses and I don't want any bloody interns around me. I've put that on me folder (Patient 22, 75yr female with non-malignant illness)* *Oh it's just be, just be noticed, as in dealt with efficiently, really. I don't care how long it takes, but as long as the person I'm dealing with, right, is aware of my needs (Patient 12, 65yr male with non-malignant illness)* *How would I put it? I don't expect to jump the queue or anything like that, but I'd just like a little bit... I'd like to see that there is attention being given to the overall aspect of where I'm at. (Patient 14, 45yr male with malignancy)* *... who's concerned about what I feel, what I am having, someone who understands what I am having. (Patient 21, 50yr female with malignancy)*

		Clean out the nurses that aren't doing the right thing. So they bloody well start from the top again but really learn nursing. (Patient 22, 75yr female with non-malignant illness) *Some staff were fantastic and the junior nurses that gone in there were, to me, not properly, to be at that level unit you need to be properly trained, and they weren't properly trained. (Patient 9, 75yr male with non-malignant illness)* *But I've got to give it to the nurses. They were onto it real fast and brought everything back real quick. And they definitely knew what they were doing. (Patient 1, 48yr male with malignancy)* *Look, the important thing, I think is to know there's somebody there. And very often, they're not. Not because they don't want to be, but there's not enough staff. We know that. The nurses are absolutely run off their feet. They are so good, but they can't do everything…… And I mean if you are in the toilet and you press the button, they do come eventually, but if you're not breathing or something like that, it's not fun. (Patient 10, 82yr female with non-malignant illness)* *So you push your button, then you wait for, can be up to 30 minutes before a nurse comes. I often lie there and think to myself, "What happens if it's an emergency?" If I'm going to wait even 10 minutes for somebody to come when you press the button, what happens if it's an emergency? How do you get help? And that's what I find is a problem…. (Patient 18, 71yr male with non-malignant illness)*

		... But when you hit the nurse button, you expect to see someone within... five or so, to I suppose maximum probably ten max... Half an hour plus is ridiculous …. one particular time was where I... I needed a urine bottle...I don't have half an hour to wait, when I need to go to the toilet……Especially when you're flushing me with stuff that's going to make you urinate. (Patient 14, 45yr male with malignancy) *…the care I get at dialysis is fantastic. The girls here, the nurses here are great. The NUM is great, so I don't have a single problem with dialysis…In fact, when I would come up to dialysis, the three times a week, I've been relieved to be here because I knew that the staff would treat me nicely…really, the best part of the day was going to dialysis, which really, it shouldn't be. (Patient 13, 61yr female with non-malignant illness)* *I must admit the girls in the dialysis area are actually exceptional. They are way and above than anybody else I've ever come across. Yeah, I mean they are super exceptional. They know what they're doing, and they're passionate about their work, they're dedicated (Patient 9, 75yr male with non-malignant illness)* *... I wanted to tell you this one. I have an experience. When they're draining the water inside my lungs... It was a trial and error, and I think it's so unfair for us cancer patients in pain. I was in pain that time. The pain was nine over ten, and you could just imagine that it was... They practice how to take off water from my lungs, and there are four doctors simultaneously trying to take off…Yeah, and all of*

		them...failed…You can just imagine the pain that I'm having, the time that we're consuming, and the strength that was taken out of me…Yeah, they were junior doctors that needs to have practice. And it's so unfair for us, especially if you're in pain because of this cancer. That you're going through with this process. I mean, please have some consideration. I'm having a pain. Do it right away and give me the best doctor that you can do it…Not the junior doctors (Patient 21, 50yr female with malignancy) Family data *No, we know that they are all competent, the doctors are good. He is well cared for. Once he goes there, then I know he is well looked after (Family 4, 53yr female carer for husband with malignancy)* *Well somebody pressed the wrong button on this machine, that he was being weaned off, and cut off his oxygen altogether. Altogether. So the rapid team was brought in and they revived him and he was all right by the morning, he still had the machine on, so that attempt of getting him off the machine didn't work (Family 12, 78yr female carer for husband with non-malignant illness)* *Then I sorted another issue that bothered the daylights out of me. All elderly, and I feel sorry for all elderly people, have got very frail skin. When they have to have their cannula in, they get prodded to such an extent to get that cannula in, that it is unbearable to watch, never mind about experience. So, I thought, 'I have to get around it somehow or other, I don't know how to do it.' But I have asked this*

		obnoxious, I am the registrar, 'I am it!', I have asked him if it was possible not to send an intern to put his cannula in. I said, 'I would really be very grateful if you could send an RMO1 or 2 who has had a bit more experience, because he's in for a long trot and an unpleasant one, let's make it as easy as possible.' And he did, he sent me an RMO1 who was an American guy who came here for some sort of training, who was very experienced, and while he was chatting, the cannula went in and no one even knew it went in (Family 12, 78yr female carer for husband with non-malignant illness) *And her oxygen sometimes, like some of them think that she should be on two, and then another one thinks that she should be on three, and then another one will come back in and say, "It should be on two." And they put it back down again. It's a bit confusing (Family 18, 59yr female carer for mother-in-law with non-malignant illness)* *Well, there's a big difference between somebody that can take blood and somebody that can't take blood but thinks they can. They won't actually listen to you. The people who listen to the actual patients are normally the best ones. For instance, with the chemo, Patient 15 has never had problems, she's got problems with her veins, but they could normally get blood in or out of any vein in her arm but if you try it in her hand, I've never, ever seen it work. Ever. You're telling the nurse that's ... She thinks that she knows it all, which there's very few of those. It doesn't happen. It's more of a challenge. "Oh, I can get it in no problems."It's just listening to the*

		patient, I think. I know they come across difficult people all the time but you've got to still listen (Family 14, 49yr male carer for wife with malignancy) *Medical team... Oh, so some medical doctors are not good because sometimes they treat my wife trial and error. (Family 15, 50yr male carer for wife with malignancy)* Bereaved Family data *So then to add insult to injury, the cardiac technician who worked in that hospital refused to turn the pacemaker off… he believed that was going to kill my father. As such, he couldn't be party to it. So here's a hospital with a huge cardiac unit and someone saying, "I'm not going to do that." Which immediately triggered tensions for the one non-medico, my brother, who is also deeply religious. So what should have been an absolutely routine 30 seconds visit from a technician was blown up into something where that whole process was actually delayed by 36 hours and just causing such needless angst, such absolutely needless angst. So the technician in fact went to the cardiologist who has one of those international cardiology practices, where he's probably at hospital for 14, 16 hours a day churning through lots and lots of procedures. Couldn't find time in that 36 hours. But what should have been very, very simple and straightforward palliation was compromised by two people, both of whom should have known better and both of who*

		had this as their core business (Bereaved family 13, 54yr male carer for both parents with non-malignant illness) *Obviously you know, it's getting the best treatment as far as like, you know, medical wise because otherwise she wouldn't be there. But to be honest, you know I guess you shouldn't, but living in Australia you assume that's going to happen anyway (Bereaved family 10, 43yr female carer for mother with malignancy)* *But what he hadn't done was actually address the issues that were important. My father had an implantable defibrillator and pacemaker, hadn't touched any of that, hadn't even established that he had one. So he hadn't read the notes. He didn't examine my father. He spoke to the one member of the family who wasn't a medico. I'm sure my brother would've said, "Please talk to my siblings." Which he didn't. Then he didn't address the one issue that really was the elephant in the room. What do you do with a defibrillator in someone who has a Glasgow coma score of three and is dying. So that was left to the family to raise with the cardiologist... So it was absolutely agreed that we would turn off the defibrillator and the pacemaker simultaneously. But we had to raise that (Bereaved family 13, 54yr male carer for both parents with non-malignant illness)* *So then to add insult to injury, the cardiac technician who worked in that hospital refused to turn the pacemaker off… he believed that was going to kill my father. As such, he couldn't be party to it. So here's a hospital with a huge cardiac unit and someone saying, "I'm*

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		suffered all night needlessly. Once the tube went in, she felt much better (Bereaved family 1, 66yr male carer for wife with malignancy) *So, some of them were amazing and really they were efficient, effective, kind and attentive and some of them were a little bit vague or too busy or didn't ... you didn't feel like you really got the sort of ... when I say attention, I don't mean attention, seeking attention, I mean the looking at Patient X, taking into account what was happening and doing whatever needed doing next or should be happening, that kind of attention is what I mean (Bereaved family 7, 56yr female F carer amily for husband with malignancy)* *Let me think. I guess what would've made a lot of difference to my friend's care was people actually checking on her, and doing proper pain assessments and I suppose the general attention to care that seemed not to be a priority. I think that would've made a big difference. It's actually the caring part of it that really stands out for me (Bereaved family 4, 69yr female carer for friend with malignancy)*
Domain: Adequate environment for care		
There was no additional detail provided in relation to this domain from a patient perspective	• Restful environment that was quiet and enabled sleep to aide recovery; • Being thoughtful of room lighting; • Cleanliness, specifically in relation to infection control;	Patient data *…and to be in a place where you can be in a room or something without much disturbance. (Patient 5, 72yr male with malignancy)*

	• Ensuring adequate ventilation (particularly for people with breathlessness), particularly in the bathroom to assist with ability to shower; • Access to a window to enable a connection to the day/night cycle, feel connected to the world, to feel warmth from sunlight and to prevent feeling claustrophobic within their environment; • Ensuring a comfortable temperature; • Being in a shared room for company and helpfulness of fellow patients; • Being in a private room to avoid being being disturbed by noise, having to tolerate different smells/odours and feeling quite confronted by other people's illnesses; • Not having frequent bed changes; • Enabling comfort when in the Emergency department • Managing infection risks, especially for those who are immunosupressed • More practical audio-visual control for the TV (not to be handheld); • Emergency access to toiletries for unplanned admissions;	*Yes, the first occasion they transferred me into a room where every second somebody was passing the room and opening the door and there was a lot of noise around and disturbance in the acute care… that was – it didn't allow me to sleep or anything. Yeh, that was the first time. The second one, they put me into a room and that was good for me. (Patient 5, 72yr male with malignancy)* *It's different, yeah, because in the ward, it's more quiet….Yeah, but you cannot avoid those loud nurses in the night. There are loud nurses that they don't care if you're sleeping or not. They just bang the door, or they don't care waking you up without any, "Oh, excuse me. I need to wake you up." No, they just go into take your hands and like that, so. (Patient 21, 50yr female with malignancy)* *One of the things I find very, very difficult is the lights and lighting, and I understand it's a ward and that they have to have lights on, but the way they have their lights in the rooms, in the ward, they can switch off most of the bright lights, and each bed has got its own light so they can switch on lights by the bed if they need to. They don't need to have the big huge passage lights on. And the light, for me, well certainly, it hurts my eyes. And I find it very difficult to sleep with the lights on. (Patient 18, 71yr male with non-malignant illness)* *So, it was absolutely imperative that there was a clean environment so... from a... kidney transplant not so much, but definitely from the*

		wound perspective, yes. (Patient 7, 59yr male with non-malignant illness) *Well I know on level 10 they just had someone going around day and night cleaning the place 100% up to scratch with health and hygiene and stuff…. That was one area that actually impressed me. (Patient 9, 75yr male with non-malignant illness)* *Just have a couple of people to go around and along the lines of your cleaner. Just to brush up and make sure the shower and toilet areas are cleaned. appropriately, there are three people using it, so.... I think once a day's a bit rough. I think twice a day... Once in the morning, once in the afternoon, I think is more appropriate (Patient 14, 45yr male with malignancy)* *Well that bathroom was an absolute disgrace, there was blood all over the floor. I don't know how on earth, another patient, evidently something had happened and the sister-in-law had to go in and clean it herself. Because she said, "I'm not having, going in there with all that germs and whatnot." (Patient 22, 75yr female with non-malignant illness)* *Oh yeah, everything was cleaned every morning. ….. So I knew if I got out and I had my bare feet, I could walk on the floor and I knew that I wasn't going to get... they talk about the hospital bugs and that you can get? Staph and all that. I don't think I had any chance of getting any of that. (Patient 1, 48yr male with malignancy)*

		Yeah, that it's clean of course. It's almost spotless, and there's not stuff in the corridors or filling the corridors. There's not a whole lot of equipment everywhere. As you're walking up and down the corridor, you really notice that. So, it looks tidy. It looks cared for really, and it's spotless. (Patient 3, 80yr female with non-malignant illness) *..there's no exhaust fans in hospital toilets, all that, in the showers. They're that small. ….Yeah, you can't leave the door open. You can't shut the door, because of the steam, and you can't breathe in there. There's no windows to open. If there is a window, it only opens about three or four inches at the most anyway. (Patient 23, 69yr female with non-malignant illness)* *My window is the bane of my existence. I just love looking at the ... at Park XX. It's everything that I wish for, in my entire life. I could stay there forever, watching that, good….when they put you next to the toilet, where you've got no ... because and then the person shuts the curtains. I hate being shut in, because I feel as if I'm in a bloody matchbox…I want to go on the western side. I always take my sunglasses, because after three o'clock, it's bikini time, when the sun comes out. (Patient 10, 82yr female with non-malignant illness)* *Light and sky, is correct. Probably the only thing I always look for. I grew up on a farm. I used to have a waterfront property, and when we moved people said, "Oh, you're going to miss the water". I go "Nah, I'm going to miss the sky." So, the sky is be all, and end all*

		really. It gives you time, tells you what time it is. (Patient 12, 65yr male with non-malignant illness) *Yeah… I think it is important to get good light into a hospital bedroom ... into a room like that, because it just helps with your recovery. You get good warmth. (Patient 14, 45yr male with malignancy)* *I went from a window to not having a window and I felt, what's the word Claustrophobic ….you can see what's going on and as if you're a part of it all (Patient 19, 69yr female with malignancy)* *I know it was the older section of the building, but the air conditioning was, initially when I got there and when I got out of surgery, it was very warm. And when we went to the next phase, to the next three weeks, it was freezing. People were walking around with beanies on. One extreme to another. (Patient 14, 45yr male with malignancy)* *No, it's okay. As a matter of fact, it's better, because if you're in a shared room, first of all you can help somebody else if they need it. And secondly, they can help you if you need it. It is much better that you are in a shared room. I'm not really that keen on being in a private room, because you are stuck like a shag on a rock, like I am here at home. If the bell doesn't work, and my bell sometimes don't work, and there's nobody to tell you, and there's nobody you can tell ... that's bad luck. (Patient 10, 82yr female with non-malignant illness)*

		There's more movement. We sometimes engage with another patient a little bit. You can help if they ask for help or be helped. (Patient 11, 72yr female with malignancy) *No, I don't mind sharing a room. As long as the room is relatively quiet for the periods which they have to be quiet. … (Patient 18, 71yr male with non-malignant illness)* *I like to share a room because I think it helps you emotionally if you've got somebody who chats to you (Patient 4, 54yr female with malignancy)* *… the negatives are you can have noise at night, you can have bad noise is a trigger for your nausea or things like that. (Patient 11, 72yr female with malignancy)* *…..the lady next to me…. she used to bring in her own food and the smell was not the best. And also her visitors used our toilet, which is a big no, no…..I'm very sensitive to smells. (Patient 19, 69yr female with malignancy)* *Well I mean the public hospital obviously is pretty rough and ready, I mean you know you've got some people in there that are desperately ill, and when you got shoved in a ward with four other people it's, it's difficult. … ….So there were people with critical health issues that you end up having to deal with their issues, and it's very stressful. Especially when you're in a similar state of health (Patient 9, 75yr male with non-malignant illness)*

		I know it's a public hospital and I know it's a public ward, but when you have patients that are in pain or that are moaning all the time, because we have a lot of patients where it looks like psychological. Could be psychological, and they like shouting and moaning. They should all be put together instead of having one like that in each ward. I mean, that's ridiculous. (Patient 18, 71yr male with non-malignant illness) *They continually change your bed. You arrive, and you're here. The day after tomorrow, "Oh, we're just moving you somewhere else." They move you three or four times, in a period of maybe a week. I find that extremely irritating. First of all, you get used to where you are. You get used to the people in your ward, you get used to the window you've got, or the window you don't have, or whatever…. and then they move you, but they don't move the cabinet that's with you, and you lose that to somewhere…. That is annoying, because you need what you had with you. That is absolutely infuriating. (Patient 10, 82yr female with non-malignant illness)* *The point is, I want to be left alone. I want to say, "This is my bed. This is where I belong." Once you're there, you want to belong somewhere not feel, "This is where I belong until they think of something else this afternoon at four o'clock." (Patient 10, 82yr female with non-malignant illness)* *Well, it was difficult the very first night because I had just arrived at the XXX and they put me in a wonderful one bed room and I was amazed that it was so good but then at one o'clock at night they*

		transferred me because they needed the room, I couldn't understand … It was just so sudden and it was in the middle of the night, I was sleeping in big pain. And they said, we really need to transfer you. And they just did it. And I was very upset. I was sad. I cried and but now I think that being in a four room has its plus and minuses. (Patient 11, 72yr female with malignancy) *This is a laugh too, the last time I was in emergency, they didn't have a bed for me. I sat in the chair for hours…. And I came in at lunchtime. And at six o'clock in the evening, I said, "Do you think I could have a bed?" (Patient 10, 82yr female with non-malignant illness)* *... not have to sit and wait. Which has happened every single time. I have not had to wait. They got me through straight away, which is brilliant….It's just that I'm so sick that I need to go and lie down basically. (Patient 19, 69yr female with malignancy)* *… when I had to go to the hospital on Tuesday, with pain, naturally, we had to go through outpatients. And there were, naturally, a lot of new Australian people working in hospitals. And I tried to tell them that I was very ill. But still we just had to wait there to get, find somebody that could realize what was going on. And yeah, it was just a misunderstanding there, yeah. That was Emergency… I'm not being nasty, but I'm just saying, it was, I should have gone straight in. And then I sat there…. a bit of pain, and a bit of anguish.*

		Because then, I didn't realize what was going on. (Patient 8, 77yr female with malignancy) *... I even experienced sitting down the whole night, and then I asked about a bed. I think the prior- I don't know if I'm right, but what I see and felt was they prioritize somebody, not me. So, I felt discriminated because I had this experience when I have, the third confinement that I had, we're both have cancer, and so happen the other lady that had cancer is a white one, and I am Asian. So, she was given a bed, while me, I was not given a bed, and I was there for four hours ahead of her. So, I felt discriminated, really. Then I asked for a bed. It took them five hours, another five hours again to give me a bed because I already told them, "Why is this woman, a cancer patient as well, like me, and I was ahead of her, and she's given a bed?" (Patient 21, 50yr female with malignancy)* *But he said, "You better get out of this hospital before you get something else." Because it's true. You get everything everybody else has got. The last time I got flu from the woman beside me, thank you. Needed that. (Patient 10, 82yr female with non-malignant illness)* *We cancer patients are being mixed with patients who are coughing, who have colds, and I think that, yeah, I understand the situation properly, but what I am thinking I write down, they should have a special place. A separate place for us, the cancer patient to avoid infections. Putting the mask 24 hours is not good for us as well, especially me that I'm having cancer on my left lung. I cannot*

		breathe properly with the mask, so I need to take it off. Now, if the patient beside me does have cough, so I'll get infected right away. (Patient 21, 50yr female with malignancy) *Yeah, that's correct. Not rapid attention.... I'll give you an example. I went into hospital X three weeks ago. It was in the height of the... the scare of the influenza was around, and everyone was sick… There was about 30 or 40 people in the waiting room. Coming off the chemo and that, my immunity is very, very low. The person that I gave my details to, I showed her the card that... Here I am, I'm on medication, I'm on chemo treatment. Now, I at least expected to be quarantined or put into an area where I wasn't around all these other people that were sick, but it didn't happen. I had to go and wait outside. I waited out there for 15 minutes, then left…. and I had the card to indicate just where I'm at, that this is what problem I have - at least look at it, and pay attention to it (Patient 14, 45yr male with malignancy)* *They just throw me anywhere, and for the fact that they knew that I'm having cancer, that I cannot mingle or I cannot be joined with other patients (Patient 21, 50yr female with malignancy)* *The worst part of being in hospital is having to hold the thing to listen to television. That's a nuisance, because you can't eat and hold that at the same time. So you can't watch the news in the evening, while you're eating your dinner. (Patient 10, 82yr female with non-malignant illness)*

		And the other thing is that, I understand now that they don't supply you with shampoo and proper soap and deodorant, stuff like that. I understand that now, but it is very difficult when a person has an emergency situation, you're going to the hospital, and you need that stuff, and you haven't got it. (Patient 18, 71yr male with non-malignant illness) Family data *Funny you say that. It's funny you say that. Me personally, it doesn't really worry me at all. And I don't think it really worries my brother, but my brother could get a window….And when dad was in the other week he was in a room that... back of nowhere sort of thing, and when they moved him, he asked, "Can I have a window room? I want to look out the window." Yeah. And they did. They put him in a window room… It was important to him, and it was good to see that they'd done their best to do what they could (Family 1, 53yr male carer for brother with malignancy and parents with non-malignant illness)* *I think this would have been very important, he was lucky, he was by the window. And that made my life a little bit more tolerable, because I was sitting by the window. If he would have been on the other side and I would have been against the back wall, it would have been even more intolerable….. So if I was sitting against the wall in the darkness, it would have been intolerable, so a window*

		does make a hell of a lot of difference (Family 12, 78yr female carer for husband with non-malignant illness) *Giving her an idea of where her day's going rather than she's in four walls, has got no idea of the time of day because she's not even near a window and she can't leave the ward, and there's just curtains dividing her and another person (Family 5, 50yr female carer for mother with malignancy)* *We've always been pretty blessed with the rooms that we've been allocated, so generally we get a lovely window to look out of and to ... You know, you can see what the weather ... It's easier to be orientated. I remember when Daughter 2 was in intensive care, she was in intensive care for a week and a half, and she lost all sense of time and place, so quite disorientated. She didn't know if it was the middle of the night or the middle of the day, and she mentioned that to one of the nurses, that she was a bit disorientated in terms of time and place. And they moved her to a different bed near a window so that she could see the daylight, and that changed everything for Daughter 2, just that simple thing….And gave her a connection with the rhythms of the day. And they always had a clock, an analog clock, in each space in ICU, but if you don't know if it's AM or PM, you're not quite sure where you're at, so it was really helpful to just be near a window. And yeah, I think having daylight is really important, seeing the weather, watching the birds fly past the window (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness)*

		and to be in a place where you can be in a room or something without much disturbance (Family 4, 53yr female carer for husband with malignancy) *As long as she can sleep well and there's not too much noise in the ward then that's pretty much all that we can expect (Family 14, 49yr male carer for wife with malignancy)* *Look, I can't complain about the environment because basically speaking, I used to just draw the curtains around him, because he was too sick to worry about it, and I didn't want to look at all these very sick people. It was enough for me to look at one, without having to look at three. So I just drew the curtains, I didn't see very much. It was a normal four bedded room, like in every other hospital that I have seen (Family 12, 78yr female carer for husband with non-malignant illness)* *the oncology ward was peaceful, its upstairs where it is all separate and we don't have to see other people / bleeding patients coming in….(Family 4, 53yr female carer for husband with malignancy)* *And also in the two bedded room, because more often than not it's a two bedded room that she's in, and having a bloke on the other side of the curtain, which is even closer quarters because it's a smaller space than a four bedded room, and having the extended families around... It's noisy. It doesn't matter if it's sleep time or rest time, there's still always people around. Being in a room where the curtain is dividing you, so you can't see out, because often too she*

		never gets a window. She's always on the door side. So the light's in her eye at night time. There's no natural light. And the bathroom tends to be in front of the bed she's in, so the person next to her is in and out of the bathroom. There's no personal space at all (Family 5, 50yr female carer for mother with malignancy) *In the single room, it's quieter, but in those rooms the doors have got to be shut because the air pressure's different for infection control. So it's really isolated as well. The happy medium is when she's in a two bedded room, and there's another female in the bed, who's not so advanced in age that they actually can have a conversation or a conversation with the family (Family 5, 50yr female carer for mother with malignancy)* *She couldn't sleep with the patients were coughing a lot. That was her only comment…..Because she was with three other patients and they were not in different stages of sickness (Family 3, 52yr female carer for mother with malignancy)* *Even just like the information giving. With fevers, she'd come in and she'd be in a single room. Putting her in an isolation room until they know the blood cultures are negative. And simple things like going in at like 10:00 at night, just waking her up and saying, "You're moving," and just packing everything and moving her off to another room without giving her any warning or telling her why or where she's going. Just the basics of, "Oh, we've got somebody who's really sick that needs this room, and you're okay now, so we do need to move you so that we can make space for someone else. In*

		you go." Then dad coming in the next morning and going into the room and there's another patient in the room, saying, "Well where's my wife gone, because I didn't know we were even moving?"….For this instance of this time when she was in the isolation room... She'd been moved out, she was in two other rooms, so they actually move her around quite frequently, she never gets to stay in the same space. She'd moved to the second room, and dad had thought, "Oh, my phone charger was hanging out of the wall in that first room," and so he did go to a nurse, and it was days later, and said, "Was my phone charger in that room? Could you just go and check," and it was still hanging out of the wall, so he got his charger back. But I was thinking, that is not great either, that nobody's noticed someone else's charger from a few patients before is still in the room (Family 5, 50yr female carer for mother with malignancy) *Well, things should be clean. Long as the floor's clean, rubbish is picked up…And, I notice a lot of the times with my brother and even with dad recently, piled up shit along the cupboards. And the nurses won't hesitate to come in and clean it up. And I found the cleaners, Hospital XX and at Hospital Y, they were always keeping the room clean (Family 1, 53yr male carer for brother with malignancy and parents with non-malignant illness)* *I would question, myself, the cleanliness of the room. But then again, in all hospitals, not in Hospital X , they've reduced the services of the cleaners and they come and they wash the center of the floor, and if it's behind the bed or next to the bed, they don't go*

		near it. So no wonder these infections are rife in our hospitals. One thing, our hospitals are now going to be fined for every infection that is not necessary to have, the best news I've ever heard (Family 12, 78yr female carer for husband with non-malignant illness) *Yeah, that's one thing, that the cleaners are on the ball. The rooms are pretty clean. There's equipment that just kind of hangs around for days and days and days. But general speaking, it's pretty clean. The ward has a no flower policy, so it actually looks a bit sterile. You can't get around that either. It has to be there for health reasons, for those people. But it's a very sterile looking place (Family 5, 50yr female carer for mother with malignancy)* *I don't think I could fault the care and the new part of the hospital there, the way it's set up. It's excellent in that it's got windows that you can sit at with lounges that as mum got a little bit better, she was so happy to sit in front of the window and look out at Botany Bay. And then the grandchildren came, one of my daughter-in-laws with two of the kids, and there was a little table and they were sitting there playing with Lego. I did buy some things because I know when the kids come, we've got to give them something to do. And mum felt ... Well, after they left, she said, "Oh, that was like a little picnic." And it just lifted her so much as opposed to being in the room. Actually, where her bed was there wasn't a window, so she really couldn't look out at anything (Family 11, 61yr female carer for mother with malignancy)*

		having enough space around the bed so that the family can actually be present. Now, in ICU, obviously, you're only meant to have two visitors at a time. With Daughter 1, we were always given a bit of leeway with that… At night, we would be allowed to have the four of us together with Daughter 1, and that was really incredible just to have that unit together, and of course there were parameters around that as well, that we didn't make noise or bump things, or it had to be a safe experience for Daughter 1 as well as an enjoyable experience. But we did feel that there was just a bit of gentleness around those rules as well (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness) *No, it's all really good. There was only once that I didn't agree with it, there was three ladies altogether and then they put a gentleman in the same room…And I don't agree with that. Not that I had anything against him, I just don't think that men should be in the same room as women because it's a personal thing and they shouldn't be (Family 18, 59yr female carer for mother-in-law with non-malignant illness)* *A big one, and it's unavoidable because it's New South Wales Health, is being in a shared room, a four bedded room that's a mix of men and women. That's a big thing. The very first admission she was in a room with three blokes, and that was really confronting for mom, because there's just three men who make noises and you're only divided by a thin curtain. At night time your curtains even aren't*

		around because they've got to be pulled back so that the nurses can see you. And sharing a bathroom with the opposite gender, with people that she doesn't know... Like showering after someone's been in there and the bathroom stinks. That kind of thing. That environment, for mom, is really tough (Family 5, 50yr female carer for mother with malignancy) *No. It's not a comfy... There's not like a lounge, kind of a nice chair to sit in that you would be comfortable on. It's just an ordinary chair that's got not much padding and it's got the backs missing. So really that's what dad sits on for a good 10 hours a day when he's there. The only comfortable thing is that we take mom's pillow in and take her a blanket to put on top of her bed as well, so it looks a bit less clinical. But yeah, for dad, it's... There's a little lounge at the end that they can go and sit in, but it's only got three seats in it. So if other people are in there, you can't actually get in there. So no, it's not comfortable for either of them (Family 5, 50yr female carer for mother with malignancy)* *Just trying to think. There probably wasn't something I really need... I was really... I know, the room he was in, there was just no extra seating. We basically had a bedside chair that Dad was in, every time I went in I got the shower stool from the bathroom. So I could sit, because there was just no seating in his single room, except for the bedside chair for the patient. And I just felt that was a bit of... I thought that was a shame. There's plenty of room in the room to actually put a relative's seat there….Because otherwise people just*

		had to hang over the bed rails, or try and sit on Dad's bed when they came to visit him…Simple stuff, we didn't want a major couch or anything, we just... another chair to sit on (Family 9, 64yr female carer for father with non-malignant illness) *No, no, in acute care then he had a bed. I had only a straight back chair. So, I came home that night, it was very uncomfortable, so I came home that night. Then the next day they transferred us to oncology ward which was very comfortable – a separate room, a nice comfortable bed for me, like a pull out sofa – that was very comfortable upstairs (Family 4, 53yr female carer for husband with malignancy)* *down the corridor a bit and there's this little, lovely, it's got a big kitchen, actually. And they've got these lounges and there's a big window, and you're looking over the XXXXX it's beautiful….. But plenty of chairs, in the ward and that, so you could sit down…It's all a bit bit homely, you know what I mean? (Family 10, 73yr male carer for wife with malignancy)* *I think perhaps having a dedicated space at Hospital X for families that's not in intensive care. In intensive care, they do have the family room to talk through all the traumas as they're happening and unfolding in ICU. I think having a space for people in a ward who may not want to have conversations where others can hear, and that would really be the only thing, and so much of that is just based on budgets. It's not really that people want to be having private conversations behind a curtain, it's just that's what's*

		available, and yeah, it's difficult (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness) *I mean, I was lucky because Dad had a room to himself, after the first day he had his own room. So that was very useful, because Dad and I had some long, deep and meaningful conversations. And I could close the door, we had privacy to do that (Family 9, 64yr female carer for father with non-malignant illness)* Bereaved Family data *Yeah, to be honest, because otherwise it does get very clinical and mum was like, you know, at the start when they asked her, one of the things that she used to get so upset about was sort of like the day like, you know, can you tell me your name and date of birth and do you know what date is patient X? And she knew but she couldn't sort of follow through with it and it used to make her upset so when the nurse would go, she'd always ask us, "What day is it again?" And you know, in the end you'd be like, "Mom, it's in the morning, it's night." So you know, it was important to have a window and have that thought that you could see out or you know, there was something more than just four walls and a TV so to speak (Bereaved family 10, 43yr female carer for mother with malignancy)* *When she moved to a two-bedded room, she had the window there. It was actually quite beautiful. This is going to sound stupid, but it was a retaining wall. But it was a light wall, and it had ivy or*

		creepers growing up through it with birds. So although it was this massive concrete retaining wall, and she couldn't see the sky, it really was incredibly beautiful, and look, dad had windows in both his rooms, but they looked out on the courtyard and across to another section of the hospital. I don't know. It probably wasn't a big issue. But for mum I'm sure, just having birds fleeting about was for her actually a great joy, a really great joy in those last couple of days (Bereaved family 13, 54yr male carer for both parents with non-malignant illness) *Look, it was really nice to have a window because we could say look out at the sky and stuff. Maybe because we had one, it didn't become an issue. Maybe if we hadn't had capacity to have a window in the room, then maybe we would have gone, "Oh, this is like a box." But we actually had, the hospital we were in had big, four bedded rooms, and they have floor to ceiling windows and a balcony (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)* *Well, more so for him, because he's the one lying there, but really I think when you're in hospital, the window is important. Ideally, if you can let a bit of fresh air in, that's even better, which is usually not possible for reasons I suppose… We'd look outside, and he'd comment on the weather. I suppose it takes you out of yourself a bit. You look out, and you think about what's going on out there, or you see, even if it's just trees and a car park, there's life out there. You can see the storm coming over, and he'd be like, "Oh, you*

		better get home. It's going to storm pretty soon," or whatever (Bereaved family 9, 57yr female carer for father with malignancy) *So, we were in this little corner cupboard of a sort of bed first right next to the bathroom and then we got moved. We asked if we could get moved to the window when that person left. So, then we got moved to the window. Then he went down to ICU and then we were back into the corner, near the bathroom. So, then we asked to be moved back to the window and you sort of try to make it as good as you can and make it nice, make it all right, make it ... because being in a dark corner was just so depressing (Bereaved family 7, 56yr female carer for husband with malignancy)* *Well, I think privacy is really important. So, we didn't have that initially on that oncology ward and like I say, the other thing is sunshine, something to look at even if it's just across to the other side of the hospital building. To be in a dark corner near the bathroom was my idea of hell (Bereaved family 7, 56yr female carer for husband with malignancy)* *The room sometimes like, you know, you understand that like mom had one lady that used to call out a lot and bang the table a lot in a shared room, which I understand, but mum had the dementia too, but mum was more happy with it sort of thing. So that used to affect her a little bit and there was a few nurses that suggested a change room, which sort of didn't happen, sort of happened and then didn't*

		happen, she was moved a fair bit (Bereaved family 10, 43yr female carer for mother with malignancy) *It was hard because every time they moved mum, especially once the dementia was... Sort of explaining to her again and they did do a good job with it. Then obviously us being her family were the ones that sort of get, you know, "I want to go home", or, "Where am I? What am I doing here and how come I've got next to this person?" I have to say that they did do that a lot, but then they did that also because of her health. Like she was better so she was back in a further room and then she was worse so then she's in a closer room to the nurse's station, which of course I understand (Bereaved family 10, 43yr female carer for mother with malignancy)* *The number of different settings like beds and rooms and environments that we had to deal with and then the number of different people and teams and nurses and each time, you've got somebody that's critically, critically ill, so each time you've got to try and ... you move into a new environment, you've got to try and make it feel a little bit nice and a little bit not alien and horrible and hospital and dark and dingy and you've got to try and work out how to make it as comfortable as possible, you've got to work the people out, you've got to ... and then even when you're in the same place, the people change and the people change and the people change (Bereaved family 7, 56yr female carer for husband with malignancy)* *We did sometimes feel a bit overcrowded I have to admit, but they never made us feel like that. They always got us more chairs and*

		the night she passed, myself and my niece was with her so you know like, there was a bed available, like a chair bed next to her, which they set up for us though, you know? Yeah. Like it wasn't extra, extra room, but there was always enough room for us and nobody ever made like, "There's too many people," we could come whatever time we wanted. So it was never an issue like that (Bereaved family 10, 43yr female carer for mother with malignancy) *Pretty much they did leave us to our own devices. We had plenty of space, they didn't push us out, that was good (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)* *The staff were fantastic. We could come and go as we wanted. That was the important thing. They made that really clear, and they made us genuinely welcome (Bereaved family 13, 54yr male carer for both parents with non-malignant illness)* *Well look, as I said, being a ward with four people rangeing from men and ... I know a lot of ... We were discussing this the other day. I know elderly people don't like it when men and women are together in the ward of four, you know, they're all mixed wards and things. There's a lot of elderly people who really have series issues with that. Because you know, like an old man, they might have dementia or whatever over there and he's exposing himself and the old lady in the corner is really struggling with ... You know, those kind of things. You know, a 93-year-old woman next to a 30-year-*

		old kind of thing (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness) *I think a lot of people just really crave privacy when they're in hospital. I think the ward situation with the curtains and whatever just doesn't ... It's so '60s and whatever, it just doesn't really work… Some people are happy with that kind of situation, but for most people it's just ... I was saying to someone the other day, I was in this shared ward, and they were like, "Oh, I just hate hospitals." It's amazing how many people have just said the same thing. "I just want my privacy. I don't want people looking into my room. I don't want to be on show." Kind of thing. I just want to be treated with dignity and privacy and that kind of accommodation just doesn't give that. So people say they'd rather have a small room, but just be there on their own, than have these big, shared wards and that kind of thing. Yeah, just have your own private bathroom and those kind of things as well (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness)* *We didn't leave Patient at all, We didn't leave his bedside. Most of the time we couldn't find a chair to sit on as his family member. I stayed with him overnight, and it wasn't until the second night that I was actually able to actually lay down somewhere (Bereaved Family 3, 43yr female carer for brother with non-malignant illness)* *It's little things, I think as well. I think, for families, there is often not enough, even chairs for people to sit on in public hospital. There was certainly no where for us to sleep. Once he was admitted, we*

		didn't leave him, so you would usually sleep just leaning up against the bed. I think eventually, they found a blanket and a pillow for us to have, which was nice, and just things like that, that often ... It's not set up... Acute care settings often aren't set up for families to continue to participate in the care, and continue to provide the care that they've been providing at home (Bereaved family 3, 43yr female carer for brother with non-malignant illness) *There was one jason reclining rocker that my sister and I took turns of, that was I suppose the only thing, in building... commissioning units like palliative care or oncology. It might be nice to think that people are probably, in all likelihood are going to have to stay in (Bereaved family 5, 56yr female carer for mother with malignancy)* *So, it'd be great if there was any design features where, I know we had a microwave. We could use a microwave and a kitchen area. Any sort of bedding would be nice, because to sleep on a concrete floor for a night or to put two chairs together, and then try to be a reasonable human the next day is pretty hard (Bereaved family 5, 56yr female carer for mother with malignancy)* *there weren't any seats for us to sit down so we all stood around the bed for the whole day. There was one chair by the bed and at one stage, Patient's daughter came up with her three year old and she was sitting on the floor playing. I think it was Wife actually, her grandmother, said to Daughter to "Look, I don't know that Grand-daughter should be playing on the hospital floor, it's not perhaps the most sterile place for her to be". So Daughter went out into the*

		foyer and all that was in the foyer by the lifts was a whole lot of stacked up furniture, beds and tables and things. I don't know why, whether they're emptying a ward out or something. So there was no patient room, we weren't shown any family room or waiting room. So a nurse pulled down one of the tables that were stacked there and Grand-daughter did some drawing and played at that table. So there certainly weren't facilities. There was a coffee shop downstairs that you could go to (Bereaved family 6, 68yr female carer for brother-in-law with malignancy) *I mean naturally it's a hospital so it's not great but that ward is a little better. There's like a kitchen with like, you know, cold water and ice and a microwave. So that was very, very helpful (Bereaved family 10, 43yr female carer for mother with malignancy)* *the only other thing I would say is, so they had a small little tea and coffee room that had, you know, little packets of tea and coffee that were atrociously revolting. And then there was a cafeteria in the bottom of the hospital that was then atrociously expensive, and they were your only two options, so there was nothing else around the hospital that you could walk to. And we did, I think we did uber eats at one stage, but I mean, that week we must've spent hundreds of dollars on cafeteria food that was horrible…Its just, it'd be good if the quality was better and price wasn't so exorbitant (Bereaved family 11, 33yr female carer for father-in-law with malignancy)* *but there was nowhere that you could go other than in the room, because it wasn't a palliative care space. Whereas when we went*

		down to pal care, there was a family room and stuff, but on the wards, there definitely isn't that capacity. It's kind of like either you're in the room or you have to go to the cafeteria with everyone else. There was no private space where you could go and get a cup of tea, nothing like that, where you could bring it back to the room. They did leave us plenty of time to have plenty of room and space (Bereaved family 8, 56yr female carer for mother-in-law with malignancy) *The other important thing that we had the room to ourselves, so I'm just looking back to other times she'd been admitted and in a mixed room, and how horrible that is when you've got someone who's dying and you're in a mixed space. Because you just, you don't have the room for the family to come in, you don't have the time to have a personal conversation without everyone listening in, you know? (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)* *Not a minute of privacy to talk about what was going on. I remember the oncologist came to visit us sitting by the bedside and the woman next door is peeing in her seat, kind of thing, and on the floor. It's just like, I want to be listening to this conversation, not that (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness)* *Just that total lack of privacy. Especially you know you're dealing with, in our case, it was a diagnosis of death, but Patient and I never had one moment where we could just talk without someone*

		... You know, everyone can hear in the room. My girls were really delicate, because they were 18 and 16 kind of thing, that's a really difficult age for them to be dealing with that (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness) *I know when dad was in there when he had his stroke, I'd be sitting there and just wanting to talk to him about lovely things that we had done or whatever, and the whole room is listening in because they've got nothing to do but ... They're not being rude or anything, but yeah. So it's very hard in that kind of situation. You just want privacy (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness)* *Then they had this theory that, "Oh, but it's good for them, because then they can talk to the other patients." I said, "Well if you want someone to talk to my husband, we will be here 24/7." I said, "But we just want some privacy." We have lots of friends and lots of family, so Patient was getting a lot of visitors and whatever, and I was trying to control that. But you feel a bit bad that your visitors are then disrupting the other patients and things like that, because sometimes they can get a little bit rowdy, or whatever. But I like to be there for a family member if they're in hospital. I'm always visiting and that kind of thing. So yeah, to have some privacy and ... Yeah, is very important (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness)*

		It doesn't... Isn't particularly good for care however, when you've got a terminally ill patient surrounded by surgical care patients, who have different social issues going on in their life. One of the things I suppose that you want at that end stage, is you want to be able to have people come in and say almost their final goodbyes to somebody, with a bit of privacy. Instead of separation by a curtain (Bereaved family 5, 56yr female carer for mother with malignancy) *When we were actually, he was very, very close to dying. We had to really beg them, "Please, can he just die in a room by himself, please? Can you not die in a four bedded room?" (Bereaved family 3, 43yr female carer for brother with non-malignant illness)* *Thank god. That's where he died in that room. So, thank goodness she did. I mean, imagine somebody dying on public ward. It would just be so awful. I can't imagine how awful it would be. It's bad enough anyway (Bereaved family 7, 56yr female carer for husband with malignancy)*
Domain: Family involvement in care provision		
• Company and family connection, including family support, is indispensable in providing comfort and emotional healing • Familys feeling respected as partners in the care of their loved one	• Family vital in assisting understanding of information provision; • Comfort of a partner being involved in information provision so as to enable the ongoing sharing as part of a longterm partnership;	**Confirmatory quotes:** Patient data *Absolutely beautiful, but I do feel, I always tell them, "Go now, go home to your family, I'm fine," But the support is wonderful, love. I've got so much love and support around it's... No chance to get depressed at all. (Patient 8, 77yr female with malignancy)*

	- Important for hospital staff and processes to be supportive of family involvement through enabling access for visits at any time, comfort when staying overnight to enable rest and also more explicit guidance in relation to timing of medical ward rounds.	*But yeah, just all round, the whole family's been 100% behind us and it's been really good (Patient 1, 48yr male with malignancy)* Family data *Yes. I had quite a number of phone calls in the first two days, three days of Dad being there. Sometimes even at 11 o'clock at night. And each time I was phoned by a member, it was usually the nursing staff, again, I found them very good. They first of all, immediately said, "Look, Dad's still here... and we're just seeking your permission to do this", or Dad said "Look, he'd like us to ask you would this be all right?" And approached, again, very nicely. I got off the phone each time and I thought, "That was really nice" I felt very reassured by it (Family 9, 64yr female carer for father with non-malignant illness)* *It was an extra battle on top of all the other things, and so when she just needed a bit of a boost, the family would come in together and we'd be allowed to just sit with her and be a unit, and that was a real blessing (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness)* *Yes. When I went to the oncologist, I felt pushed away from the conversation. The conversation was directed solely to my mother who is someone who likes to go into telling a story. The way she gives the information can be quite lengthy and you're going, "When are you going to get to the point about the pain?" That's what actually happened. And so if I tried to interject, I was just pretty well*

		shut down. And I thought, "Oh, well. I don't know." But in the end because I had a notepad with some questions, mum was asking me lots of questions before we went for the stent and I said, "Look, I'll write them down, and when we get there, I'll ask."…Well, I tried to convey that to this person, and he wasn't really interested and in the end he finally did turn to me and when I started to ask, he said, "Well, I've answered that when I spoke to your mother." I said, "I know, but there's this ... " I can't even think of what the question was, but I said, "I wanted to ask this." I just felt pushed out of it, and I thought, "I'm with my mum for the last five years now, 24 hours a day, and I do know a lot about what's going on as well." And her way of expressing things aren't exactly ... She kept saying the pain is all the time, and it's not. It's after meals. This is back then. And, yeah, she wasn't quite expressing it the way it was occurring from what she'd been telling me over the time that I'd been with her (Family 11, 61yr female carer for mother with malignancy) *And there was always this big delay about, if I just happened to visit and one of the residents would come in, I'd just question, without me sounding arrogant either, because I've got to be careful that my role for Dad's... I'm his daughter, I'm his Family, I'm his advocate, I'm not his doctor. But because of my medical training, you can't stand back and watch something that feels inappropriate either. And so I was just trying... try and play that role carefully, because I certainly didn't want people to... Always there's this worry that somebody will mistreat your loved one because you're being a little bit overbearing. And I was just trying to get the balance right there*

		as well (Family 9, 64yr female carer for father with non-malignant illness) *But it was always present, to an extent, that I never expected, and to this day I do not understand it. I, as I said, I'm the last letter in the alphabet, not the first. I'm not a clinical person, and why should anybody respect my opinion is really and truly beyond me, but I understand that because I am with him all the time, I obviously know more, at times, than any of them. And I only found that out last week, quite as an interesting one, because at our discharge from hospital, his respiratory specialist said to me, 'You're an angel, without you, we would not be a team.' And he said, 'Next time, when the team members say he doesn't need antibiotics, and you think he does need them, you are in charge of this. You are the one that are prescribing them, and not them.' He said, 'If you meet any opposition, you are to ring me, or they are to ring me.' I kind of laughed, and I thought to myself, 'This is all too much, I mean, who am I to do that?' Well, with the situation Saturday week, when I decided it was time he started on antibiotics again, and I found out that the GP was on school holidays and there was no one I could consult, it was the weekend. So I dished out the antibiotic on Saturday, and the GP phoned me on Sunday morning, she was back from holidays, saying that his blood test results weren't too good and I did a wonderful job of starting him on antibiotics yesterday. And I thought, 'That's a new one,' because the GP is only new, we didn't have a GP for seven years who could do a house call, and now we have a wonderful GP. Anyway, she said,*

		'Professor so-and-so wrote me a personal letter and he advised me that I'm to listen to whenever you suggest that he needs antibiotics.' 'And I'm to do as you said.' And she said, 'That's why I'm so pleased that I wasn't here yesterday, and that you've started him on antibiotics.' I nearly fell off the chair. I nearly fell off the chair, that he went to the trouble of writing to her, telling her this. So I have never been excluded, I have been always in the middle of it, from their point of view I'm very important. From my point of view, I am absolutely not important! So we kind of differ there (Family 12, 78yr female carer for husband with non-malignant illness) *They respect me, and I'm obviously part of the team, but if they didn't, I somehow rather would not have been paying very much attention to this, simply because I am not a clinician. I'm not, I really don't know much about it, but I learn quickly, I'm a smart cookie when it comes to that (Family 12, 78yr female carer for husband with non-malignant illness)* *Nobody knows the patient like, obviously themselves or somebody like their partner or Family that's been there for quite a while. They know, not better than the nurse, but a lot in more detail than what the nurse knows (Family 14, 49yr male carer for wife with malignancy)* *Just the last admission, yes. What dad said actually was quite sweet. When the lung physician came, he's a professor, so he's got all these things. Dad Googled him, and dad's very impressed because he's a member of this society, that society, he's got all his*

		creds up online. And his bedside manner is just delightful. The first time dad met him dad had given mom's history, and apparently the guy had thanked him for the history and told him how wonderful it was that he was so articulate and knew everything about what had happened. When dad was relaying that to me when I was sitting with them, he said, "He said that I was really good at this, and that actually made me feel really proud." I thought, "Oh, you poor fella." (Family 5, 50yr female carer for mother with malignancy) *I remember with Daughter 1, a week and a half before she died, the nurse that was looking after her said, "Would you like to wash Daughter 1's hair?" And I washed her hair in the bed, and we laughed and we just ... Daughter 1 just loved it, and that memory will stay with me forever. It was just such a life-giving experience, and in a sense it was just handing me a bowl of water and a towel, but it was doing it with an understanding that this was significant, and with just a knowledge that these memories are so important. And the dignity of being allowed to participate in Daughter 1's personal care by giving her hair a wash, yeah. It's just very special (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness)* *And they kept me in the link, which was good. I didn't feel like I was someone that was just a nuisance relative coming in, I felt like I was being kept in the link in that regard (Family 9, 64yr female carer for father with non-malignant illness)*

		It could have been better, because I just kept on asking, and I just kept yeah, but it was not ... They don't easily come the information. I would wait and just kept on asking and just begged people. But I was not in the dark for too long. I have been there the whole day. Sometimes the way things you know ... You don't know when the doctor is coming so you just wait and you can't step out, because they might just come and you miss out on information. Yeah, so that one, the timing of it because they just say Oh we'll be in in the morning so then you hang around for the whole morning (Family 3, 52yr female carer for mother with malignancy) *but I think, too, for those situations, where the patient is really educated and the family is educated by the team, they know if the medication's not right. And so we can then go, "Oh, can you just double-check that? Because that's not the regular dose." (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness)* *Now, that's just part of that sense of ... I don't know, being included in what's going on for Daughter 2. You know, you're not just ... And I felt like I was really listened to. If I had a concern about Daughter 2 and I would voice it, then they would explain the reasons why such and such was happening, or particularly when she was in kidney failure and we didn't know what this was going to lead to. Was it going to lead to dialysis? Would it be permanent? What were the implications? (Family 8, 52yr female carer for father with*

		malignancy and bereaved carer for daughter with non-malignant illness) *And so I think I've got so many wonderful examples of where the healthcare team would sit us down as a family and would explain where, whether it was Daughter 1 or Daughter 2, we're up to in their disease progression. And what they had tried and where they felt that they'd had some breakthroughs and where they'd had some challenges. And the next steps moving forward, why that would be helpful and what the experience might be for the patient, even to the point of, "Well, there's a 15% chance that the patient will get through this," so that you know what the challenges are. You know what you're looking at in terms of, you know, "Is my daughter going to survive this," or, "What are we looking at for my dad in the days ahead?" It's just that reality check but done with a softness and a care that make it possible to receive in a way that is sort of ... It just strengthens and ... Yeah, and I suppose it's different for each family and each patient, but for me, I like to know what's actually happening clinically and to be invited into that space is a great honor and really, really helps (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness)* *With Daughter 1, we had a room called the family room where when difficult decisions had to be made or things were progressing in a way that were just very challenging, we would all be invited into a very welcoming space. And the whole team would actually sit with*

		us, so it was a representative from each department would sit with the family, and they would all participate in the meeting. And so from a clinician's point of view, I'm assuming that there's a lot of support in that, that the team is broaching some very difficult issues for a family. But from the family's point of view, you just have the sense of total patient care, that you're removed from the clinical environment into the family rooms so that tears can be shed in private and conversations can be had in private, and there's just a dignity with all of that, that we really appreciated (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness) *I think a family conference would be ideal, but it's never been broached. I have suggested that to dad, that maybe we could see how that might work, but I think that just... I don't think he actually understood what I was meaning by that. I would think that they would be standard practice, that at some point in three years, when they've given her three years, that there would be some kind of a family meeting about where do you go next? Because really, she is coming to the end of the time (Family 5, 50yr female carer for mother with malignancy)* Bereaved Family data *But they've got to be open to advocacy. I was saying it nicely, kind of thing. I was the person that would be going in and taking cupcakes to the nurses, and all that kind of thing. I wasn't been an*

		aggressive kind of a person, but I wanted the best (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness) *Now, when Patient was sick, I said to her that all of this stuff was a road that we had to follow and we would be hand in hand until we get to the end and you have to go one way and I have to go the other. But in the meantime it's a shared experience. And this is something that we will do our best to deal with. It's not your problem, it's our problem. And to me, that is the most important thing that the ... I mean, everybody's aware the palliative care people are on your side, sort of thing. But it's ... yeah, you're in the trench together and they need to understand that, you know? (Bereaved family 1, 66yr male carer for wife with malignancy)* *And I think then obviously, then the trust that goes in trusting and listening to family members who have been there for every step of this journey, really listening to them, and the role that they've played in that person's care, because, so often, they're experts in it by that point. I mean, my brother had been an alcoholic for 15 years, he had been acutely dying for three months, and probably chronically deteriorating for at least a year prior to his death. As a family, we had talked to him about what his needs were. We'd understood where things were coming from. But, in a high dependency setting, it is much more about the numbers, and the lab results, and the figures, and those sorts of things, rather than quality care for*

		someone who's at the end of life (Bereaved family 3, 43yr female carer for brother with non-malignant illness) *With the doctors, again, yeah I think a lot of it is an arrogance with a lot of them. They really ... You don't know anything about the situation, or whatever. Yeah, well I'm seeing my husband's symptoms all the time, you're popping in for two minutes of a morning. You're not really seeing the symptoms that he's portraying, or whatever, and you're not seeing the fact that you're not checking his medication chart to make sure that he's being medicated, and things like that (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness)* *Because you know nurses come in and go, but they're only there for one shift, and sometimes there's a big difference in the thing, but you might have stood there by the bedside for four hours. So you've seen lots of changes and things in them, and the times when they're in for observations may not necessarily be when they're most alert, or whatever. Or they could be very alert, whereas, the rest of the time they're doing nothing, kind of thing. So talk to the family about what their observations of the patient are (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness)* *Often they do physio, the physio's there for five minutes. I'd say to them, "Can you write in a book what you're doing, and what you would like us to do. We're here for four hours a day, how can we ..."*

		Like with dad with his stroke, how can we ... Can we get him to squeeze a ball? Can we get him to squeeze our hands? Can we get him to touch his nose? Whatever. Leave us a list of things that we can do, because most family members are more than happy to help or whatever. But unless you know how to help, you don't want to be doing the wrong thing either. But it's such a better use of resources, and it saves time for the nurses and things as well, if the family can take an active role in the care of the patient. Often, as I said, I think Familys are happy to do more for their relatives when they're there, but they often don't know what they can do, kind of things. So again, just that communication in letting them know. Look, it'd be great if you could take your mother, father, or whatever, for a five-minute walk every hour, or whatever. Just little things like that that just gives them the instruction. Or if you could help them with their lip care whilst they're here, or just little tips on how you can help your thing, or get them to squeeze the stress ball for five minutes. Or get them to do their blowing thing after the heart surgery to get the balls to rise. They forget, and they lose track of time. They think they're doing it, and that they're blowing the ball (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness) *They elicited repeatedly, gently, and in a timely way, what do we need to do to provide great care? With that question asked genuinely, there was a genuineness about it. It wasn't, I asked this question because I walk into the room. I asked this question because I actually care. I don't think there's anything else that they*

		could possibly have asked. If you asked that question and actually mean it, that kind of does it all (Bereaved family 13, 54yr male carer for both parents with non-malignant illness) *So, my view was well, I might only be a minor team member, but we're all a team here. So I've got to speak up when I think something's not right. Many people won't do that and they'll just listen to the doctors and say, "Okay, no problem.". Yeah, I didn't say I drove it, it was just that I didn't allow myself to be driven. So, I had my hand on the steering wheel as well, that's what I'm saying (Bereaved family 1, 66yr male carer for wife with malignancy)* *up until that point, it did feel... The role of the Family, was for you to do the work and we'll tell you how and when to do it (Bereaved family 5, 56yr female carer for mother with malignancy)* *that just helped enormously, even though it didn't really change anything, but I just felt like I had been consulted and talked to and that they did have it under control. It's just really all I needed to know. It wasn't going to change much, but after being ... I felt like I was dangling on a string all day after him being in ICU all night and dangling on a string. So, the tension was just so high and then to have that sort of happen and get so upset and then the interview and then she did that, it just made it ... well, I was able to carry on after that (Bereaved family 7, 56yr female carer for husband with malignancy)*

		Yeah, I did and probably a lot of it was because I was there all the time pretty much and I kind of insisted on being included. I mean, I didn't really have to but I was there asking questions and if they said, oh, we're going to do this, I would say, why? And question things if I didn't think they'd explained it. Mostly they did explain things reasonably well (Bereaved family 7, 56yr female carer for husband with malignancy) *The family that are with the patients, they're going to know their family, that family member, better than a doctor (Bereaved family 11, 33yr female carer for father-in-law with malignancy)* *Well the nurse came later, and I told her, I said, "Look I've put the oxygen up, because his levels were low." And she didn't really say anything, sand she left, then the doctor came back. And the doctor abused the crap outta me. Yeah, so he starts like, saying like, "You're not allowed to touch machines, you know, we're responsible for dad, and being the smart allic doctor." And I said to him, "Well, listen." We were there arguing, it was full on arguing at pretty much an emergency. And I said to him, "If you guys aren't gonna monitor my father, the machines are on, I've been doing this for almost 2 and a half years, monitoring my father. If he's in hospital and you guys aren't going to do it 'cause you're too busy, then I'm gonna do it. And that means I'm gonna touch whatever I have to touch to make sure he's getting the oxygen levels that he needs." (Bereaved family 12, 54yr male carer for father with malignancy)*

		I can see him, as I'm approaching through the doorway, he's trying to talk to her and she's saying, "What are you saying? What are you saying?" And as soon as I went into the room, I could see my father was distressed, I could see what he was distressed about, he was slightly blue. And I looked at the nurse and I said, "Nurse, he is telling you he can't breathe. Get the nebulizer, and put him on it. Put it on him." (Bereaved family 12, 54yr male carer for father with malignancy) *I guess it's kind of engaging with family to say, "Look, these are some things that you can do. As much as we would love to do this for your mother and every patient here, we can't do it for everybody. However, we can show you how to do it and it's perfectly safe. You're not going to cause any damage to your loved one by doing these things like massaging their feet with cream." Just little things so families feel like they are doing something, rather than just sitting in a room waiting for someone to die. I think that enablement of the family in care, I think is important (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)* *But for us, we had been doing the night shift at home with him. I had been doing all his showering and bathing, and all the dressing. We had been doing all of it, and then suddenly to get to the acute care setting, and not really have the ability to continue to be a part of his care team was ... It was hard, because that's how you felt you were helping him by providing that care…. And what seems to be, like you said, a second hourly turn from a nursing perspective, but*

		for that family member, that could be the last time that turn happens. It's all valuable (Bereaved family 3, 43yr female carer for brother with non-malignant illness) *I suppose one of the things that I would always do if somebody had a Family that was with them in hospital, was to check how much the Family wanted to be involved in the care. I mean I was happy to do whatever was needed and that was fine, but nobody checked whether I was happy to do that or not. They just left us to it. I was confident in getting her out of bed, taking her to the toilet, helping her out of the shower and that sort of thing. But certainly not everybody's confident in knowing how to care for some sick person with a chest drain hanging out of them, into a shower you know? And nobody checked. So I suppose I might have appreciated people saying, "Would you like help with that, or are you okay?" (Bereaved family 4, 69yr female carer for friend with malignancy)* **New data to support additions:** Patient data *My wife comes to most of my medical appointments. It's like being bankers, they always travel in pairs, and well she's a pharmacist so she understands what's going on (Patient 12, 65yr male with non-malignant illness)* *She understands the talk, I don't. I'm a poor dumb builder. I can build you a high rise building in the city. I understand all this creatinines or whatever they are, and the rates and the height and*

		whatever else. Anyway, that's just how I see it. (Patient 12, 65yr male with non-malignant illness) *….. every time I went and had to go and have an appointment with a doctor, I'd have my mother-in-law or my brother with me, so if there was something that I didn't pick up, they picked it up and we all sort of remembered "Oh, what was that about?" And I thought "Oh, this was about that", whatever it might have been, and the same as when I was in hospital with (brother) and they'd come in and (brother) and they would both listen and decide and both talk about it. (Patient 1, 48yr male with malignancy)* *It's easier to remember it all because when you're bombed out on drugs, well not bombed out, but you know what I mean you sort of got so many tablets in you for your pain and it's hard to sort of take everything fast. (Patient 1, 48yr male with malignancy)* *I like that she knows. I think it's important that, I mean, we share everything else, we need to know, but also with her, she's a pharmacist so with her, with her knowledge, she helps me understand what's going on. (Patient 12, 65yr male with non-malignant illness)* *Because he can sleep well. Well, it is very important for him to sleep well so that he will kind of care for me the whole... You can just imagine the whole day, the whole week, he's looking after me. He's assisting me…….. Even going to the toilet because I'm so weak. (Patient 21, 50yr female with malignancy)*

		I think it would help if when the doctors doing their rounds is, you know, every morning or whatever, if they could give you some sort of indication of when they'd be in the ward so that you're family member wouldn't have to get there at eight and stay until midday, and the doctor comes at 11:30 (Patient 13, 61yr female with non-malignant illness) *It's a strange world the hospital world. If you work in another job, you have to interact with other people and you realize that your job isn't the bees knees, but if you work in a hospital, it's like working on another planet. Everything else in the outside world just gets turned off. People don't have appointments, everything that happens in the hospital is the most important. Which it probably is, but you still need to realize that people need to go to work and have that appointment to talk about their mother. (Patient 13, 61yr female with non-malignant illness)* *Well it just depended. If he was there, then they shared that information. But a lot of the time, he wasn't there at the time that they came around because it's a bit of hit and miss. You don't have a designated time. But the times that he was there, yes, they passed on the information. We sat and talked about it, so that was really good. (Patient 4, 54yr female with malignancy)* Family data *This is very much my experience because family and friends say, 'What are you doing there? You should be home resting, because*

		he's well looked after, you should be home resting,' and my answer to this always is, 'I feel I must be there when the specialist is there,' because Patient X's's English is not wonderful, he wouldn't get the gist of the medical anyway, and I have to be there (Family 12, 78yr female carer for husband with non-malignant illness) *My role was to be his advocate and his interpreter. If it was me in there it would be different, but Dad's 91 and a bit deaf and he was below par... obviously a little bit confused, I think, because of the renal failure. So it was very important that he had a go-between (Family 9, 64yr female carer for father with non-malignant illness)* *No, that was a difficult part is not knowing when the doctor's going to be there. I think I was just lucky that the times I was getting there in the morning, I happened to catch Dr. XXX probably three times in one week…Any time I went to the coffee shop, I said, "I'm downstairs. Could someone call if the doctor comes." But it doesn't always happen even though I've told them…But it would be nice if you could organize a time and say, "We'll be there," or, "We'll get there 15 minutes early," so that we're there so that you can catch them, but it must be a phenomenal thing to try and work out because you've got so many people that you're dealing with (Family 11, 61yr female carer for mother with malignancy)* *Just that if we knew a time when the doctors were going to be there or if they could arrange a time to be able to talk you through plans and things, probably would be more ... I was lucky that I'd gotten there at times when they were there, but I can see that I'd have a*

		different story to tell if I wasn't…If I was a working person and couldn't be there, I'd be really in the dark (Family 11, 61yr female carer for mother with malignancy) *So I cannot expect them to change anything they're doing, because if they don't come when they said they can come, it means that somebody was sicker and needed their attention, and I think it would be terribly unreasonable to expect a specialist to come. Having said that, it would be very helpful if one knew. Very helpful (Family 12, 78yr female carer for husband with non-malignant illness)* *I could sit there for eight hours and not move, and then I'll walk to the bathroom and the doctor will come (Family 12, 78yr female carer for husband with non-malignant illness)* *I think for dad it's the comfort factor that's allowed him to start to ask questions. He feels like, at that level, that he's probably a little bit more involved in decision-making. But when they forget about that and they don't say, "Oh husband/Family, by the way, we've found this and we're going to get this person involved in the care," when it just kind of happens, then he's back to feeling like, "I just don't understand what's going on." (Family 5, 50yr female carer for mother with malignancy)* *And then you wait all day like you're waiting for this Doctor to come and then they come when you're not there you know? (Family 13, 56yr female carer for mother with non-malignant illness)*

		And you ask them, well, what time's the doctor coming in so that I can be here at that time, but they never seem to be able... Oh, anywhere between eight and 12 you know? (Family 18, 59yr female carer for mother-in-law with non-malignant illness) *Because it's the hospital doctors. So you just got to have who's there. But yeah, trying to catch up with them, is pretty hard (Family 18, 59yr female carer for mother-in-law with non-malignant illness)* *So my poor dad, when mom's in hospital, and this is for both those really long admissions, dad will be in there at 8:00 in the morning, too scared to get there later in case he missed any of the doctor rounds, and he wouldn't leave until 8:00 at night. The only time he'd go out was to the bathroom or maybe to get something to eat, but just sit there in the hospital room just to be mom's advocate to find out what was happening (Family 5, 50yr female carer for mother with malignancy)* *No. There's never a time, which is why dad sits there for the entire day, just in case he misses it. In the last admission there were twice where he'd been really frustrated because he's hung on, hung on, hung on, really needed to do a wee, gone out because the visitor toilets are off the ward, gone to the toilet, come back, the team's been and gone. He's only been missing for five or 10 minutes. So they haven't thought, "Oh, we see husband X here all the time, so maybe we just better wait or come back instead of having a discussion with Patient X." … If there was contact that they could... That's a great idea. A calling card to say, "Yeah, we came at this*

		time, and this is what we spoke about. And if you've got questions before we visit tomorrow, you can page the registrar or the resident or whatever to clarify stuff." (Family 5, 50yr female carer for mother with malignancy) *Just that if we knew a time when the doctors were going to be there or if they could arrange a time to be able to talk you through plans and things, probably would be more ... I was lucky that I'd gotten there at times when they were there, but I can see that I'd have a different story to tell if I wasn't. If I was a working person and couldn't be there, I'd be really in the dark (Family 11, 61yr female carer for mother with malignancy)* *Dad had said, "When's the team coming? We don't know." Nobody had come in until late that evening, so he'd been left worried and wondering all day what was going to happen or what it all meant (Family 5, 50yr female carer for mother with malignancy)* *I quite often miss their visits as well, because I'm at work or doing whatever, then I just... Unless you sit in there all day, it's easy to miss them (Family 5, 50yr female carer for mother with malignancy)* *I just happened to realize if I went in at a certain time, because I'd consult all morning and my only time to get away there was probably about three o'clock in the afternoon. I found out a couple of times, if I got in there about then, often there would be just a ward round going on and I thought... and I said to Dad, "Jeez, I've fluked it today, it was great". Because otherwise, I know they are*

		busy et cetera, et cetera. And so I didn't find it easy, but I did fluke it a number of times, which I was very grateful for (Family 9, 64yr female carer for father with non-malignant illness) *Yeh – just if there are set times like morning and afternoon if we can talk to the doctors, then we know the progress and yeh, it is a bit hard to talk to the doctors, I didn't know when they were coming. That would be helpful. If there is a set time when they are doing their rounds and we can talk to them, then we know that at that time we can talk. We just wait for them to appear, so yeh, having a set time yeh. Because I am working, the problem I faced was, because I am working, because I don't know what time the doctor is coming there, I had to be there the whole day. If I knew exactly after 4 o'clock he will come then I can leave work and be there to meet him. But because there is no set time, I had to be there the whole day waiting, hoping, I don't want to miss them I don't know what time they will come (Family 4, 53yr female carer for husband with malignancy)* *I know they go and do their rounds in the morning but other than that, no. You don't get to know when they're coming around. It's just a waiting game which can be frustrating (Family 14, 49yr male carer for wife with malignancy)* *they would let us, should the need arise ... Daughter 2 went into kidney failure at one stage and she was just ... It was an extra battle on top of all the other things, and so when she just needed a bit of a boost, the family would come in together and we'd be allowed to*

		just sit with her and be a unit, and that was a real blessing. Yeah (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness) *But the other big thing is about dad and where dad fits, and his comfort factors. The big thing that's missing is that they focus on the illness. They don't focus on anything that makes her feel better, and for mom, that's dad and what makes dad feel better, so that he can keep going on and be the Family. I'm sure he's completely burnt out, and I don't know how to help him with that because he's not keen to access help for himself….. But then there's no delving into, "How are you doing? Do you want to see a social worker? Why are you here? Can we do this? Can we do that?" That would be helpful (Family 5, 50yr female carer for mother with malignancy)* *I felt that it wasn't just about Daughter 2, I felt that it was like a family focus rather than just a single patient focus. And sometimes when the doctors would do their rounds at night, they'd look at me and they'd say, "You look really tired, Family 8. I think that you might need to have a really good sleep and just have a bit of a break." And I just felt that was so lovely, because it was like they had eyes to see what was going on with the family, and they'd be asking about my ... Because I've got a son, Son 1, as well and he was 16 when he lost Daughter 1, and then sort of going straight into this with Daughter 2, and it's sometimes difficult to be as present to your other children when this sort of thing is happening. And so I always felt that the team were very concerned about Son 1and just*

		concerned about the family, and they would ask questions to make sure that the support network wasn't crumbling or that Daughter 2's support network was actually being supported as well. And so that was a really very positive experience, and I appreciated being asked, "Are you okay? Is there anything that we can do for you as well?" (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness) *I do not expect support, because I'm not sure that ... I don't think it's the hospital's duty. I think I have to take care of myself and if I'm feeling challenged, I'll have to fix it myself. The job is my mother, so just deal with it. Yeah. If they have the time they would ask me casually, "How are you?" But in the system there is no, I was thinking a Family support group maybe might be helpful. I need to learn from others…. It would be good, but I'm not expecting. Maybe a support group to learn from, but I don't want to take the time from the doctors to speak to the Family. I don't know if that should be the doctor or maybe a social worker role? (Family 3, 52yr female carer for mother with malignancy)* *No, there was no self. There was no me. There was just my mom. The only one who asked me was the palliative care doctor, and this is maybe on the third month, and she said, "How are you? How are you doing?" That's a surprise to me because there is no self in this whole thing. There's no me. There is just what my mother needs. So I have chopped that. I've postponed me(Family 3, 52yr female carer for mother with malignancy)*

		Oh gosh, I tell you what, I would have loved to have had a chat with the doctor every day…Just a quick update, just so that I knew that what I was seeing and observing was actually correct and I could interpret stuff for Dad (Family 9, 64yr female carer for father with non-malignant illness) *So possibly just a time where I would have been given... were able to ring and they could... probably me ring them up or them ring me, and just really just probably three or four minutes, that would just be useful and have you got any questions? And this is what we're planning. It's kind of knowing what's in the loop (Family 9, 64yr female carer for father with non-malignant illness)* *It would be fantastic. .. after doing a round, it would be excellent, because then you're getting the latest of what's going on there…I'd be very happy with the registrar involved to do that…I think the registrar, from the team I ran into, I think was more able to do that. I think the resident was very nice, actually, but I think the registrar was much more savvy. Because I think the resident was probably doing a rotation through a renal unit, or something like that and it possibly wasn't their forte (Family 9, 64yr female carer for father with non-malignant illness)* *One day at about 6 o'clock, the specialist came, 6pm, the specialist came and she was worried, thinking the cancer had gone to the brain and she said the next morning they had to do a CT scan of the brain. So that was very distressing because… yeh…. But the next morning at 10 o'clock they took him for the scan and they said*

		that afternoon they will tell us the results. So the whole day I was waiting there and we were so worried, we were so anxious to know the results, but the doctors didn't come and tell us. So, I was waiting and waiting and then by the end of the day I asked the nurses, and they said – no the doctors were here, they said the doctors came to the ward at about 4 o'clock. But they didn't come and talk to us. So I said I need to know about this. So the nurse said, if it was bad news they would have come and told you. So, if they didn't come and tell you, then that means everything must be ok. So, I had to hear that from the nurse and I had to be asking the nurse what was going on and that was like…. Because we were so worried. And they had come…. Then the next day, I went early, I went there by 9 o'clock, because I thought 9 o'clock the doctor will come on the rounds,… so then I can talk.. but they didn't come – I couldn't see them – then they came at about 11 o'clock or something and then they came and told us there was nothing on the scan, that is was clear and we can go home (Family 4, 53yr female carer for husband with malignancy) Bereaved Family data *Yeah, it's like life, it takes a village to raise a child, and it takes a village to care for any person, especially someone that's hospitalized and they're not thinking straight, they're not ... As I said, they become very quickly institutionalized. I've seen it because we spent so many time in hospital over the last couple of years. You just see them. They just kind of shrink away to a shadow*

		of themselves while they're there. They're frightened of the nurse. Often, especially with the elderly ones, they're frightened of the nurses. They think they're going to get in trouble from them if they question anything or if they do anything, or if you question anything, kind of thing. Which is very sad why they've got this fear of them, kind of thing…. Look, some people just don't like to make trouble. They think it's making trouble if you're asking ... You know, they don't want to ask for things, you know what I mean? But it's not asking for something it's getting what you need to get better. You're not going to get better unless you're getting your medications, unless you're getting clean towels when you're having a shower and you've got wounds and things like that. Unless you're questioning why, where the test ... Do you want to be in hospital for another three days just because they haven't scheduled your test. You were scheduled that day, well why weren't you able to have it, kind of thing? You've got to keep pushing, otherwise things just don't get done (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness) *I went to the hospital as a nurse, but more importantly as my brother's advocate, so I could see what was happening through my nurse's eyes, but I loved him as my brother. And what I could see happening was, is that, I didn't feel like there was one medical person advocating for Patient. It was me needing to be the advocate, and everyone else would come in and put their two bobsin…. I guess, being a nurse, I could go in to nurse over a little bit, and advocate for him from a medical level, but they'd be so*

		many families out there who don't have that medical knowledge. To fight – you had to fight just to get to make sure your family was looked after (Bereaved family 3, 43yr female carer for brother with non-malignant illness) *There was no way I was happy to go home and leave her there, because I thought obviously no one else is gonna keep an eye on her overnight. So I then stayed for a couple of nights… I thought neither of us felt confident that she would get proper care (Bereaved family 4, 69yr female carer for friend with malignancy)* *I felt a lot of responsibility for my friend's welfare while she was in hospital. Probably more than somebody who wasn't actually on the staff and their job was to look after her. I felt the burden of responsibility that I had to make sure that she was okay, because nobody else was (Bereaved family 4, 69yr female carer for friend with malignancy)* *So, I think the nursing staff were wonderful and the doctors. Again, it's this thing of getting the doctors, making sure that they get there and they see him and he has enough time and that they think about it hard enough and that they do the right thing to ... it's all really stressful. God (Bereaved family 7, 56yr female carer for husband with malignancy)* *So, because also ... so, I was doing a lot of that running around stuff and that can we get a room near the window, could we have an extra blanket, all that stuff, and then also being nice to the staff,*

		bringing them something nice, talking to them, chatting to them, being friendly. But also if any specialist came ... Patient X was capable of asking questions, but often he wasn't feeling well and he didn't ... and I would really ... I suppose in retrospect probably grilled people a bit and often they'd look really surprised and say ... and when the ICU team came up, the very first time when he was red flagged, I was asking them a lot of questions and they said to me, oh, are you a doctor? And I went, no, I'm not. I just need to ... it's my husband, I need to know (Bereaved family 7, 56yr female carer for husband with malignancy) *We were always waiting for him, which was really stressful, you know, where is he, and then if something happens and you miss him, if he zooms in to do his hospital round, it was awful (Bereaved family 7, 56yr female carer for husband with malignancy)* *They would say, "We'll meet you at 11 o'clock." Or, "We're here at 11 o'clock if you can come in, we'll have a chat." Kind of thing. If you left a question for them, there was always someone would always ring you and they would answer it, kind of thing (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness)* *The ward was very clean, and the nurse unit manager would be popping in regularly and just talking to the family and things like that. Yeah, so they were very good like that. You often got to speak to the specialists and things. They would say, "We'll meet you at 11 o'clock." Or, "We're here at 11 o'clock if you can come in, we'll have*

		a chat." Kind of thing. If you left a question for them, there was always someone would always ring you and they would answer it, kind of thing (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness) *Yeah, look, it's good that you asked that, actually. In honesty, it was absolutely appalling , hadn't thought of that. It was absolutely appalling. So - Neurologist fantastic, came in on Saturday night, brilliant. Cardiologist, as I said, busy interventional cardiologist. So his ward rounds were often at 6:30 in the morning, and you'ld say to the ward - We're upstairs, we're literally 18 metres away. Please let us know. This was a colleague of mine, for God's sake. With the defibrillator, I had probably left three messages in his rooms and eventually took the unusual prerogative of just ringing him directly on his mobile, which is not good form. It's not the done thing. In terms of the general physician who was looking after my father, we saw him once. Then we were pretty much at a 24-hour bedside vigil. So there was always someone with him, and we saw him once in that time (Bereaved family 13, 54yr male carer for both parents with non-malignant illness)* *But we get so pissed off when Telstra tell us that – we've got to do better. When Telstra say we'll be there on Friday, and he goes, at morning or afternoon, they go, I can't tell you. I go, "Well, I'm sorry. It's really, really hard to deal with you as a company and why should it be... We've got to say that about patients also (Bereaved*

		family 13, 54yr male carer for both parents with non-malignant illness) *The staff were fantastic. We could come and go as we wanted. That was the important thing. They made that really clear, and they made us genuinely welcome (Bereaved family 13, 54yr male carer for both parents with non-malignant illness)* *Yeah, we were always welcomed there. Nobody kicked us out or anything like that. Nobody said, "It's time to go" or whatever (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)* *Most of the time we couldn't find a chair to sit on as his family member. I stayed with him overnight, and it wasn't until the second night that I was actually able to actually lay down somewhere…There's nowhere to lay down (Bereaved family 3, 43yr female carer for brother with non-malignant illness)* *It's little things, I think as well. I think, for families, there is often not enough, even chairs for people to sit on in public hospital. There was certainly no where for us to sleep. Once he was admitted, we didn't leave him, so you would usually sleep just leaning up against the bed. I think eventually, they found a blanket and a pillow for us to have, which was nice, and just things like that, that often ... It's not set up ... Public hos- ... Acute care settings often aren't set up for families to continue to participate in the care, and continue to*

		provide the care that they've been providing at home (Bereaved family 3, 43yr female carer for brother with non-malignant illness) *Then the palliative aspect of the Family, although I thought they were lovely, again, I was just kind of left really high and dry. Everybody else was getting all these social people coming and talking to them, and I was just kind of beside myself having to deal with everything, and being in a public hospital ward and when you feel like somebody that you really care about is really unwell, it's just very hard (Bereaved family 7, 56yr female carer for husband with malignancy)* *I had nobody talking to me. Nobody saying ... I ended up getting really upset about it actually at that stage. And then eventually, I got a ... I think it was a social worker came to talk to me and I tried to ... I think it was mentioned that I could have a social worker come and they said yes and it took days for her to be able to come and see me for whatever reason we kept missing each other or she kept ... or she got called away to somewhere else or whatever, whatever. It just took days and days and days and when she finally talked to me, I was a bit beside myself and I was in tears and I really felt like ... and she didn't really do that much or say that much, but it was just such a relief to talk to somebody that was vaguely interested and sympathetic I suppose (Bereaved family 7, 56yr female carer for husband with malignancy)* *I had been trying to talk to the specialist about the surgery..the interns, was all I managed to speak to. So six days after surgery I*

		finally got ... I'd been leaving notes, "Can you please contact me? Can you tell me what time you're coming, and I'll be here to meet you." Patient would never know what was going on, kind of thing. Then finally he rang me at home and told me that my husband had been diagnosed with ... "I've just told your husband he's got stage IV bowel cancer. He probably won't live, but we'll see what we can do." Kind of thing, it was very offhand. He said, "Are you sitting down?" I went, "No, I'm not sitting down, because I'm racing out the door to come and visit my husband to make sure he's all right, because you should not have told him on his own that this is what his situation is." (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness) *You know? Because when things, like you said, when things are going wrong you can't get a hold of these specialists. You can't. You just can't get them. You got no one to talk to. The nurses say, I can't tell you anything because the doctors got to tell you, which is what they are told. You just are left in the dark until you can actually, physically ... Many times I waited at Hospital X for Dr. XX to come out after his theater to 10:00 or 11:00 at night and sometimes he wouldn't come. They would say, he is coming, he is coming. I would wait until 11:00 and he wouldn't come. He would finish his surgery at 10:00 and he'd go. Fair enough, but I had been waiting all day (Bereaved family 12, 54yr male carer for father with malignancy)*

		Yeah, look, it's good that you asked that, actually. In honesty, it was absolutely appalling , hadn't thought of that. It was absolutely appalling. So - Neurologist fantastic, came in on Saturday night, brilliant. Cardiologist, as I said, busy interventional cardiologist. So his ward rounds were often at 6:30 in the morning, and you'ld say to the ward - We're upstairs, we're literally 18 metres away. Please let us know. This was a colleague of mine, for God's sake. With the defibrillator, I had probably left three messages in his rooms and eventually took the unusual prerogative of just ringing him directly on his mobile, which is not good form. It's not the done thing. In terms of the general physician who was looking after my father, we saw him once. Then we were pretty much at a 24-hour bedside vigil. So there was always someone with him, and we saw him once in that time (Bereaved family 13, 54yr male carer for both parents with non-malignant illness) *I'm not sure. If there was it would've been XXX. I'm not aware that they did. Because that was one of our questions that I think it would've been, that's definitely an area that I think could be improved, is when someone dies in a hospital , what happens, what's the paperwork, what's the process. There was nothing on that end. We had a bit of trouble finding out what the process was, especially in terms of when does the funeral home take the body and all that sort of thing, like the chain of custody and documentation. If there was actually something, like even just a document, cause people may not want to talk to a nurse or a doctor about that. If they could just be given a document that, you know,*

		like a pamphlet thing that says, This is the process, this is what you can expect, these are the timelines. You know, in Patient X's case he passed away on late Friday evening, early Saturday morning, which meant that the paperwork couldn't be processed til the Monday, so things like that, it'd be good to know, to be able to just given something that you could go away that you could sit down and read yourself rather than having to talk through that cause that's not a very nice thing to talk about….Yeah, so then the death certificate, the family member, XXX had to sign some forms to say, to obviously release his body then as well. I'm not even fully across what that process was. My husband actually handled that bit. But those legal formalities around that chain of custody of the body being certified it's dead and then going to the funeral home, or wherever (Bereaved family 11, 33yr female carer for father-in-law with malignancy) *just having people quietly talk through their processes in that particular ward, that particular hospital with that particular funeral director is a really important part of the process. ..So I think making sure that those conversations are had, no matter what the experience, previous experiences or roles have been, is just so important and to elicit particular preferences in how a body is treated has nothing to do with your professional background. That's stuff that just needs to be talked through. I think, again, people do really, really well there…It was just a conversation. I don't think paper would have helped because they are decisions about what needs to happen, in this case, the next relatively short period of*

		time. So I'm not sure that... Certainly, look, if families had no idea what to expect, but I don't think that would've helped, and I don't think it would have helped to have it before either of my parents deaths. So I'm not sure how that would work. The funeral directors had a whole lot of stuff that they provided subsequently. That issue of how do you move the body from the ward to where, and what are your preferences in that process is a very immediate conversation. It's,,, ahhh – could we have had it earlier? I don't think so…I suppose we could, but really no. So you're left with some immediacy and that's where probably bits of paper may be helpful in distress. But for us, it was clear what we wanted, and we... Yeah, I'm not sure any other resource would have helped. ..So look, yeah, I had incredibly competent nursing staff. But if you are on a ward where there are agency stuff, they had no idea, that would be dreadful. This was a hospital where, if they did have a morgue, it wasn't mentioned. I doubt that they did. Their need as a hospital was to get that body out of the hospital, not just off the ward. But that was done without any sense of hurry or lack of decorum (Bereaved family 13, 54yr male carer for both parents with non-malignant illness) *If it was a quality control thing, like, "Hey, give us some feedback," no. That wouldn't be appreciated. But if it was a, "Hey, we just want to see how you're doing. Let us know if you need anything. You know, here's an offer for counseling should you need it," that would be amazing….Like it would've been so nice to hear from the nurse that was, you know, the nurses that were there from us, that were*

		there with us at the end. If they had sent an email saying, you know, "We're just thinking of you. If you need anything, let us know," et cetera, et cetera. I mean, that would be really lovely (Bereaved family 11, 33yr female carer for father-in-law with malignancy) *So we didn't hear from the hospital again. That's probably okay. But yeah, didn't hear from the hospital. We went back there to thank the ward probably late the following week for all of their care, that that was the only other... That was the only other contact we had with the hospital (Bereaved family 13, 54yr male carer for both parents with non-malignant illness)* *Yeah, I actually contacted the hospital. I was sad that we never heard back from the hospital, so we literally left after Patient died, and then never heard from them again, really. We never even got a discharge summary, which I was always quite surprised of that, 'cause even though that he died, he died in an acute care setting. I didn't understand why we weren't given a discharge summary. And I don't think as a family we ever quite understood, and still to this day don't understand what he died from. I think we are still, while we know he was confused, and while we know, I don't think any of us have been able to put the course of events together, to allow us to feel like we really understand why he died. Even though we knew that he was dying, it wasn't the way that we thought he would die. Things went off course for us (Bereaved family 3, 43yr female carer for brother with non-malignant illness)*

		Interviewer: Having some sort of bereavement follow up, you think would be helpful? *Yeah, just someone to check in on you. We never saw a social worker or anything like that. Just someone just to check up on you. It does feel very much like we just went there, he died, and we left. I did make contact with the hospital after he died hoping to have a session with a medical officer, and go through his notes, but I never followed that up, 'cause I just ... We decided as a family that rehashing it all would be too hard, so we left it. But we will always be ... It will always be a little bit of a mystery to us as to what really happened (Bereaved family 3, 43yr female carer for brother with non-malignant illness)* *Not at the time, but post mom's death, in the last little while. The Cancer Unit X do things like they send a letter. Acknowledging mom's death and saying, how sorry they were, they did have a brochure in there if we needed assistance. I think there we... I just a letter the other week where, something I think about, I can't go because I'm at work. Something like the second week in June. They have a service and a morning tea. I think it is at Suburb X. That anybody who has been bereaved from Cancer Unit X and in three months time… is invited to (Bereaved family 5, 56yr female carer for mother with malignancy)* *Interviewer: Yes, and does that feel supportive for you?*

		No, because I'm a bit jaded now with the service. I think once again it feels a little tokenistic (Bereaved family 5, 56yr female carer for mother with malignancy) *interestingly enough, I just came across it because I was tidying up some papers, on the ... he died on the 2nd of July, on the 8th of September, I got a letter from Organisation X, which run Hospital XX, saying, we are the bereavement support team at Organisation X. We were given your contact details by the palliative care team at Hospital X who helped care for your husband Patient X. We work in collaboration with Hospital X to provide bereavement support and the team requested that we provide you with some information about the service we offer. Firstly, we would like to say, blah blah blah. That came on the 8th of September. .. Which just seems really weird. When I got it, I went, really? Now? Why now? (Bereaved family 7, 56yr female carer for husband with malignancy)* *No. I don't think so. I think it's the reverse. We were very so grateful to the nursing staff on that ward that we wanted to get some thing really good as a present and Patient's daughter came up with the idea that ... she said the microwave on that ward's really crappy and all the patients and all the nurses use it and she said, we should get them a new microwave. So, that's what we did and the girls took it up. I couldn't go up, but they took it up and we took flowers and stuff and actually, the first time we left the oncology ward, we gave them some nice chocolates and flowers and things. No nobody, I don't remember anybody ... what did happen was that I went to see*

		the oncologist afterwards and talked it through with him and I kept thinking I'd go back and see the neurosurgeon, but I've never quite got round to it (Bereaved family 7, 56yr female carer for husband with malignancy) *Yeah, look, absolutely. Absolutely. So we were there with my father as he died. The nursing staff were just, again, so respectful, offered to let us wash his body if we chose to, offered to let us stay as long as we wanted. It really was very, very beautiful and again, respectful (Bereaved family 13, 54yr male carer for both parents with non-malignant illness)* *It was very much like that, and certainly even at the time of his death, we weren't given much time to spend with him after he died. You could see that there was a pressure for us to wrap things up, and get going. We as a family, we laid out his body, and we washed him. And I stayed till he was put in the body bag, and I never felt beyond that point that his body potentially was treated respectfully. Because once the wardsmen came to pick him up, you could see that, he sort of threw him onto the trolley, sort of style thing and you could see that he wasn't treated respectfully. He very much fell into the pattern of being a job, rather than a person requiring care, if that makes sense…It was very much about a task; collect the patient in bed 27 sort of thing, rather than respectfully care for someone who's just passed away (Bereaved family 3, 43yr female carer for brother with non-malignant illness)*

		She wasn't articulate by this stage and she continued to decline, and died on the Sunday night. Sunday the 24th of Feb at twenty to eight. And just to add to this, my sister and I, waited until 1 o'clock that morning for somebody to come and pronounce her dead… we waited in the room with her and we were told several times, that we're very busy and nobody could come. Then at the time when the poor young registrar came to call it. She then said, "Oh, your mom's... I'll call the death at well at 1 o'clock this morning." And we said, "She actually died at twenty to nine last night." To which they said, "Oh, well does that really matter?"..Yes, that really matters. So we had a bit of a tussle with them. Talked to them about the patient matters manual and who can... The difference between calling a death and pronouncing a death. Probably didn't like that, but anyway. The next morning the oncology team rang and said that, "Yes, the death certificate would reflect the time and date that she died." …Apart from the incident on the final night where she had died, and the nurse there I think was very submissive in that sort of power dynamics between nurses and doctors. So, didn't want to rock the boat by trying to get a clinician in earlier. This nurse particularly kept saying, "Oh, we're really busy and you know, they're caring for other patients." So really played down the fact that mom was still an individual (Bereaved family 5, 56yr female carer for mother with malignancy) *We just waited there... My sister and I just sat there in the room with her…We had this one nurse, who just seemed like... "I've rang the doctor, now you just... They're a doctor, they're busy. You sit there*

		and wait." "Your mom's dead. Nothing we can do for her now. They're treating important people. They're treating people who are alive. They're busy."…"You've got to understand." I think you know... I think about 11 o'clock we asked again, and they said, "They're very busy" and we said, "Is there only one doctor who can call her death in the entire hospital, is there no-one else?", "No, well, the doctor from this service is busy and you just have to wait." But then it was when they came up, and it was like, "Oh, let's just call it now. Half past one on Monday the 25th", and it was like, "No, I don't think so."…But then there's this statement, "Does it really matter?", "What do you mean does it matter? Yes, it matters." (Bereaved family 5, 56yr female carer for mother with malignancy) *You think that he's not gonna breathe anymore then suddenly there's another breath and it's completely bizarre, but the really nice thing was that they just kind of really left us to do whatever we wanted after that and we were all sitting there and talking after he died and they just continually said, take as long as you want and whatever you ... etc, etc. So, we rang the funeral place from there and we were all sitting talking and talking about what we wanted to do with the ashes and I decided that we'd split them four ways and we decided to do four different things with them ... we did all that probably a couple of hours after he died and then the others left and I stayed there, I don't know, for another ... I was talking my head off to him…There was a very nice nurse actually that was Japanese that I talked to in the corridor before that and she had said ... and they'd all, actually several people had said, just talk to him, he'll*

		hear you. There's a lot of research to say he'll hear you. Just keep talking to him. … In Japan they have this belief that even once they've died that they can ... and she reckoned there was research done that they can still hear even after they're dead. So, she said, they were all saying just talk to him because I was talking to him anyway and I just talked to him for, I don't know, another hour after everybody else had left and then I said, okay, I'm finished and he had to be taken away and I was very ... I couldn't just walk out and leave him and I thought, oh, they'll just walk in and take him, but there was nobody there. So, I just ... I couldn't sort of leave him in case somebody that wasn't meant to went in there or something went wrong. So, I had to kind of stand there and wait until they actually came. I don't know. I had to wait for quite a while because it took a while for them to come. But they did continually say, take as long ... the nursing staff were fantastic. The actual doctor was hopeless, the one that was on the ward that day. He was useless. He was young. He was very tentative. Maybe it was the first person that had died on him, I don't know. He was sort of ineffectual and not very ... a bit hesitant and a bit ... he was pleasant enough and he actually completely stuffed up the death certificate too. It had to all go back and be redone…That was the funeral home that did that. I didn't have to do that. But they couldn't release Patient X because the death certificate was all ... there was something wrong with it. He hadn't done it properly…But the nursing staff were all really good and they really emphasized take as long as you want,

		do whatever you need, talk to him (Bereaved family 7, 56yr female carer for husband with malignancy) *But as I said, like at the end of the day, honestly, the way you guys are with people, and I have to say just before you go, even the doctor that checks to see that mum, like to sign off on her death, she even said me, "Please don't think it's weird that I talk to my patient and I know that, you know, basically deceased. But I ask them if they don't mind me touching them." And I thought it was just lovely. You know what I mean? Just so lovely. 100%. And that's all we can ask for. It's just, you know, that's all you can ask for. Yeah. So, yeah. Thank you so much. (Bereaved family 10, 43yr female carer for mother with malignancy)*
Domain: Financial affairs		
• Concern about hospital and living expenses for family members, given a lengthy hospitalization • Proactive provision of information about financial supports to enhance comfort and decrease stress	• Need for greater information about broader supports that may be available to assist a person living with a chronic and complex illness; • Information provision about supported parking options; • Impact of living in a remote location where care is required in a metropolitan centre;	**Confirmatory quotes:** Patient data *We get a lot of help, love, from the government, with subsidies and medications. So it's a wonderful government, wonderful country, yes. (Patient 8, 77yr female with malignancy)* *Ah yeah, not so much because I had a couple of... I had a pet scan I had to do was about $800 or something. I had an MRI I had to do which was about $600, but that was about all I had to pay. Everything else was done by the system and it was really good, like it didn't cost anything. I didn't have to really fork much money out. (Patient 1, 48yr male with malignancy)*

		Family data *Was it the social worker that had said, "Have you accessed the Family's Payment yet?" I already knew about these, so I'd already started applying for them because I've just retired from work, from teaching…Yes. I've been getting that for just over a year now from another time mum went to hospital, I guess….There's no one to give you advice there, but I do know under the library there's parking there and I tended to park there and walk over…. And it's so expensive to use the car parks at the hospital (Family 11, 61yr female carer for mother with malignancy)* *Yes, because I'm trying to get a job because I want to work for myself. I mean, so I don't get cobwebby in my head, but the timing is difficult. I worked in the state elections so that is good, because the hours were afternoon to evening. So, yeah (Family 3, 52yr female carer for mother with malignancy)* Bereaved Family data *Because a lot of stuff I've found out really by default. Like, we could've ... His incontinence. I, only in the last year, got a rebate, because it was costing us a fortune in nappies, because I was always having to buy them. And there was a specific pair that were the only ones that worked, that suited him (Bereaved family 9, 57yr female carer for father with malignancy)*

		New data to support additions: Patient data *I suppose that's the big let down is I don't know what facilities are available to me like the things on the side. I know what's available to me here at the dialysis unit but you know? Can someone come and clean my house? You know, because I'm over 65 there's a whole range of things. I don't know whether it's driven by finance or not, or whatever. (Patient 12, 65yr male with non-malignant illness)* *Yeah. Maybe it could be that same person or another person who would know all the ins and outs of NDIS or the hospital ... That would be very good. (Patient 13, 61yr female with non-malignant illness)* *Something of my concern. I don't think family members get enough support in the way of parking. It's horrible to park. (Patient 14, 45yr male with malignancy)* *It would be helpful for us especially if I'm confined because the fee, the parking fee is so expensive. And if you're not working like us, both of us are not working…It's very too much for us, and where we will get the money to pay for it? (Patient 21, 50yr female with malignancy)* *Not all the nurses in the ward knows about it….Yeah. Not all. Because we asked a lot of nurses, and "Oh, I do not know about that one." So if the head nurse is not there, you do not have any idea about that one. (Patient 21, 50yr female with malignancy)*

		we would travel there every month for 10 days and whatnot…. even though your accommodation was paid for, it was still very expensive because we had to get taxis everyday and eat and the food was double the amount what we have to pay here in Town X….. We used to pay out of our pockets. We'll have our fares and whatnot but about $1200 a 10 days we'd go through….. That's an expense when you're on a pension…. it was over 1 full pension would go just on that trip. (Patient 22, 75yr female with non-malignant illness) Family data *When my brother was in hospital, and when mum was in about a year and a half ago, when we first went there we...everything being an emergency, we went to hospital units. And while we'll stay there for a week or so, until we could work out other accommodation. And, I think the care that way was really good. They do tell you, you tell them what you need. They help you out as much as they can (Family 1, 53yr male carer for brother with malignancy and parents with non-malignant illness)* *My personal experience is, I have to get to Hospital XX by 07:15 in the morning to secure a parking spot outside. If I don't do that, I have to drive in and then it will cost me $55 a day, which I have had to pay. $55 a day and that doesn't allow me any exit. If I exit at any time and want to come back in again, I'll have to pay another $55, if I stay more than four hours a day…I certainly can't afford $110 a*

		day (Family 12, 78yr female carer for husband with non-malignant illness) *There is a thing at that hospital where once a day, if you have got a pension card and if you're visiting a patient, they stamp your ticket and it costs $5 then for parking rather than $35, which that's been a really big help for dad….it's taken three years to find out about that….Someone just randomly mentioned it on the ward to him (Family 5, 50yr female carer for mother with malignancy)* *Yeah. He mentioned that you can get a weekly pass which is a hell of a lot cheaper. Also, if you're just coming in for the day, you can either, if you're having treatment, you can get a parking ticket from the reception when you make another booking. That allows you to get out. Or you can use your pension card at the office in the carpark (Family 14, 49yr male carer for wife with malignancy)* *But I don't expect to park for nothing. But if they made it reasonable, you wouldn't not mind, you know what I mean?...Oh also, you've got the disability parking spot, but very, very difficult out in the streets to find one of them (Family 10, 73yr male carer for wife with malignancy)* *Even the free wifi. There is a free wifi there (Family 15, 50yr male carer for wife with malignancy)* Bereaved Family data

		Because I have a job and I don't have any concession cards or anything. So every time I got there and I got stuck and actually had to leave my mum a couple of times to move my car and then I paid for it as much as I could. I found that really unfair and my aunty who was on a pension. You know, you can only go in once a day. We really had a problem with the parking. Absolutely. Like if you've got somebody that's terminal and that, I don't think you should have to charge for parking….Yeah. So you don't mind paying something. I don't mind paying something, but as I said, it worked out and I ended up making sure, and I know this sounds horrible, but I'm making sure that my niece or my auntie was with me because they had concession cards and then they could only either pay the $5 or get in for nothing…But in the end, that just, you know, I was working less and it was costing me a fortune of money that I just didn't have, you know. And then the time that you want to spend with your mother, I'd spend driving around and around and around the block trying to figure out where to park or parking miles and miles away just so I didn't have to pay for it (Bereaved family 10, 43yr female carer for mother with malignancy) *Then the fact that I had to pay $500 to get out of the car park, because nobody really – well I noticed it was an hourly rate. It just continued all day and all night…It's one of those car parks that's contracted out to somebody else, but I assumed like most of those sort of car parks there's a maximum daily rate. And I just assumed that well I'll be paying the maximum daily rate, but it was*

		accumulating hour by hour all day and all night for three days and three nights. So it was a bit of a shock to the system (Bereaved family 4, 69yr female carer for friend with malignancy)
Domain: Maintenance of sense of self / self-identity		
• Profound impact of a terminal illness; • The need to maintain independence; • The need to live well; • The need to maintain a focus on work	• To maintain wellness, within the context of their illness; • To isolate their illness from their full life – not to become their diagnosis; • Importance of physiotherapy to help patients be as well as they can be • To support their sense of self and connections with others, enabling a sense of control and avoiding becoming institutionalized; • To enable access to technology to support social connections; • To support making decisions about their care, in line with their personal needs to be able to live as well as possible; • To take control of their daily routine with a focus on physical activity and doing tasks they are able to do. • Comfort in being known within the hospital, when they have experienced multiple admissions, likening this to feeling in a more homely environment;	**Confirmatory data:** Patient data *That's with capital letters, god help us. Emphysema, no look, and I've just ... actually you'll laugh ... on the calendar, the day before yesterday, there was a thing which said, "I am sick and tired of being sick and tired." I hung that up above my desk. That's about it, yes. (Patient 10, 82yr female with non-malignant illness)* *Yeah, it all started February this year, 2019, that I was diagnosed with a, I think it was a stage four cancer, which originated in my uterus, that metastasizes in my left lung and liver. So, yeah, it all started there that my life was so stressful, and I'm so down as a human. It's difficult, and everything was hook on that illness that I have….Yes, and family, the relationship, everything, the way I see on myself, more especially…And everything, everything about my life, my work, because I need to stop working. I need to stop everything that I do most of the time because of this illness. So, it killed me on the hospital and on things like the house, and especially the first three months. I was in and out of the hospital because lots of infections that I had, yeah. So, it was so disappointing. It was so... Was just like a hell. ..It is just a hell.*

	• Access to beauty treatments for those who require it • To engage in meaningful activity on a day to day basis to assist in their wellbeing; • Access to reading materials (papers/magazines) or puzzles/games, access to information about what is available across the hospital and encouragement for patients to get out of bed and engage in an activity; • Need for humour • Support gained from own spiritual beliefs	*Yeah. Even my belief and faith to God was lessened, and I questioned him a lot. (Patient 21, 50yr female with malignancy)* *Yes, yes. They say, "Patient 8, we'll do that, we'll do that." Yeah, no, because I said I felt well in hospital and I was able to do a lot of things, you know? (Patient 8, 77yr female with malignancy)* *I haven't focused on it because my major focus has been on my health which is at times, you know…Very serious, life or death. (Patient 9, 75yr male with non-malignant illness)* *But, in hospital, of course you are a patient. You are different. There's no doubt about that. I don't know how that changes, but I think it does impact on how you feel about yourself and your illness. (Patient 3, 80yr female with non-malignant illness)* *I like to be treated as a normal well individual. Because that's where I keep my consciousness, my self-view of myself. Is that I am well, all is well, in terms of keeping myself positive….I've found a way to be very... to live very well, in the state that I'm in. Which is now fairly rapidly deteriorating. (Patient 16, 60yr male with non-malignant illness)* *So I started knitting booties for a lady at work, who's having a baby. I can normally knit booties in two hours, and it took me like two days. I think that helped, doing that. And I went for a walk, which is good to do as part of your getting back on track with yourself. So I walked down to the newsagent, and I teach preschoolers. So I found all these books that I thought were relevant to certain*

		subjects that we might be able to use them for. So of course I bought them. The next walk I did was a bit further to the chemist. And we had some ladies at work who were pregnant and expecting babies, so I found some things to buy for them. So I think, that was great that I was mobile, that I could get around and do those things and be able to do those things. It allowed me to be me too, because I could go and get those things to them, because I was making nappy baby for one lady, and I bought a present in the chemist for her, and I bought another present. So I was able to sort of, yeah, be a little bit of me. And that was good. Buying the books and that sort of, my daughter teaches as well as the same center as me. So, I could share with her the books and said, look what I got at the post office and and she took some of the books home because she really loved them. So I think that was really good. (Patient 4, 54yr female with malignancy) Family data – nil illustrative quotes Bereaved Family data – nil illustrative quotes **New data to support additions:** Patient data *I like to be treated as a normal well individual. Because that's where I keep my consciousness, my self-view of myself. Is that I am well, all is well, in terms of keeping myself positive….I've found a way to be very... to live very well, in the state that I'm in. Which is now fairly rapidly deteriorating. (Patient 16, 60yr male with non-malignant illness)*

		That is right, I'm still here. I'm still swinging. I'm still doing shit…. Let's not think about how we can die, let' think about how we can live…Let's live well(Patient 16, 60yr male with non-malignant illness) *So, I treat this now, I get up at six or five thirty in the morning and it's going to work for me. That's what I put it down to….I put it down, so I go to work. Finish work at 12 o'clock, right, and then the rest of the day is mine. So that's how I blank it out in my mind….I isolate it out from other things in my life and I just put it in a box, right, and that keeps me sane, or keeps me detached from it. (Patient 12, 65yr male with non-malignant illness)* *Look, I think I spent so long as a highly capable, physical, mental, sexual, human being. This is a very recent event in my life. And now, I'm living somewhere quiet with lovely neighbors and the fact that I've got motor neurone disease is almost incidental. (Patient 16, 60yr male with non-malignant illness)* *You know? A lot of my friends say, "Why do you do the dialysis at home? Do hemo in there and then you can just go in three times a week and they'll do it for you and you can just sit and allow them to do it." I resisted that enormously. I want to be in control of my care and live and you know almost pretend it's not happening. I'm a normal person. Not a renal patient. (Patient 3, 80yr female with non-malignant illness)*

		Yep. I tend to avoid the whole of lot of stuff I could be involved in as a renal patient. I avoid being on the internet with renal groups... once I get up in the morning and get up from the chair and cover it up so I don't have to look at it, I just don't want to be involved with... I've got my catheter in all the time, of course. So, that reminds me but I don't really want to be involved as a renal patient all day. (Patient 3, 80yr female with non-malignant illness) *People don't realize how important physiotherapy is. It's bloody important. It's probably more important than the doctors, who are not listening anyway (Patient 10, 82yr female with non-malignant illness)* *Oh, physios would be great. Some of the people don't realize how much it does help, but it really does help a lot. Even if it's just teaching people how to sit up in bed if they can't, or how to get out of bed to go to the toilet. Or, anything, because physio is so important. (Patient 10, 82yr female with non-malignant illness)* *One area that I thought was a bit disappointing when I was in the ICU was the, what do you call it, the people that do the physio stuff. I thought that was pretty slack, in fact, substandard. They just weren't... You didn't seem to get adequate treatment, or the treatment you got was half baked, in my book... Yeah, yeah. I thought that area was really lacking. In fact, below par. (Patient 9, 75yr male with non-malignant illness)*

		I may go through emails and the telephone and all the connections I've got. I've got friends here and in Italy. My problem is almost trying to keep up with all of that. Sometimes it just too tiring, but I try, I try not to let it go, because it is myself…..It helps me still feel Patient 11 with my interests, with my friends, with what I have always done (Patient 11, 72yr female with malignancy) *I'm not going to do home dialysis because that's taking the hospital home and into our house. Right? I'd rather come to hospital here and do it here, right. It's all don't dusted and at 12 o'clock today I'm finished. I go out and my friend is picking me up today, right. And we're shopping for pickles and were going to the Greek place to get some Galactobouriko and I'm taking him to Faros Brothers, the fish seafood place over at suburb X…Yeah, so I maintain life. Right? If I go home I don't go out, I just sit at home. (Patient 12, 65yr male with non-malignant illness)* *…refusing dialysis it means looking after it. I can have a longer life span. And do what I want to. So yes and enjoy life and that's what I'm doing…. if I have a bad day I think "Oh well tomorrow I'm going to go out and have a lunch. And something like that. But I get out of the house. I force myself. Once I'm out I start improving. (Patient 22, 75yr female with non-malignant illness)* *Make sure I still go out with my girlfriend's because that promotes a sense of self. I try to make decisions about myself, but then that's very difficult when I no longer drive and when I'm being cared for fully by my husband. I find that difficult. What else do I do? I think*

		it's just maintaining the things that I used to do. That's what I try to do. (Patient 13, 61yr female with non-malignant illness) *Well, it's basically, for me, I take control of everywhere I go I suppose. Maybe I'm a little different. When I go to do my ketamine infusion, I walk around the ward and I count out steps, right, and I do 10,000 steps before six o'clock in the morning. I take my little gurney with me and I time it. Right, then the staff are there cheering me on. It's, you know, the number of laps, I have to do 30 odd laps to get my 10,000 steps up. Right? But, the staff cheer you on, if I'm there for three or four days doing my laps because I worked out I lived in suburb X and I worked out 10,000 steps would get me home. (Patient 12, 65yr male with non-malignant illness)* *Definitely darling, that's very important. As I say, I like to do little things when I can, to make me, to make me feel normal…… because I said I felt well in hospital and I was able to do a lot of things, you know? (Patient 8, 77yr female with malignancy)* *As soon as I'm in a hospital, whatever time I wake up, I get out of bed and I'll sit in the chair or go for a walk up and down the passage. The nursing staff will say "You think you're well enough to do that?". I was like "Yes I'm doing it to get well". And a lot of them can't understand that(Patient 22, 75yr female with non-malignant illness)* *So as a patient, we need to go somewhere to walk. I do not know how are you going to do it, but we need something to do that will*

		get involved a physical aspect, not only the mind. (Patient 21, 50yr female with malignancy) *Yeah. I went to this rehab for my hip, but as you can tell, there's a lot of other things that needed help as well. From the stroke I've had last year, I've gone to a hand upper clinic, at hospital X, which I found quite ... Not enjoyable, but it was a good thing to do because it makes you focus on putting screws into holes and stuff like that. I could have had some of that upper hand work done at the hospital at the same time. That would have been good if that could come as well. (Patient 13, 61yr female with non-malignant illness)* *You do lose a sense of yourself every time you come in ... You become more easily institutionalized… I hate it. (Patient 13, 61yr female with non-malignant illness)* *...once you have a chronic illness, you do adopt the... because people talk about you as a renal patient all the time and as you get older, you lose your identity anyway because people see you as an old person. You're really invisible. Just wait 'til you turn 80. It's really interesting. If you've had a lot of senior roles and then suddenly it's all... I don't mind it because I quite like my anonymity, but it's very interesting. But, in hospital, of course you are a patient. You are different. There's no doubt about that. I don't know how that changes, but I think it does impact on how you feel about yourself and your illness. (Patient 3, 80yr female with non-malignant illness)*

		And, I think it would be easy... it would be very easy to just relax and buy into it, and be the helpless renal patient who everyone has to look after. It terrifies me. It absolutely terrifies me that that could happen to me. But, I can see how some people allow it to happen because it's much easier and then you don't have to put any effort into it. (Patient 3, 80yr female with non-malignant illness) *…and as we go down, somebody says, "Oh, hello Patient 10. Oh, hello you're back again. Hello, Patient 10. Do you know everybody at the hospital?" I said, "This is my second home. I know everybody here." Even one of the tea ladies said to me one day, "You shouldn't be on seven, you should be on 10, that's where you belong with your lungs." Because the tea people know more than all the others, because they know their patients. (Patient 10, 82yr female with non-malignant illness)* *The fact that they understand what I'm going through. What I've been through. And the fact that I've known them for... they're like family, really (Patient 7, 59yr male with non-malignant illness)* *I can't do anything. I can't get my face waxed, which is dreadful. My girlfriend doesn't have hair in her face, I do. It depends, some people do, some people don't. And I will very soon become a bearded lady(Patient 10, 82yr female with non-malignant illness)* *You've got to see the funny side of things too. (Patient 10, 82yr female with non-malignant illness)*

		This is my sense of humor. "Well, what does one say, I'm going to the theater yet again. Don't think much of the dress code. Never get to see the show, pay a load of money, and fall asleep. Right? It's going to be the 12th time this year. Don't see the value in it and so I took the surgeon aside on Monday and told him this is the last time, I'm canceling my subscription. The venue has no drinks, during and before. Right? And all you get is a weak cup of tea afterwards"….. and I read that out when I went on to theater on Monday. There was a surgeon, and anesthetist, and a nurse in the room, right, and I read it- the anesthetist pissed herself laughing….It's just a bit of fun, and everybody has bit of fun, because you can't be deadly serious about it all. (Patient 12, 65yr male with non-malignant illness) *Oh, man, if you stop laughing, you might as well give up. (Patient 16, 60yr male with non-malignant illness)* *And also, I like a bit of humor in there too. (Patient 8, 77yr female with malignancy)* *I mean the reading room, I watch people, right, they just go and sit in a room. They sit and look out the window or they go outside and smoke. You know, well here in dialysis well I've brought a jewelry box in here and sanded it and polished it that I was making. Right? I can do it with some wood chisels and some knives and I brought them in here and I polished the steel. (Patient 12, 65yr male with non-malignant illness)*

		But I'm trying to extend what I'm doing by getting involved with this diabetes alliance foundation….at the moment I can say it would give me a reason to push on, yes. (Patient 9, 75yr male with non-malignant illness) *It allowed me to be me too, because I could go and get those things to them, because I was making nappy baby for one lady, and I bought a present in the chemist for her, and I bought another present. So I was able to sort of, yeah, be a little bit of me. And that was good. Buying the books and that sort of, my daughter teaches as well as the same center as me. So, I could share with her the books and said, look what I got at the post office and and she took some of the books home because she really loved them. So I think that was really good. (Patient 4, 54yr female with malignancy)* *there used to be a library that a volunteer would bring around a trolley and it had games on it like Checkers or things like that. That they would leave you with for the day or for a couple of hours or something. Then come back and pick it up so people didn't swipe it obviously. To do stuff like that. (Patient 13, 61yr female with non-malignant illness)* *when I pack my bag to go to hospital, I always pack something in it to do. Right? I'm not going to sit down and do a jigsaw puzzle but you know that's an idea, small jigsaw puzzles would be an idea for some people to do (Patient 12, 65yr male with non-malignant illness)*

		If they had a thing on the TV ... it just went through and help something like, these are some of the things that you can do. Like an information pack that didn't get too into the nitty gritty of it. It just said do you know that you can ... there's a podiatrist service and this is the number. There's a hand clinic, this is their number... Just listed the things that are available. (Patient 13, 61yr female with non-malignant illness) *They used to have another thing …They had a pink lady that used to come around that sold things like magazines and Lifesavers and stuff like that …. They used to come around about the same time every morning. It really helps the day go if you can buy a magazine or a newspaper, instead of having to wait for the evening when your visitors come where you're too tired to read it anyway. (Patient 13, 61yr female with non-malignant illness)* *So I was thinking, what am I going to do? I do like to knit and do a lot of crafty stuff. So I got family to bring in my knitting. I've been a bit slow at it because I have neuropathy in my fingers and so I used it as an opportunity to push through. So I started knitting booties for a lady at work, who's having a baby. I can normally knit booties in two hours, and it took me like two days. I think that helped, doing that. And I went for a walk, which is good to do as part of your getting back on track with yourself. So I walked down to the newsagent, and I teach preschoolers. So I found all these books that I thought were relevant to certain subjects that we might be able to use them for. So of course I bought them. The next walk I*

		did was a bit further to the chemist. And we had some ladies at work who were pregnant and expecting babies, so I found some things to buy for them. So I think, that was great that I was mobile, that I could get around and do those things and be able to do those things. (Patient 4, 54yr female with malignancy) *Yeah, yeah that would be good. Almost sort of like a recreation room. You can go into this recreation room and have a game of cards or yeah… something like that (Patient 22, 75yr female with non-malignant illness)* *I know it's the patient's choice but I just think somebody as you said, pastoral care or social worker that comes around and taps into the patients and just does it. I think when the patient comes in as a new patient maybe. (Patient 4, 54yr female with malignancy)* *Yeah. I mean, I'm not a religious person at all but, sometimes I've had different people of different denominations come in and sit down and have a yarn for half an hour or an hour. Not even trying to convert you to any denomination or anything, but it's just nice to chat. They don't even talk about religion, just have a respect for them, and what they believe it's just nice to have a chat really. What do they call it, it was a name for those people ... the pastoral care people. I think it's good, and they come into here at the dialysis and have a chat you know. It breaks up the boredom, breaks up the day. (Patient 12, 65yr male with non-malignant illness)*

		You know, I wanted some positive, some confidence, because we believe that, I mean I am a Christian, I always believe that there is always hope and we have gone through that – we want to overcome this problem, we were given negative feedback but at the time we were devastated but we were given a lot of encouragement from my point of view, a Christian background needs some help, some counselling, because I had people around me who were praying for me, and I think that was the additional strength we had more than anything. (Patient 5, 72yr male with malignancy) *I have been working for two years with a spiritual and energetic healer. Who has energetically worked on my body and my lungs and my electrical, and what have you. I don't tell any of my doctors this….Because, it's too far out for them. Even talking about crystals and... look, I used to do crystal healings. (Patient 16, 60yr male with non-malignant illness)* *And I got off my own path. So, I'm actually back on my spiritual path and without this disease I would have stayed in a very negative place. So, it's kind of bizarre, but even though I'm going to die sooner, I'm more being true to myself now than I was for the last, we'll say, 10 years, or whatever. (Patient 16, 60yr male with non-malignant illness)* *I just pray hard to God that God will going to guide them in what they're going to do with me. (Patient 21, 50yr female with malignancy)*

		Well, I need to be tough always. I need to combat all the pains, the nausea, the vomiting. I learned, well, at first I do not know how to handle those. I find ways how to keep up on those feelings like the nausea, the vomiting, and other pains that I had. I just, well, based on my experience, prayer helps, from God. (Patient 21, 50yr female with malignancy) Family data – nil illustrative quotes Bereaved Family data – nil illustrative quotes
Domain: Minimising burden		
- Ensuring one is not a physical or emotional burden for family members	Nil	**Confirmatory data** Patient data *Well, see people say, "Why don't you ring your son." Now my son of course, is the next one on my list, but I live alone….the thing is my son lives suburb X, I live in suburb X. He's got his own family. They do ring him all the time, but I said, "I wish they'd leave you alone." (Patient 10, 82yr female with non-malignant illness)* *I find that quite difficult because I was extremely independent person, and now after I rely on my husband to do .... I hate being ... I feel like a burden. My husband assures me that I'm not and that it doesn't matter, and he's quite happy to do it, but it's not really what you sign on for when you get married. (Patient 13, 61yr female with non-malignant illness)* *I do sort of sense of I am a burden and I'm beginning to feel a bit like it with my girlfriends, as well… now somebody always goes and*

		researches the places that we're going. Which is very kind of them because there's places that are just can't go but that makes me feel like a burden. (Patient 13, 61yr female with non-malignant illness) *Yes, definitely..I think most people feel that way…That's a personal thing within yourself and it's just thoughts. I mean, I feel that way and it will eventually it will get worse. So, you can't help feeling that way. (Patient 19, 69yr female with malignancy)* *I feel that…. it is burdensome, because sometimes, you want something and you know it's just a small little thing, but you need help to do it. (Patient 18, 71yr male with non-malignant illness)* *Well I was being unfair on my wife, who works, so I elected to come to hospital and just spend the night in hospital. Get to dialysis the next morning. (Patient 12, 65yr male with non-malignant illness)* *Well, there are several issues, I mean, I haven't driven in six and a half years, right. So, I rely on my wife to drive me, but I never ask anybody to pick me up and drive me somewhere. If someones going my way, right, I'll get a lift…. I mean, she has to give up certain things, you know, to take me to medical appointments or things…. It's things she has to give up and she has a right to her time. I mean, I don't own her time she owns her time. (Patient 12, 65yr male with non-malignant illness)* *It's 37 years or something 36 years. Right? But, still you know, she owns her time, and I own my time, but we share time together. But, she shouldn't be sharing my illness time, right, we should be*

		sharing good time. That's how I feel about it. (Patient 12, 65yr male with non-malignant illness) Family data – nil illustrative quotes Bereaved Family data – nil illustrative quotes
Domain: Respectful and compassionate care		
• Preservation of dignity; • Clinicians being compassionate; • Clinicians being supportive; • Feeling welcomed and deserving of a hospital admission; • Treated with care, respect and with a focus on dignity; • Staff anticipating needs; • Staff being responsive; • Staff demonstrating cheerfulness and care	• Respectful and compassionate tone of communication; • Connect to each patient and not talk about personal aspects of social life; • To be treated as a human being; • Clinicians to be empathetic, supportive, honest and trustworthy; • Staff to be friendly with a nice manner and to show common courtesy; • To ensure a patient is comfortable before leaving the room; • To be cared for by someone who appears happy to be at work; • Care to be less mechanical and more compassionate; • To minimize patients' feeling powerless • To be cared for in a way that does not judge circumstances leading to certain health outcomes	**Confirmatory data:** Patient data *Being a 77-year-old, probably old school. I do get embarrassed. I went in with my legs, so stupid, went in with my legs unshaven. And I just said to them. They said, "Patient 8, don't worry about little things like that, we don't take any notice." Just little things like that, you know? So, dignity, yes, love, there certainly was. (Patient 8, 77yr female with malignancy)* *Yeah, it's lack of compassion. She's just like a woman with answers- You know, you ask question and she going to answer it just like reading books….. It's too mechanical. It's yes or no. And well, with a patient like me, I need more explanations and more compassions on what to do. (Patient 21, 50yr female with malignancy)* *So, with the doctor, it felt very much like part of an industrial process…Part of a scientific study….. Yes, okay, lab rat 123, your markers are here. Okay, you're dead in two and a half to three years, next! (Patient 16, 60yr male with non-malignant illness)*

		It's like they're wardens in a prison. They think that's what they're are instead of bloody nurses. (Patient 23, 69yr female with non-malignant illness) *He just didn't care. I honestly want to know what he does at that hospital, I don't think it's much. His heart isn't here. (Patient 22, 75yr female with non-malignant illness)* *They smile, they're friendly, and they take an interest in you. (Patient 13, 61yr female with non-malignant illness)* *We had excellent nurses there – we met a lady who was very kind and nice, always helped me and caring. The majority of them were like that. We had also bad experience of one person who was not like that – she wouldn't smile at you, she would just take all the figures and then go and try to find the vein, and then if she can't find it – 'oh you have not taken enough water' and try to sort of harass me and I said 'oh no – I have' – and she couldn't even put the IV into the vein so ultimately some other nurse came and did it. So, there was that, but also you have to ask her for a warm thing, otherwise she would just walk away – so you know how they put a warm pad on top of my hand so the pain won't be there much … but exceptional care by the other people, cannot blame anyone – just that one, she wouldn't even talk much, you have to ask her questions and then you didn't always get answers….. But anyway, that is the only one, just a minor thing (Patient 5, 72yr male with malignancy)*

		... 90% of the time, the nurses introduce themselves... come in and introduce themselves and say they're going to care for me, and they are respective and treat me with respect, and are lovely. They're very caring and very communicative. (Patient 3, 80yr female with non-malignant illness) *They make me feel confident that, this is the first time I am going in, I don't know what will happen, but they were so nice to me. I expected them to be like that, to be human and nice and smiling and talk to me and tell me what they were going to do. They ask how are you? and some asked about my background – so they made me comfortable sitting on that chair and I can forget about what is going to happen. And when they do things, they do it very carefully, so that it doesn't bring me a lot of pain and that is very good…very good. (Patient 5, 72yr male with malignancy)* *So, in that regard that they treat you accordingly, and they treat you with understanding and as I said, empathy.... and they're also very honest and trustworthy. (Patient 7, 59yr male with non-malignant illness)* *I went to the bed, and he said, "Don't sit down, I'm speaking to you. Don't speak when I'm speaking. When I'm speaking, nobody speaks." And he treated me like an absolute two year old. One of the other patients said, "I've never heard anybody talk to somebody like that in my life." He was dreadful, and then he walked out. I said, "I've never gone through that, ever with any doctor. Whoever he is, I*

		have no idea who he is." Well, that was Doctor X (Patient 10, 82yr female with non-malignant illness) *Compassionate just being... Compassionate just goes being nice and supportive to me, that's my idea of being compassionate. (Patient 8, 77yr female with malignancy)* *But deep down... of course naturally I just wanted to get out of hospital, but that was just me... yeah, no, not one of them spoke harsh or turned around and got angry when they had to do something, like there was times when I needed to go to the toilet and I was more embarrassed in having to do that, but they were "No, don't worry, this is our job and this is what we do and this is not the first time and last time we have to do this, so it's all good." (Patient 1, 48yr male with malignancy)* *That I was treated with respect. (Patient 3, 80yr female with non-malignant illness)* *This happened to me quite a few times, actually. I would call out something because I was sort of just like a turtle on my back. I couldn't move, I couldn't do anything so I'd call out to get some help. Then a couple of nurses in particular said to me, "Don't call out again. I've got reports to write. I haven't got time for you." That just ... Oh, I was so mad. (Patient 13, 61yr female with non-malignant illness)*

		Oh, they're just very friendly, very open, very friendly. Just nice people. (Patient 19, 69yr female with malignancy) *The nurses are so friendly. Especially if they are Filo's like me (Patient 21, 50yr female with malignancy)* *Only if the staff take notice of you and listen to you. Some of them couldn't care.. They just walk in, give you an injection and go and make out they're doing something and all they're doing is sitting having the talk (Patient 22, 75yr female with non-malignant illness)* *Or they just bring your pills in, they do, and they just put them there, you know, and they're in such a hurry. You've either got to gulp them all down, like you might have about maybe ten pills to take. (Patient 23, 69yr female with non-malignant illness)* *Again, the staff, some of them are very empathic and you really... they do everything. You feel they're caring for you, they like their job. They do it - They do it with kindness, they do it with patience, they do it almost as a mission I would say, while if it is just a job that is bothering and burdensome, then you feel it, you feel it in their voices. You feel it in their attitudes. You feel it in the way they can roll their eyes up towards the patient rather than the other. I'm not saying that this happens frequently, but it happens. (Patient 11, 72yr female with malignancy)* *There's no talking. The nurses are all very busy. It's like you've got one nurse looking after three or four or five people, six of them, I*

		don't know what the numbers are. So they don't have time to talk to you and worry about your individual needs. (Patient 18, 71yr male with non-malignant illness) *But I've got to give it to the nurses. They were onto it real fast and brought everything back real quick. And they definitely knew what they were doing. (Patient 1, 48yr male with malignancy)* *Look, the important thing, I think is to know there's somebody there. And very often, they're not. Not because they don't want to be, but there's not enough staff. We know that. The nurses are absolutely run off their feet. They are so good, but they can't do everything…… And I mean if you are in the toilet and you press the button, they do come eventually, but if you're not breathing or something like that, it's not fun. (Patient 10, 82yr female with non-malignant illness)* *So you push your button, then you wait for, can be up to 30 minutes before a nurse comes. I often lie there and think to myself, "What happens if it's an emergency?" If I'm going to wait even 10 minutes for somebody to come when you press the button, what happens if it's an emergency? How do you get help? And that's what I find is a problem….(Patient 18, 71yr male with non-malignant illness)* *... But when you hit the nurse button, you expect to see someone within... five or so, to I suppose maximum probably ten max... Half an hour plus is ridiculous …. one particular time was where I... I needed a urine bottle...I don't have half an hour to wait, when I*

		need to go to the toilet……Especially when you're flushing me with stuff that's going to make you urinate. (Patient 14, 45yr male with malignancy) *... the attention to your problem, the attention to your wounds. I had one nurse just by visualizing and looking at me and noticing me, could identify if I needed pain relief. (Patient 14, 45yr male with malignancy)* Family data *I know nurses have a lot of patients to look after and even all the staff, the food people, the cleaners, and everyone, that you've got lots of the same thing to do over and over again, but being able to talk to patients and speak to them gently and wake them gently, encourage them to take their tablets instead of a stand over tactic or approach. But I didn't see that. I saw very good care, the way that everyone worked with mum (Family 11, 61yr female carer for mother with malignancy)* *And following up there. Look, I mean he was just caring. His approach was very caring, which was appealing… And then I didn't feel he was swanning in and doing his job. He was doing it very compassionately (Family 13, 56yr female carer for mother with non-malignant illness)* *It's sort of not just about the knowledge, but having that care factor, that compassion, that they know how difficult it is for you to have*

		someone in hospital, and that they can meet those needs in a way that, yeah, it's helpful, and can maybe have a bit of a joke, because dad's got a pretty good sense of humor, but same with us. You can tell us something serious, and don't have to make a joke about it. I'm not saying that, but you can sort of have a joke with the family and be serious as well. It's sort of that like conversation that you can... Yeah. So having the knowledge base is really important, but also having that, that they're caring for them, and knowing that they're being well cared for (Family 13, 56yr female carer for mother with non-malignant illness) *Yes. I think, any observation I had with him in the emergency department was extremely positive. They were superb. They treated him and spoke to him in terms he could understand. They repeated things for him. I thought... he was only there for, what, 12 hours? But my experience of that was very positive. Some of the nursing staff up on the wards I found excellent, really good, would be very cheery with him. Come in, ask him things, et cetera. I thought the bulk of the nursing staff I saw up in the wards, although I felt they were very overworked and overstretched, I can tell you. But whenever they did come in, I thought they really gave him great respect. It was wonderful (Family 9, 64yr female carer for father with non-malignant illness)* *Yeah. The doctor, with your wishes, Dr. XX who is a palliative care doctor, he gave us the forms to have a chat about when we first saw him and then when we were in the ward, in the heart ward, was*

		a doctor who, she said, "What are you wishes? If anything happens, if Patient 15's heart stops or anything like that?" I said, well give us some time to have a chat about it. She literally walked out of the curtain, washed a cup out and she came back and said, "Okay, what is it?" Yeah. That wasn't good…. Sometimes you've got to be a bit more compassionate (Family 14, 49yr male carer for wife with malignancy) *Yeah, well, see, it's like 70 percent of nurses are there as a job and the other 30 percent are compassionate about their job…. Some are fantastic and some are, "I'm doing it this way and you shut up because I know what I'm doing." (Family 17, 69yr male carer for wife with non-malignant illness)* *They should be treating you with respect like you treat them (Family 1, 53yr male carer for brother with malignancy and parents with non-malignant illness)* *What I wanted from that was, first of all, that his dignity would be upheld. I was very worried that he would be over investigated and would go through a million procedures that may, in the long run, have been not useful to his quality of life and just been more trauma for the man, because he was in such an awful state when he went in. So it was more my concern that he was heard, that people didn't go over the top for his individual situation (Family 9, 64yr female carer for father with non-malignant illness)*

		They repeated questions, when he clearly didn't understand them. And he's had a couple of accidents in the bed and on the ward, and again, just very gently approached it. Rather than being roused on, you didn't get that sense of "I haven't got time for this". It was like, you're the focus here. It's all right and often nurses would try to make a bed and when he was sitting on the toilet, and their running in and out all the time, just making sure he's okay, while they're trying to do their job. I just sensed there was great empathy and compassion (Family 9, 64yr female carer for father with non-malignant illness) Bereaved Family data *So there was two nurses that were compassionate. The rest didn't care and didn't have a clue (Bereaved family 12, 54yr male carer for father with malignancy)* *So, respect to me includes things like having regard for the person's dignity and consideration for their feelings, and some empathy with the position that they find themselves in (Bereaved family 1, 66yr male carer for wife with malignancy)* *Look yes, there's some wonderful compassionate people. Some really compassionate doctors and some compassionate nurses. But then there's some that don't kind of ... They're just there to do their job and whatever. I suppose it's hard for them, it is draining for them over time, and whatever. I think it's a bit like teaching, it's just one of those professions your heart's got to be in it or go somewhere else,*

		kind of thing. Because yeah, it is a very hard profession. I admire the nurses and things like that. We always, whenever we've got relatives in there or when dad was in with his stroke on a Saturday afternoon I took big cheese and fruit platters in for the staff for their afternoon tea. Because I appreciate what they do. The stroke ward that he was on, they were honestly the best ... I mean we actually donated a chair, one of those stroke chairs for them when dad passed away. Because we just said the poor things were just so wonderful, and so attentive and everything, but they just didn't have enough chairs for the stroke victims to sit in. Dad was so much brighter and more engaged or whatever when he was sitting up in a chair than when he was sitting in the bed. They could see that too, but they just didn't have enough chairs to offer us (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness) *I wanted her to have a dignified experience, because she'd been in the same hospital previously and I walked in on them, and she was being cleaned down with the curtains open and relatives and families from other patients in the room as well, fully exposed to everybody who could see her. For me, it was about making sure that they maintained her dignity, gave the family some space to be around her, and gave her adequate pain relief (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)* *But as I said, like at the end of the day, honestly, the way you guys are with people, and I have to say just before you go, even the*

		doctor that checks to see that mum, like to sign off on her death, she even said me, "Please don't think it's weird that I talk to my patient and I know that, you know, basically deceased. But I ask them if they don't mind me touching them." And I thought it was just lovely. You know what I mean? Just so lovely (Bereaved family 10, 43yr female carer for mother with malignancy) *It was just a matter of when, not if, and we both understood that. And what was important to me was about her care was that she was treated with respect, which she was, that her pain was managed wherever possible, which I'll give them 5/10 for that. That she was able to maintain her dignity as best she could and her needs came first. You know? It was all about trying to make her life as good as it could be given the restrictions placed on it by her by her illness. And that's what we did (Bereaved family 1, 66yr male carer for wife with malignancy)* *Oh everything. Her physical care was fantastic. They were making sure... They'd roll her. Make sure there was no bed sores and just really meticulous with their administration of medication. But, even more than that, the care in terms of their spiritual care. The emotional care. The way they treated her with respect and dignity (Bereaved family 5, 56yr female carer for mother with malignancy)* *I think as a Family. As a child. As a parent, going through that. That's all you want. You want the patient to be really, perfectly cared for well. To be respected as an individual. So for them to be... Yes, nursed in a way that you would want to be nursed. I thought if*

		that was me I would be happy with the way the care was provided by the nursing staff. So, from my point of view, yes, I thought the clinical care she was given was great. The spiritual care she was given... The respect that we were shown as Familys, by the nursing staff was fantastic. They seemed to have a much better handle on the roles as Familys, than the medical officers did (Bereaved family 5, 56yr female carer for mother with malignancy) *And then you've got other doctors, like the doctors that are actually going to look after him, saying, "Now, what can we do, so he doesn't come back here again?" This is the attitude I'm getting. They're telling me, "What can we do so he doesn't come back here again?" In other words, we don't want him here, because we can't stop what he's got. And stuff like that (Bereaved family 12, 54yr male carer for father with malignancy)* *It's stupid because some of the doctors will say, "This is a hospital, this is not for people that are dying." And I'm saying, "But isn't that what the hospital used to be for? So it's just an attitude, the attitude is, "This is a hospital, all we do is fix people. People that are dying can go somewhere else, we don't want them."..That's the attitude I'm getting. Was getting (Bereaved family 12, 54yr male carer for father with malignancy)* **New data to support additions:** Patient data

		Look, just that you're treated equal. Everyone's treated equal. (Patient 14, 45yr male with malignancy) *As an academic and teacher at uni, I always said this to the nurses, "Don't call your patients Love or Darling." That is probably my major thing when they say, "Hi Lovey." You know it's just not okay. I don't want them call me Dr. XX. I want them to call me P3 but I just don't want Lovey or Darling or Pet …It just feels awful actually. I don't know why it feels so awful but so many patients would say that to me when I was caring for them, that I suppose I picture that, and so now as a patient... I realize people say that to you. It's really sort of a throw... sometimes, I think it's a bit lazy rather than finding out what your name is. Somebody said to me, "P3, I'll come back?" I sort of think, well they will come back because they know who I am. They know that I'm P3. I'm the patient. (Patient 3, 80yr female with non-malignant illness)* *So, mine is mainly the way I'm spoken to or the way... yeah. (Patient 3, 80yr female with non-malignant illness)* *Well, first of all ... for a start it's the attitude. It's not what do you want. It's a tone of voice, even when they come into the ward, how people talk to you. Look, there was a nurse ... I can't remember her name now, I should really ... and she was looking after the lady across the way. And the lady was not very well. People would come in and say, "Oh, come on. You haven't eaten, why don't you just try this out? Oh, well, okay. Never mind." And they'd walk out. And she*

		came in and she said to her, "You haven't eaten anything. Why don't we try this? Let's have a look. We haven't had this. Let's try a bit of bread." It was the tone of voice.And the lady probably did eat six bites of something, but it's the tone of voice. Not, "Oh, well it doesn't matter. You haven't eaten anything, so what?" And because she approached her with that ... inside, I wrote about her, because what she did and how she approached patients was impeccable. And it made such a difference to the patients. (Patient 10, 82yr female with non-malignant illness) *Ones who care and even you can tell them a joke and all that. They look after you really well. Then there's others. (Patient 22, 75yr female with non-malignant illness)* *Well, a nurse gets to know their patients, I suppose, and needs to know their needs, and I think when a new nurse comes on, the first thing she can do, besides introducing herself, which she should be doing anyway, she might just say, "Are there any things you need? Anything special that I've got to look after for you?" Just get to know your patient… And I'm not talking about having to give her a whole life story. Just maybe one minute or two minutes to find out my personal needs while I'm there. (Patient 18, 71yr male with non-malignant illness)* *But I did write to the hospital about her, because she was so good. But I mean she got the lady to eat something, but it was because she treated her as a human being. She got her to eat a few bites, because it was a different tone of voice. And I know that sounds*

		strange, but it does make a difference. (Patient 10, 82yr female with non-malignant illness) *So, in that regard that they treat you accordingly, and they treat you with understanding and as I said, empathy.... and they're also very honest and trustworthy. (Patient 7, 59yr male with non-malignant illness)* *Sometimes you're feeling the voices of the nurses and impatience , we're all human, I understand it very well and certainly it hasn't happened with me, but I try to be very aware of the others. ... So easiness of tempers. And when you are in a lot of suffering, you have to try and really keep your problems at bay if you have them at home or whatever. And sometimes I know this very difficult time, I'm not judging anybody, but I'm saying that from what I hear sometimes around from the perceptions of certain patients, I feel that they're the best of care is the one that really considers you as a person rather than a number. (Patient 11, 72yr female with malignancy)* *the people involved in my healthcare right from the very start have always treated me like a human being. Like, they didn't treat me like a number. (Patient 7, 59yr male with non-malignant illness)* *What made him brilliant was he treated me like a human being, I suppose. (Patient 10, 82yr female with non-malignant illness)* *I don't know it was an atmosphere that those nurses didn't care either and he was dying with leukemia…. Well, all they can talk*

		about is their boyfriends and whatnot, what they're going to do when they knock off work. (Patient 22, 75yr female with non-malignant illness) *Yes. Nice manner. I suppose it'd be a lot of people who wouldn't like to chit chat to nurses, but I figure if you, I was in there for nine weeks, in March, you're in there a long time. It's a long time to be alone. Not alone, but separate from your family and spend days with ... If you don't get a visitor, it's a long day. You would like the staff to not necessarily notice you don't have a visitor, but just be that little more pleasant on a day to day basis. (Patient 13, 61yr female with non-malignant illness)* *Just a general attitude to the nurses on the ward. I don't have to be your best friend, but a bit of common courtesy, I suppose, would be better. (Patient 13, 61yr female with non-malignant illness)* *They do everything well, but see as a person you feel if you are in connection with them or if you are just a burden to them... (Patient 11, 72yr female with malignancy)* *The tone of their voice, not with me. Not with me, but I hear with the patient. I'm talking general here. (Patient 11, 72yr female with malignancy)* *And... every single person I spoke to was just polite and none of them ever really sort of... sometimes you can tell a person when they just don't want to be there? I never got that feeling if someone helped me and they're thinking "Oh look, she doesn't want to do this*

		or he doesn't want to do this." I never got that. I never got that vibe at all with any of them. (Patient 1, 48yr male with malignancy) *Oh, well they just make sure that you're more comfortable, you know, "Can I get you anything? Can I help you get to the bathroom?" Just little things, you know? (Patient 23, 69yr female with non-malignant illness)* *What I expect – well it is to be nice to the patients, be human, and explain to me everything that is happening and also to be there to help me…. Listen to me (Patient 5, 72yr male with malignancy)* *Oh, it's the power. Patients feel they're at the bottom of the power-triangle. They shouldn't feel like that but I'm sure a lot do just from stuff I've done…. It changes, and I know that, but it's interesting as a patient, you do feel like that. (Patient 3, 80yr female with non-malignant illness)* Family data *Well, an excellent nurse is someone who always smiles. ..And, I think though the biggest thing is probably smiling and being happy (Family 1, 53yr male carer for brother with malignancy and parents with non-malignant illness)* *It's the same thing really. Smiling, happy and keeping the patient or me parents or even me happy and positive (Family 1, 53yr male*

		carer for brother with malignancy and parents with non-malignant illness) *sometimes I'd come in in the morning and I'd see one of them and I'd think to myself, 'Ugh! For the rest of the day, he or she's on, ugh!' But then somebody else comes in and it's lovely! ..They're doing everything, but their whole demeanor is, 'Why am I here?' (Family 12, 78yr female carer for husband with non-malignant illness)* *It's the access, it's her friendliness, it's her treating you as an equal. She comes in as a breath of fresh air (Family 12, 78yr female carer for husband with non-malignant illness)* *The Irish nurses are trained in a different manner to ours, definitely in a different manner, and the patient needs come first. And they are very respectful and very kind, and behave very professionally. They are a completely different breed to ours. Completely different. I can't say that I have ever seen or come across one of them that would show, 'I don't want to be there.' That you could see it, they're completely different to ours. They are what I would call dedicated to the profession (Family 12, 78yr female carer for husband with non-malignant illness)* *What did he do that was really helpful and supportive? Well, he spoke very kindly to mum (Family 13, 56yr female carer for mother with non-malignant illness)*

		Number one, that they listen to you, they're not grumpy. Like I mean it's a service industry. It just a bit like being in hospitality. It's like, "Let's not sort of drag our feet around and look like they're sad lumps and that they're so stressed that they've got no time to talk to you." (Family 13, 56yr female carer for mother with non-malignant illness) *It tends to be on that particular ward from my perspective as well, that it's just task-orientated. It's not person-focused to talk to at all. It's just, "Okay, I'm here now, I've got to do your obs. See you later." They don't come in between. There's not conversations with patients. It's just all around the tasks and what they've got to get done (Family 5, 50yr female carer for mother with malignancy)* *When she had the last admission, she spent part of the time on a different ward it was a really dodgy-looking, old, crappy ward that you wouldn't want to be in. But mom commented that she'd had a really nice experience there because the staff were really nice and kind. They were the words she used. "They were really nice and they were really kind, and they're cheerful and happy." Then we got transferred up to her ward (Family 5, 50yr female carer for mother with malignancy)* *It looks like... On a day to day shift, if you think about a morning shift on a ward, good, respectful care is coming in and saying, "Good morning, patient X, I'm looking after you today. How are you feeling today? Is there anything I can do for you? This is what we're going to do today." Giving her an idea of where her day's going*

		rather than she's in four walls, has got no idea of the time of day because she's not even near a window and she can't leave the ward, and there's just curtains dividing her and another person. So just respectful is acknowledging her as a person, she's in an environment that she's not comfortable in. And asking is there anything that they can do for her, and telling her what they can do and what they are going to do for her. That's respectful care. And handing over to the next staff, so that it's not just about the procedures, it's about the person and the family as well (Family 5, 50yr female carer for mother with malignancy) *With Daughter 1, I just felt that there was a deep empathy and there was just a compassion that was palpable, so it didn't feel that it stepped over the professional boundaries at all. It was still within those boundaries, but it was very gentle and very life-giving for the families. And obviously, the character of the individuals involved in creating that safe soft space was just outstanding, you know? And we were very blessed to be carried, because that's essentially what we were, we were carried by these beautiful people through just an absolutely horrendous experience (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness)* *I think, and this applies to all of the settings that we've been involved in, that there is a sense of coming alongside at a level that ... I suppose there's a bit of a vulnerability that goes along with this, because as a clinician you can have your armour on and just issue*

		instructions and people do what you say, and that's a safe space for a clinician. However, to become a bit vulnerable and to remove some of that armor takes courage, and it takes a deep wisdom. Yeah, a very special character that can be a bit more vulnerable themselves, but still within a professional frame, so it's ... I don't know, really. It's almost like an art rather than a science, and very much having the right people in those contexts who are willing to come alongside and be vulnerable with the actual patients and their families. We've had clinicians weep with us, and I just think, "How many people has your heart been touched by? Because this is your world." And yet there's a softness there that keeps them in that role and keeps them, I suppose, with that clear understanding that what they're doing is so vital and so important to the families and to the patient. But it's somehow forming them as clinicians as well, so it's not something necessarily you can just learn from a textbook, it's something I think you learn through experience, perhaps if you have that particular bent, if you have that empathy, but not to be broken by it as well. Like I say, it's an art rather ... But I think that people who have this sort of degree of empathy are often drawn into those more critical areas of medicine anyway (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness) *I've been on the other side, but it's so different when you're a Family and you're on the receiving end of the gentleness and the softness that humanity can afford in a sense, that there's just an extra kind of dimension to this (Family 8, 52yr female carer for*

		father with malignancy and bereaved carer for daughter with non-malignant illness) *Well, we haven't come across many that aren't friendly. They're very friendly. You get the odd one here and there but that's just human nature. With the doctors, they're always in a rush. They give you a mouth full of long difficult words to understand and then they leave. Where the nurses will actually explain it down to layman's terms (Family 14, 49yr male carer for wife with malignancy)* *Yeah, they're very... What I'd call it is being pretty human, sort of thing, you know? (Family 10, 73yr male carer for wife with malignancy)* *The tone. The tone, speaking so fast as if ... Yes, I noticed that also that that younger doctor spoke slower towards the other patients while he was as if deliberately confusing her. So, she did feel, you kind of feel when someone is not kind to you (Family 3, 52yr female carer for mother with malignancy)* *As patients and their families, we see things differently, we see the team from a different perspective, and we experience such overwhelming kindness in some people that it just changes the way that you see the world, and it's really life-changing. ..Her dedication to her job, her competence and the way that she just enabled us to all feel so comfortable because she was onto everything. If there was any little thing, she was across it straight away, not in an overbearing way, in the most appropriate and life-giving way*

		(Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness) *If there are any concerns, like I really can't ... They're a special group of people, they really are, and there's just a gentleness about them that means that they're unhurried as well, and that's very important, I think, for people in my dad's situation, to just not feel like there's a lot of bluster going on, but that the staff can be very present to my dad and chat to him and be just very aware of his concerns (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness)* *It is. I suppose there's this assumption that to be in the position that clinicians are in, that they have the clinical competence, that that's sort of like the baseline. But to be able to function in an emotionally-charged environment like the loss of a child or the loss of a parent or just severe trauma like Daughter 2, I think it takes great communication. And so just because you have the clinical, you know, you've got the brain that enables you to learn, and you're able to deliver on clinical care, that's fantastic and it's amazing and wonderful, and that's what you're there for at the end of the day. But there's just this extra requirement that is really key to, I think, good outcomes for the family and the patient, and for their post-hospital care as well, because when they return home they've got the peace of knowing that they've actually had the care that is required, they've been carried, they've been blessed (Family 8, 52yr female*

		carer for father with malignancy and bereaved carer for daughter with non-malignant illness) *But they still talk happy and positive and can joke around. They can take a little joke back too (Family 1, 53yr male carer for brother with malignancy and parents with non-malignant illness)* *Respectful care would be, when you are being spoken to, that you are being spoken to as an equal, that you are not being treated as a half-wit or an old and demented person. I think that's very important (Family 12, 78yr female carer for husband with non-malignant illness)* *It's the access, it's her friendliness, it's her treating you as an equal. She comes in as a breath of fresh air (Family 12, 78yr female carer for husband with non-malignant illness)* *But it just becomes this sort of sense where you're carried, whether you're away from the ward or if you're up in the ward, you just have this sense of a continuity of care. And even in the ... I've got to put in a bit of a plug for the canteens and the café at Hospital X. The staff are aware that they're not just serving coffee, you know? They're providing sustenance for people who are in trauma, and they are very gentle with the customers. It's just quite ... That was our experience anyway, that it was like this flock of angels that just sort of descended on us, and they were all absolutely beautiful. No matter if it was the cleaner or the ... It didn't matter, it's like the whole team sort of takes on a particular posture, which is really life-*

		giving. Yes. Yes, and that is so important as well. It's important I think for the cleaners themselves to know that they're actually being just a beacon of light in a dark place, too. But yeah, it didn't matter who it was, we felt that each person had a part to play. The team doesn't just stop at the clinical level. It's holistic (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness) Bereaved Family data *We came across a lot of, probably fifty-fifty in terms of whether a nurse or a doctor, you know, showed empathy, showed that they actually cared. Some of them were just there, doing their jobs. They don't particularly care, had obviously seen everything, were just kind of fed up, you know, maybe burnt out, sick of their jobs, didn't want to be there. And when you're in the- you know when you're the family member of someone who's passing away, you feel that. You can feel that they don't want to be there, that they don't really care. At first, it was their body language and the way they talked. They were more, I suppose leaning in, whereas those that didn't really care, they didn't really show eye contact. It was just kind of coming in, check-in, doing the bare minimum, not really engaging in conversation except where necessary…You know, just very clinical. Whereas ones that you could tell actually cared, they deliberately showed empathy and engaged in conversation and would ask, "How are you doing? Are you okay? Do you need anything?" Those*

		kinds of things (Bereaved family 11, 33yr female carer for father-in-law with malignancy) *Yeah, and you need... the thing is, the way they're thinking, cause it's a job for them. Say this is a job, it's like my job, going to work every day and, just say I deal with the same thing every day, day in, day out. They are the same - They're dealing with sick people, day in, day out…They're dealing with people that are dying, day in, day out. But they've gotta understand that they're dealing with someone's family member…So that it's not... you're not dealing with a house that you're building, that something is wrong, or a car that you've repaired but it's not running properly, this is actually a human being. Respectively, they've chose that to be their profession (Bereaved family 12, 54yr male carer for father with malignancy)* *Look they can't do miracles, especially when someone has like a bad chronic disease like a stroke or something like that, but you know, treat them like they were. They're still treating them like they're a person, just not a body in a bed, kind of thing (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness)* *That's the attitude, the attitude is…. no one, and a lot of the nurses, not all of them, but a lot of them, are not interested in the patient. They just want to do their job and go home. And maybe a lot of the doctors too (Bereaved family 12, 54yr male carer for father with malignancy)*

		Also, I think it's just that personalizing thing. "Yeah, we've met your dad, XX, and he's ..." I mean, sometimes you get ... Like, that's what I was saying. There's a mix. You get the nurses that you see them when you've gone to visit and they come in and go, "Oh, your dad's been telling us all about when he was in Brisbane, and these type of things." You know that dad's engaged. I'm not saying that anyone has to tell me anything about my father, but I could tell the nurses that liked dad, and got on with him. But the thing is, it's not about liking. It's just about engaging, and checking everything's right. The other thing, I know you're asking me what it is about them, but I suppose that's the thing I noticed is that dad would say, "That's a good nurse," but what usually happened was there is some engagement. I suppose it's taking a sincere interest. But naturally, not everyone ... To some people, maybe it's more a job, and they're tired. They've got families at home. They're not that interested to start up conversations, which I totally get (Bereaved family 9, 57yr female carer for father with malignancy) *Honestly, incompetent could be the only word to describe them, kind of thing. Then others are just so professional, kind of thing. Some of them are just doing their job, and then others are doing their job with a passion and interest, and whatever. So yeah, you can certainly see that. You can certainly see experience and things like that as well, people that are used to dealing with people and whatever. Yeah, some doctors honestly you get the feeling they're just there to rake in the money. Others you feel like they're there to make a difference, kind of thing (Bereaved family 2, 52yr female*

		carer for husband with malignancy and father with non-malignant illness) *To be honest, it was their personas, the fact that I could see the rapport that they'd built with my mum, you know, I'd come in and sit and watch them and they'd be, "Hey person X," you know, and they'd have a conversation with her. They knew her little stories, they knew who I was, "Hi Bereaved Family 10, how are you?" You know, just it's really honestly the little things like that that you could see, and to be honest, though even my mum was sort of in and out a lot, she even then, when she didn't really know where she.... She knew she was in Hospital XX but she couldn't really tell you what year it was, but she had nothing but high praise for them. You know, like she loved them all (Bereaved family 10, 43yr female carer for mother with malignancy)* *Yeah, just the treatment. As I said, just her conversations with the nurses and like I'd come in and she'd be telling me these stories about the nurses like they were long lost friends. And when they'd come in to give a medicine or look after something, and all of them would come and find me "We loved patient X." So I knew that she was looked after that because they knew about it. They didn't just know the medical side. They knew who she was (Bereaved family 10, 43yr female carer for mother with malignancy)* *It had understanding and compassion, and it was about a person, It wasn't about a scan. The scan was there, it was discussed. But it was absolutely about a person. Under the circumstances when he*

		probably left dinner on Saturday night with his family to come and meet a family he'd never met and would never meet again, it was extraordinary, absolutely extraordinary. So that was wonderfully reassuring and very special (Bereaved family 13, 54yr male carer for both parents with non-malignant illness) *it is the simple stuff. This is not about whether you had a side effects from drug X, or drug Y would have been better. This is simple humanity (Bereaved family 13, 54yr male carer for both parents with non-malignant illness)* *Well, there was no connection. It was literally, "I'm just taking your temperature, I'm taking your blood pressure, and now out of 1 to 10." There was no thought in it, no critical thinking behind why am I doing this and does this scale actually mean anything to this person? How do I engage with them to actually get them to give me an honest, a deeper answer and an answer that's actually a real answer, rather than trying to please the nurses so that they don't make a fuss? That kind of thing (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)* *This is going to sound really weird, but sometimes it's just in the way people come into the room and engage. Like, there was some nurses that were, you just warmed to, and it was just, there was something about them and the way they spoke to you, the way that they spoke to patient X, the way they walked into the room was respectful. There were others that blasted in, like they were in charge. Like the one I was telling you about that just came in with*

		her butterfly cannula and just shoved it in patient X's arm and walked out, tried to walk out. That was probably the two poles of…. and there was everything in between. It's just the way they talk to you, I think, you know? I can't really put my finger on what it is. You know it when you see it, and you feel it, but you certainly know it when you feel the ones that don't care…There's some nurses you wouldn't leave. Well they were either rough with the way they did things, so patient X had to be turned, and they would come in and they'd be quite rough with her, or just the bare minimum, rather than checking to see if she was comfortable. They just went, "We're going to turn you now" and they'd just flip her and put a pillow behind her and go, rather than the ones that were actually, "Is that comfortable?" Talking to her while they're doing it. Again, it's just the manner, the way in which they engage with patient X, they didn't engage with her, and whether they checked to see what they'd done had been actually a positive or negative experience for her (Bereaved family 8, 56yr female carer for mother-in-law with malignancy) *When people just popped in to check how you're going, even though it wasn't necessarily vital ... Like, time for them to obs or something, they just pop in and say, "Just checking up on you guys. Is there anything that you need?" Just a simple question like that, that isn't attached to, "I have to be here so I might as well ask." It was just an additional kind of, "Just checking in on you." That kind*

		of thing (Bereaved family 8, 56yr female carer for mother-in-law with malignancy) *Also, I think it's just that personalizing thing. "Yeah, we've met your dad, XX, and he's ..." I mean, sometimes you get ... Like, that's what I was saying. There's a mix. You get the nurses that you see them when you've gone to visit and they come in and go, "Oh, your dad's been telling us all about when he was in Brisbane, and these type of things." You know that dad's engaged. I'm not saying that anyone has to tell me anything about my father, but I could tell the nurses that liked dad, and got on with him. But the thing is, it's not about liking. It's just about engaging, and checking everything's right. The other thing, I know you're asking me what it is about them, but I suppose that's the thing I noticed is that dad would say, "That's a good nurse," but what usually happened was there is some engagement. I suppose it's taking a sincere interest. But naturally, not everyone ... To some people, maybe it's more a job, and they're tired. They've got families at home. They're not that interested to start up conversations, which I totally get (Bereaved family 9, 57yr female carer for father with malignancy)* *I think part of it was the way that I am. Like, when I would go and see Patient in the evening and she would say, "I've got a new nurse today." And I would say, "Okay." And when the nurse came in, I would say to her, "And what's your name?" So that I knew who I was talking to. And I always do that with people, that's just a habit of mine. I'm the same like that at the shops, you know? My*

		daughter when she was younger said, "You go into all these shops and you know all these people. How do you know their names?" I was like, "Well, I ask them." It's quite simple really. It makes a lot of difference. When you know somebody's name, it just gives you a connection with them (Bereaved family 1, 66yr male carer for wife with malignancy) *Yeah, just the nurse that comes in and just barely engages with the patient, barely gives them eye-contact, just, "arm up / Under your tongue." That kind of thing, some of those patients, they might not get a visitor all day, you could at least be a little bit pleasant to them, or whatever (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness)* *... If health professionals could change in any way they could change, that part of themselves to show empathy despite people circumstances, and really put themselves in someone else's shoes, and just listen to the journey that these families have been on. Because for most families, it hasn't been easy, and it will never be easy for my parents. They've buried their son. They've buried their only son. And it will never be easy, but it just is nice to think that, there isn't a stigma attached to the fact that he was alcoholic (Bereaved family 3, 43yr female carer for brother with non-malignant illness)* *But she was just so ... she had a lovely manner and efficient but kind, not emotional particularly, but warm and really straight forward and she ... so, although I got a little bit emotional when I was talking*

		to her, it was a huge relief and it was just ... and after the interaction, after getting so upset like I say, that is the only time in my entire life over anything I have completely lost the plot and just screamed and yelled blue murder at people, I have never done that before. After that, and then ... and I've never had such a horrible experience as that interview with that consultant, and then, somebody making me a cup of tea was, well, that's nice, but that's not really going to help. Her saying that was just really valuable I suppose because it was kind of she'd listened to what I'd said, seen what's gone on, she knew what the problem was and she was just saying it's all right, you get ... not you've got things out of proportion, but just remember, we're here, we're looking after him, don't worry, we're not just sending him back because we can't be bothered or because we're not sure. We're sure that he's going to be fine to go back and we are going to be monitoring him carefully which is all the other doctor needed to say, but he said none of that. She was so nice about it, that was kind of ... I don't know if you know ... I guess that's a common thing, but when you're really strung up about something, when somebody's really nice, it can actually make you cry, but you're actually crying because you're so grateful (Bereaved family 7, 56yr female carer for husband with malignancy) *I suppose he was maybe a bit more deliberate and a little bit more, like took a little bit more time and was a little bit more ... yeah, quite calm, very calm and very ... it's interesting isn't it? Quite gracious but very calm, very dignified, very ... I suppose a little bit more time and attention and sort of slowing things down a bit. And being very*

		nice and really sort of, not becoming your best friend, but really ... I don't know. A lot of kindness. Yeah. Somebody that sort of radiated out kindness, but very quiet, quite quiet. I just thought he was a extraordinary nurse, but now I think ... I mean he was an extraordinary nurse, but now I think maybe in retrospect, he also thought, well, this is a certain stage of a certain process and was reacting accordingly in a very wonderful way. But at the time, I just thought he was a lovely nurse and he was so kind and nice to have around and I was really pleased he was looking after Patient X and I did say that to him a few times because I think I did go home on Friday night (Bereaved family 7, 56yr female carer for husband with malignancy) *So, some of them were amazing and really they were efficient, effective, kind and attentive and some of them were a little bit vague or too busy or didn't ... you didn't feel like you really got the sort of ... when I say attention, I don't mean attention, seeking attention, I mean the looking at Patient X, taking into account what was happening and doing whatever needed doing next or should be happening, that kind of attention is what I mean. So, sometimes you felt like you were kind of ... it's a really tricky situation, I'm sure everybody says the same of being in that ... on a ward or or wherever you are, trying to be as nice as you can to everybody and at the same time, trying to make sure ... try and get certain things to happen to help the situation for Patient X (Bereaved family 7, 56yr female carer for husband with malignancy)*

		Again, she was was kind and empathetic without being emotive. It's that kind of calm, authoritative, but gentle, firm but gentle kind of calm, authoritative, but kind (Bereaved family 7, 56yr female carer for husband with malignancy) *Yes, yes, impersonal, cold, disconnected. She just seemed, I don't know, she just didn't... That might have been an individual thing, but it didn't bode well, that somebody could get to a senior position like that. To me that's scary. She's a registrar, she's going to go on to be a specialist, so if that's her mannerism then how does she... you know perform capably. Moves forward, and how does she then in training what does she engender to junior staff? If that's how she presents as a role model. I thought that was pretty sad (Bereaved family 5, 56yr female carer for mother with malignancy)* *So, I think it's the attitude, and but sincere. I think sometimes, even if someone's down, they can say, "You know, I'm not having a great day today, patient XX, but I'm going to take good care of you. Don't worry." You know, how people, you don't have to give people detail, but sometimes just it's connecting. I think the word is connecting. I think the nurses that connect and make an effort, and then the other struggle is with these (Bereaved family 9, 57yr female carer for father with malignancy)* *And it's hard. It's very different to how you believe nursing would be as a profession, and as someone being cared for. You'd like to always think that your family member is much more than just the patient in bed 27. You always wanna hope that they were more*

		than that, they are people (Bereaved family 3, 43yr female carer for brother with non-malignant illness) *So therefore number one for me was just making sure that she was sort of physically and mentally looked after. She wasn't treated badly, but like she was treated like a person and like just, yeah, that was more important to us. I think (Bereaved family 10, 43yr female carer for mother with malignancy)* *So they treated both my parents with phenomenal respect. They treated them as people. Despite my mother's difficulty with mentation in those last few days as they struggled to maintain her oxygenation, their communication was really respectful. I mean, I've seen many staff in similar circumstances be incredibly patronizing and almost dismissive. Nothing could've been further from the truth (Bereaved family 13, 54yr male carer for both parents with non-malignant illness)* *I think a couple of things. One is addressing the patient directly, rather than talking across them, or about them, and making sure that you're addressing them in the mode that they want to be addressed, rather than turning up and going, "Oh darling," that kind of thing. When you're talking about particularly a woman of patient X's age, who was 90 years old, and she deserves the respect of a 90 year old woman. So the way they speak to her, not like she's an infant, but she's actually an adult woman, and she has got a brain, and can make decisions for herself, rather than making them for her. That's important. Obviously the physical dignity's important as*

		well, so if you're doing personal care stuff, that you make sure that the whole world's not looking in on that. And also maintaining just things like to me, dignity is little personal care things like your teeth. If you're talking to someone or they want their teeth, they might want their teeth in, not just in a jar next to the bed if they actually have dentures. Because it takes away that dignity of when people are looking, you know when your mouth drops in? ..," it was just those small things, cleaning someone's glasses so they can actually see. It's little things that make that dignity, for me (Bereaved family 8, 56yr female carer for mother-in-law with malignancy) *Well, I think respect is a word that, to me, today is grossly overused. It's often confused with regard. And I think probably the word regard is better. And the sort of thing I'm talking about is ... I'm just trying to think now. I know what it means from my point of view. And I always found when I was at the hospital during visiting times and when the nurses came around to see us at home and when she was in palliative care, there was not one occasion when I thought ... you know, they always spoke to her nicely. When she rang the bell, they came. And they did listen to what she was saying. I mean, she wasn't one of those people who was complaining, but occasionally things were very uncomfortable or something needs to be attended to or whatever. And if she needed to go to the toilet when she was told not to get up, again, she had to call for the nurses if she wanted to go to the toilet and they were*

		there straight away, which was good (Bereaved family 1, 66yr male carer for wife with malignancy) *I think for us, it's when you feel like they can see them as a person, and not as a patient, that I think you felt like they spent the time, obviously they couldn't get to know Patient 'cause he was unconscious, but they could get the time to know the Patient that we knew. When they come in and just ask what football team he likes, so ask about who he was as a person, to allow us to share these moments with them, 'cause they're the people that have been with us. But just allow us to share with him. I often had music on with him, 'cause Patient loved music, so I did play music with him then. Just ask us…Know he's a person, and not just a patient. I think that's the biggest thing, is ... and I know my experience of caring with sick kids is, the parents just want to feel like their child was something special. And you do, you'd love to think that if I wrote a card to that ward now, and it says, "Thank you for caring for my brother at 15 months ago.", that someone would say, "Oh yeah, I remember Patient." But I know deep down that they wouldn't. He was just a number. He was just bed 27, in for three nights, packed up, shipped off, next patient was probably in his bed within the hour after he left, and that's hard, because I understand the system. I'm a nurse myself, but you just wanna feel like they meant something (Bereaved family 3, 43yr female carer for brother with non-malignant illness)*

		I think so much with palliative care and people dying, there's so much prejudgment that happens. I know I always felt with Patient, and his alcoholism that he was judged for that. When you present to ED, and he often presented to ED in various levels of intoxication, and an injury attached to his intoxication, that there would be a judgment. You could see there was judgment made about the quality of his life, and the quality of care that he should receive because he was intoxicated. And, often, I think that's a very detrimental part of health, is that we do people's own judgments, and own values, it's very difficult for them to not bring them into the care that they provide in a hospital setting (Bereaved family 3, 43yr female carer for brother with non-malignant illness) *And Patient, I think, fell victim to that quite a lot. I think alcoholism is something. It's easy to say it's his fault. He drank, it's his fault. And we're not denying that. No, he wasn't at fault for a lot of it, but, we also understand that he was a little boy who was hit by a car, and that wasn't his fault. And that his life could have been different except for a sliding door's moment, whereby he was hit by a car. And I think that's, for me in health, I think that's ... If health professionals could change in any way they could change, that part of themselves to show empathy despite people circumstances, and really put themselves in someone else's shoes, and just listen to the journey that these families have been on. Because for most families, it hasn't been easy, and it will never be easy for my*

		parents (Bereaved family 3, 43yr female carer for brother with non-malignant illness) *And they made her laugh and she had a good laugh with all of them. You know, it was more the persona and the communication. Like as I said, you know, right or wrong, you sort of assume that the care is going to be there, but that personality and the genuine kindness that I really felt from, you know, made such a difference (Bereaved family 10, 43yr female carer for mother with malignancy)* *One of the other things that we noticed was, so the cafeteria people, they obviously then recognized us after a few days. They're like, "Oh, what are you guys in for?" in quite a casual sort of way and it'd be helpful if there was training for cafeteria staff on, we have a palliative care ward which means its very likely that you will have people who are here while their loved ones die. How about some consideration and empathy training type thing. ..I'm sure there are some that are, you know, that are more familiar with what goes on and so possibly a little more empathetic, but not everyone was in our experience (Bereaved family 11, 33yr female carer for father-in-law with malignancy)* *All the staff, the kitchen staff, the ward staff, the medicos, allied health, the couple of encounters with pharmacy, the communication was just beautiful, and the physical care couldn't have been faulted (Bereaved family 13, 54yr male carer for both parents with non-malignant illness)*

		Like I've been there, where they'd come in, and they'd just start doing things, and they wouldn't say who they were. Even the cleaners. Cleaners are probably one of the most important groups of the team in the hospital. I like it when they say, "Hi. I'm Sonia. I'm just going to clean. Is it all right if I do the ..." You know, like of course it's all right. They can clean whenever they want. I think it's just that humanness. It's connection and communication. That's what makes them good (Bereaved family 9, 57yr female carer for father with malignancy)
Domain: Trust and confidence in clinicians		
There was no additional detail provided in relation to this domain from a patient perspective	• Communication that builds trust and confidence including the way a clinician talks to a patient, honest and understandable information provision and ensuring a patient is fully informed about their care. • Clinicians being attentive, responsive and mindful in their care delivery • Achieving a good clinical outcome (feeling better) • A confident, competent and efficient clinician • A strong, caring, compassionate and professional approach to care	Patient data *The way they spoke to me and explained to me – and yes I trust from the way they speak to me. (Patient 5, 72yr male with malignancy)* *Yeah. And If I ask a question, I get a direct answer. (Patient 17, 66yr female with malignancy)* *Oh, to be honest, to have good communication skills with them…To be able to understand, if I don't understand any medical terms or to be able to get my message across... or be able to get their message across to me that I can understand what the course of the treatment would be. Over the term of the hospital stay. (Patient 7, 59yr male with non-malignant illness)*

		Confidence, I get confidence from the medical staff when they talk to me and they tell me exactly what's going on. Obviously, I have to trust what they say because they're the doctors. …. But it's good that the doctors don't just talk. They've got to followup. (Patient 18, 71yr male with non-malignant illness) *That when she comes into the room, she speaks to me, to my face. Tells me what she's about to do. …I'm absolutely amazed at some of the fabulous nurses we have. Young first and second year graduates. Some of them I've taught, actually, and I'm thrilled to see how good... what fabulous nurses they are in terms of their communication skills and their approach to people. (Patient 3, 80yr female with non-malignant illness)* *Isn't looking at other things or checking her mobile or something else. Just being attentive, I suppose, being in the moment. Being mindful. (Patient 3, 80yr female with non-malignant illness)* *Again, it's the way they talk to you, again. Not, "I haven't got time." Or, this ... I know they don't have time, but I hate sometimes calling them. But if I can't breathe and I'm in the toilet, I need somebody to help me. That's desperation, because when you can't breathe, you can't breathe. It's not a lot of fun. (Patient 10, 82yr female with non-malignant illness)* *And if I feel something's not working, I let them know, and then they look into it. Then they, they change it or try something different or*

		something like that….so they're open to feedback. Even though I'm not medically wise, they... You know your body better than anybody else don't you? (Patient 17, 66yr female with malignancy) *And that's what I need, well it's reassurance. It's confidence. It's someone's there knowing and thinking about you. (Patient 12, 65yr male with non-malignant illness)* *Oh, you just feel it, it's intuitive…..Well, people should be sure what they're doing, and know you have to have confidence in them. Not to feel that they are doubtful and they're asking you. (Patient 11, 72yr female with malignancy)* *The way I've been looked after. The confidence they had... Look, I went into my surgery saying, "Look, if I'm sliding on the table, please just let me slide." But under all assurety, they said, "No, you'll be right. You don't need to be thinking stuff like that. You just need to think positive and you'll be okay, you'll get through this." You know? And sure as hell, I'm here at home now. I came home last Friday (Patient 14, 45yr male with malignancy)* *And you can tell... you can just tell when you talk to them that they were confident in themselves too (Patient 1, 48yr male with malignancy)* *Well, some nurses are very, very efficient, and they seem to know what they're talking about, and with those people, you have a lot of faith and trust and you listen to them and you go with what they're saying, because you have confidence in them….But it's the nurses*

		that install that confidence, and then you have other nurses, which you know that whatever they're saying, they're just talking rubbish. They're just talking for the sake of talking. And you don't trust them and you can't wait for their shift to be over. (Patient 18, 71yr male with non-malignant illness) *Obviously, is across what she's doing (Patient 3, 80yr female with non-malignant illness)* *....being strong and caring, but not overdoing it ….Strong… definite….. Yeah. And that strength follows like for you …. Connects you know. (Patient 19, 69yr female with malignancy)* *You know what, to be honest, we need to trust in whether we like it or not because there are no options. Honestly, I don't trust my oncologist…Because she's too... She doesn't have any compassion(Patient 21, 50yr female with malignancy)* Family data *Well, normally I judge people... more or less judge them by their personality. And the way they act. And, I think a lot of the times in looking people in the eyes. And, that's the more or less way sometimes it's just the way they approach themselves (Family 1, 53yr male carer for brother with malignancy and parents with non-malignant illness)* *Because it's not just one person, it's a team of people. And they really put all their ideas together, what would work best. So, you're*

		looking at more than one person's knowledge. So, to pool people's knowledge and get the best of care I think is a great approach. I was pleased to see that there because it's my first experience in the hospitals with cancer, so to see so many different teams of people working together is really good (Family 11, 61yr female carer for mother with malignancy) *I'm told, I don't feel this myself, I'm told that I can smell a bad doctor or a bad nurse a mile away (Family 12, 78yr female carer for husband with non-malignant illness)* *Particularly, I think, he's very happy when he has the Irish nurses.He feels confident with them, he loves them. He feels so much safer with the Irish nurses than he does with ours!... The Irish nurses are trained in a different manner to ours, definitely in a different manner, and the patient needs come first. And they are very respectful and very kind, and behave very professionally. They are a completely different breed to ours. Completely different. I can't say that I have ever seen or come across one of them that would show, 'I don't want to be there.'That you could see it, they're completely different to ours. They are what I would call dedicated to the profession. Some of ours are, others are not. Like in any profession. But my patient, he just loves when he sees he has an Irish nurse come in (Family 12, 78yr female carer for husband with non-malignant illness)* *Good question. Well, I think that they listen to you, number one and that they look you in the eye and they have the body language of*

		being present is all. Yeah. And that they're looking to you and they might relay back what you said that you can hear that they've heard you, and be caring to the patient. (Family 13, 56yr female carer for mother with non-malignant illness) *I don't know, you just tend to see the ones that are more caring or observant and willing to listen (Family 18, 59yr female carer for mother-in-law with non-malignant illness)* *But dad, I think because it's been three years of building conversations with the oncologist and the palliative care doctor, because they have fairly regular visits outside of hospital time with both of those two, that dad now feels comfortable enough to ask basic questions. There's no probing questions, and not questions of what happens next. It's just we're here in the now. But I think dad's comfortable enough with these two people, because they're so familiar, that he's okay to ask questions or to clarify things. The other thing I've noticed with dad now is that when the consultant comes and he's got the entourage, there's a reg, a resident, medical students, whoever they've got with them, dad will have a conversation and ask them other questions, and then actually look at the others to see if they're paying attention or if they've got something else to add as well (Family 5, 50yr female carer for mother with malignancy)* *I've also noticed that dad will now sometimes stand up to put himself up on the same level as the gents, because most of them are blokes that come in the room. So I think he feels there's that*

		comfort and trust with that particular hematology oncology guy. Because mom's had such bad experiences. I've said to her and dad, "You do understand that you're paying for your care, and you can go to the private hospital down the road, because they do have an oncology service. They've got inpatient andoutpatient. If that's something that you might like to try..." And mom's said yes but dad has said, "No, I don't want to do that, because I'd prefer to be on this ward, because I know some of the staff and I know the doctors." (Family 5, 50yr female carer for mother with malignancy) *I think for dad it's the comfort factor that's allowed him to start to ask questions. He feels like, at that level, that he's probably a little bit more involved in decision-making. But when they forget about that and they don't say, "Oh husband/Family, by the way, we've found this and we're going to get this person involved in the care," when it just kind of happens, then he's back to feeling like, "I just don't understand what's going on." Does that make sense? (Family 5, 50yr female carer for mother with malignancy)* *My confidence in the consultants is when they listen to questions and answer the questions, whether that's matter of factly or however, but they actually take the time to listen, and don't just say, "Oh, you don't need to worry about that." I respect the hematology oncology guy and the lung physician, because of the way that they listen. Different bedside manners, but they both listen. One's smiles and one's just blank. I respect that. My respect level drops the further down the chain you go, and I think that's... My perception's*

		probably different to somebody who's not got a nursing or midwifery background, and that is the level of knowledge and the way they implement that with the person (Family 5, 50yr female carer for mother with malignancy) *The first admission, I really challenged the registrar, so the very first time when they told mom she had cancer and that it was not curable and stuff. The reg, I'm assuming was a very junior reg, was really not great. Really poor communicator, really poor bedside manner. Didn't listen to anything that was being said. And I pretty much went to town on him one day. Not rudely, but just called him on a few things. Then he still wouldn't listen, overrode what I was asking and suggesting, sent a little resident in to tell me that that's not what's going, and so the poor resident... Then for me to say, "Well he doesn't make decisions. Go to the consultant, because the consultant makes the decision, not the registrar in this case." They were a bit like, "Don't pull those strings (Family 5, 50yr female carer for mother with malignancy)* *I don't trust them unless they... If I don't feel like they've got the skills yet and the knowledge yet, then I don't trust them to be good information givers, and personable people with mom and dad. When the lung physician came in, he did have an entourage with him, and they had done the CT to compare from the previous CT, and... I still don't know who the person was that actually said it to mom and dad. But there was a young woman. I don't know if she was a resident or whatever. Anyway, he deferred to her. He said,*

		"You can tell them," giving her the opportunity to break bad news. She was like battle ax blunt, and really fast with her speaking, and clearly not comfortable having a conversation. But left the room without answering any questions either, just saying... (Family 5, 50yr female carer for mother with malignancy) *And not using layman's terms. She said to them, "Oh, you've got diffuse nodules in both lung spaces, and it's in the pleura, and we're going to look for a primary." And dad's like, "So what does that mean? She said, "Well that means cancer." Mom and dad's first thought, "Well, clearly she has cancer, so okay, we'll move on from that, because that just means cancer. It doesn't mean..." They didn't understand that that mean that they were looking for a different cancer (Family 5, 50yr female carer for mother with malignancy)* *Those people, it's just like, "Don't come back, because you don't really know what you're doing yet." (Family 5, 50yr female carer for mother with malignancy)* *Okay. Well, we've had a couple of those, I think everyone does, and I think that's where the team is so important, because there's a disarming quality to being cared for by a team that is just functioning really, really well so that when you do come across someone who's having obviously a bad day or just don't have those skills that we've spoken about, you know that you can rest in the goodness of the team that is actually present there for you, and this one individual just may not have the right skills (Family 8, 52yr*

		female carer for father with malignancy and bereaved carer for daughter with non-malignant illness) *But you've got a team of people who do, so it's almost as if there's this kind of critical mass that if you have a team of people that by and large have got the skills, that can carry those who perhaps don't, but they might be great clinicians in other ways. You know, they might be very competent in a range of areas but just don't have those personal skills, so it sort of softens those rough edges as well (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness)* *She could answer any of our questions, and if we had questions that perhaps weren't appropriate for her, she would bring in the person that would be most appropriate. She was so involved in total patient care for Daughter 2, so in terms of ensuring that Daughter 2 was being looked ... It was as if she was like this ... She sort of transcended so much of what happened and was just aware of everything that was happening for Daughter 2. It didn't matter if it was the meals, if it was just the physio. You know, it didn't matter what aspect of her care, she was across it. And if there were any concerns, we felt that she was the person that would advocate or would notice things that were perhaps not quite right. And like I said, she would come in on her days off, she was there seven days a week, she would run in and ask Daughter 2 each morning, "Are you okay? How did you sleep? How are you feeling? Any questions? Any issues? You know, you know you can contact me*

		any time." (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness) *And if there was anything that Daughter 2 needed, she would tell the team and then she would go back home for her day off. You know, that's the level of care. It was just phenomenal. I suppose she knew our story and she just wanted Daughter 2 to live, because we'd already lost Daughter 1 (became teary). She did everything she could to keep Daughter 2 alive (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness)* *we felt safe, and we knew that everything that could be done was being done, and we knew that potentially that wasn't going to be enough. But just the comfort of knowing that everything that can be done has been done is just ... You know, you can't ask for more than that (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness)* *It is. I suppose there's this assumption that to be in the position that clinicians are in, that they have the clinical competence, that that's sort of like the baseline. But to be able to function in an emotionally-charged environment like the loss of a child or the loss of a parent or just severe trauma like Daughter 2, I think it takes great communication. And so just because you have the clinical, you know, you've got the brain that enables you to learn, and you're able to deliver on clinical care, that's fantastic and it's amazing and wonderful, and that's what you're there for at the end of the day*

		(Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness) *But there's just this extra requirement that is really key to, I think, good outcomes for the family and the patient, and for their post-hospital care as well, because when they return home they've got the peace of knowing that they've actually had the care that is required, they've been carried, they've been blessed (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness)* *Confidence, preparedness to listen. Preparedness to take questions. A sense that they're not being defensive when questioned and queried about something (Family 9, 64yr female carer for father with non-malignant illness)* *And primarily again as the observer, to see that they will listen and speak to the patient first. Not to me or to the other staff. But to speak because the patient is central. And that gives me confidence. Even if they're medical treatment's not good, if they'd actually centred the patient, where I think the patient is central to what we do. If they'd centre the patient, then there's always going to be good... for me there's always going to be a better feel about things (Family 9, 64yr female carer for father with non-malignant illness)* *Yes. Because he took charge (Family 3, 52yr female carer for mother with malignancy)*

		I think it's just the communication (Family 6, 30yr female carer for mother with malignancy) *we are confident, the specialist is very good. She is very experienced and very knowledgeable, she is very good. We have confidence in her (Family 4, 53yr female carer for husband with malignancy)* *With the nurses, and the doctors, you can only give them a chance. You can't really say, "No, I don't like the way you're dressed." Walk away. You've got to give them a chance. You can't just write people off. They could be the best people in the world. You just don't know. It's just a matter of giving them a chance, that's pretty much it, isn't it? Yeah… If you're in the ward, you might see two or three different doctors. You do get to know the better ones, just with the bedside manner. That is a big one if they've got a good bedside manner. If they just come walking in, give you a mouthful of information and then walk away. That makes it very difficult…Just taking the time to explain in better detail whatever they're trying to get across. We're not all doctors and nurses that have had hours and years of medical training. The more detail the better (Family 14, 49yr male carer for wife with malignancy)* *Because he took the time to talk to her. Like he didn't come in and say, "Oh. Right-o," and off he goes. You know, where the nurses sort of go, "Oh yeah. Yeah. Right-o. Yep." That's it. They don't ever say, "What would you like me to do?" From what I gather, they sort of like to tell you what they are doing. They don't ask you…Yes. Tell*

		you want to do, yeah (Family 17, 69yr male carer for wife with non-malignant illness) Bereaved Family data *To be honest, it was their personas, the fact that I could see the rapport that they'd built with my mum, you know, I'd come in and sit and watch them and they'd be, "Hey person X," you know, and they'd have a conversation with her. They knew her little stories, they knew who I was, "Hi Bereaved Family 10, how are you?" You know, just it's really honestly the little things like that that you could see, and to be honest, though even my mum was sort of in and out a lot, she even then, when she didn't really know where she.... She knew she was in Hospital XX but she couldn't really tell you what year it was, but she had nothing but high praise for them. You know, like she loved them all (Bereaved family 10, 43yr female carer for mother with malignancy)* *And they made her laugh and she had a good laugh with all of them. You know, it was more the persona and the communication. Like as I said, you know, right or wrong, you sort of assume that the care is going to be there, but that personality and the genuine kindness that I really felt from, you know, made such a difference (Bereaved family 10, 43yr female carer for mother with malignancy)* *Yeah, just the treatment. As I said, just her conversations with the nurses and like I'd come in and she'd be telling me these stories about the nurses like they were long lost friends. And when they'd*

		come in to give a medicine or look after something, and all of them would come and find me "We loved patient X." So I knew that she was looked after that because they knew about it. They didn't just know the medical side. They knew who she was (Bereaved family 10, 43yr female carer for mother with malignancy) *I suppose when they were open about their experiences, thoughts, feelings, et cetera. When they showed that they were human, I guess. We had one lady, a lady nurse, she was Fijian. She was lovely. Her name was XXX at hospital X And you could say that she bordered on completely inappropriate, but it was so nice to have someone who just sat there and talked to us…You know, she sat down with us, she talked to us. I suppose she distracted us with some of her stories about different things. She was pretty good at reading the situation to know when she needed to leave us alone and when it was okay to come in and talk to us (Bereaved family 11, 33yr female carer for father-in-law with malignancy)* *I guess if you ask a question, they knew the answer to that, and if they didn't know, they said they'd go and find out about it. They didn't try and make some crap up. The ones that actually came in and asked about how we were going, how's patient X going, when they came in and did things, actually explaining what they'd done, and what the outcome of what they'd done was. Yeah, I guess that (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)*

		Listening. So, when you talk to them about something, and they respond. It's that thing of reiteration, and saying, "Yeah, we can do that," rather than, "I'll look into that," or, "Maybe." Because, I think that's something that sometimes happens is because they're under pressure, you don't always feel it's definitive. Like the nappy thing was a classic, because I'd ask, and then on the next day on a new shift, new people, there still weren't the nappies. I'd say, "Look, I asked yesterday. I don't mean to bother you. I don't mean to be a pain, but could we please have a regular supply?" In other words, can someone actually look and see that there's one nappy left. That sort of thing…Yeah, it's about listening. I think it's the way, when you communicate, you look someone in the eye. Looking people in the eye, and actually acknowledging and having a sincerity. I don't know. It's just we're all human, and you can usually tell if someone's listening or not, or they're just jumping off to the next thing. Also, I think it's just that personalizing thing. "Yeah, we've met your dad, XX, and he's ..." I mean, sometimes you get ... Like, that's what I was saying. There's a mix. You get the nurses that you see them when you've gone to visit and they come in and go, "Oh, your dad's been telling us all about when he was in Brisbane, and these type of things." You know that dad's engaged. I'm not saying that anyone has to tell me anything about my father, but I could tell the nurses that liked dad, and got on with him. But the thing is, it's not about liking. It's just about engaging, and checking everything's right. The other thing, I know you're asking me what it is about them, but I suppose that's the thing I noticed is that dad would say, "That's a

		good nurse," but what usually happened was there is some engagement. I suppose it's taking a sincere interest. But naturally, not everyone ... To some people, maybe it's more a job, and they're tired. They've got families at home. They're not that interested to start up conversations, which I totally get (Bereaved family 9, 57yr female carer for father with malignancy) *Honestly, incompetent could be the only word to describe them, kind of thing. Then others are just so professional, kind of thing. Some of them are just doing their job, and then others are doing their job with a passion and interest, and whatever. So yeah, you can certainly see that. You can certainly see experience and things like that as well, people that are used to dealing with people and whatever. Yeah, some doctors honestly you get the feeling they're just there to rake in the money. Others you feel like they're there to make a difference, kind of thing (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness)* *You make generalizations and there were one or two nurses who were caring. After that night and then they took her down the next afternoon to put another tube in. There was no way I was happy to go home and leave her there, because I thought obviously no one else is gonna keep an eye on her overnight. So I then stayed for a couple of nights…Yeah, I thought neither of us felt confident that she would get proper care. I think we felt confident in the doctors, they seemed to know what they were doing which was*

		encouraging. But I thought that the nursing care, and it's hard to know because there were people there that knew me. The nurses on this ward didn't, but there were other people coming in and out of the place that did know me. So whether me being there affected how much attention they paid, I don't know. If I hadn't had been there would it have been ... I mean I wasn't there that first night and that was really awful (Bereaved family 4, 69yr female carer for friend with malignancy) *I had no reason to feel not confident, because the care in the outpatient was very good. But it was that inpatient admission that was really quite horrible (Bereaved family 4, 69yr female carer for friend with malignancy)* *Let me think. I guess what would've made a lot of difference to my friend's care was people actually checking on her, and doing proper pain assessments and I suppose the general attention to care that seemed not to be a priority. I think that would've made a big difference. It's actually the caring part of it that really stands out for me (Bereaved family 4, 69yr female carer for friend with malignancy)* *There's some staff that you felt, yes, you just knew they were on the ball. The palliative care registrar, I never felt that she was invested fully in mom's care. She was the one who, yes... Maybe that first experience tainted me with my experiences with her, but I just*

		thought that her conduct was a bit unprofessional (Bereaved family 5, 56yr female carer for mother with malignancy) *Certainly felt trust in the nurses and what they told us. I felt trust in the palliative care specialist. She was beautiful. She was really lovely. I didn't feel sort of a lot of, a lot of... Don't know if confidence is the word. I didn't feel aligned to the oncologist. It was a bit like, "Oh, mom's a bit of a name and a number I've only seen a couple of times." She's not going to be on my radar for much longer (Bereaved family 5, 56yr female carer for mother with malignancy)* *A little bit, yes. It did feel like, "Oh, well, we've got her end stage, we did our best. It just didn't quite work out. Ah." Thems the breaks. It was a bit like that. I'm not saying flipant. But it just didn't seem... I suppose the way he didn't acknowledge palliative care could have been done better. It was like, "Oh, well, that's life." It wasn't like, "Oh, yes, we could have done a whole lot better." It was sort of inability to recognize that there's a difference between an outcome and a process. Maybe he's not connected to process enough. That sort of a focus on outcome. It's not totally what healthcare is about (Bereaved family 5, 56yr female carer for mother with malignancy)* *I think that they had time for you. It seemed that things... It wasn't a burden to ask an extra question or two... For someone to come back and say, "Hey, look I thought about this" or "here's a reference to this" or "why don't you try that?" It was sort of just, it could be just*

		even little things. That would help (Bereaved family 5, 56yr female carer for mother with malignancy)
Domain: Maintenance of patient safety and prevention from harm		
• Families did not always feel hospitalization led to improved care outcomes • Sub-optimal care impacts patient safety with the following areas noted to compromise care: poor communication; not using a palliative approach; poor integration of the family into care; poor nursing care; and lack of timely attention • Need for support for families to enable their ability to 'speak up'	• Importance of accurate medication prescription and administration • Managing an error within the electronic record • Pressure injury prevention and management • The need to feel their care is safe and they don't have to continually have full oversight of their care at all times, whilst so unwell • Understaffing contributes to being left without assistance for simple tasks, despite needing this help • Lack of staff time leads to a lack of deeper communication • Pressured staff leads to mechanical and task oriented care • Lack of staff leads to unresponsive care	Confirmatory data – previously only reported by Families so patient data not provided in this section Family data *I don't know. Okay. I'm totally uncertain. I'm honestly, I'm not sure. I mean, I was half and half. Basically, my good result out of it all would be just to get her out as quickly as possible and get her home, but obviously had to be careful of her medical condition (Family 13, 56yr female carer for mother with non-malignant illness)* *I feel like yes, day to day, the nursing practice is fine, she's safe. The thing that I feel is not safe, when she's in hospital, is wanting to keep investigating. From my perspective, three years ago, they said, "You've got an incurable disease, and the process will be that you may have three years of your life left." That's a given, so she's not going to get better. The thing that I feel is not safe is them wanting to go and investigate and find more things wrong and let's treat all of these more things, because at the end of the day, you're not going to change the outcome. You're being more invasive, you're being more traumatic, you're having her in the hospital far*

		more time than she's home, where she's the most comfortable, but then you're not providing stuff that's going to make it comfortable for end of life care yet. And that she's getting close. I feel like yes, on a day to day level she's safe, but overall she's not safe. Does that make sense? (Family 5, 50yr female carer for mother with malignancy) *I'd probably be comfortable with that because you'd hope that it'd be something that would improve what's going on…And sometimes there's two sides to the story. I'm thinking of another stay when she was in Hospital XX, and I can't remember what the nurses had done that wasn't good for mum. I don't know if it was an accident she had going to toilet or something like that. But the initial reaction by my brothers and I was that nurse should be reported, but then somehow the story got to me and it wasn't how ... Mum's perception of how it was isn't always what's really going on. I have had a patient in another bed tell me, "Oh, you're mother was offered to go to the toilet several times. She didn't want to go." And then, of course, she had the accident. She didn't want the bedpan, that sort of thing. So, I thought, "There's always two sides to things." Sometimes you might not have all the information (Family 11, 61yr female carer for mother with malignancy)* *So there is a problem. I was going to make an appointment and see the nursing unit manager about it, but then I thought about it very carefully and I thought, 'No, if I see her, she'll give me all the reasons to say why it can't be done any other way and nothing else*

		will be done about it, I'm going to go further than that.' But as we were getting ready to be transferred to the private, I thought, 'Why bother?' Why bother, it would be quite an effort and, you know, why bother? But then one of the treating specialists said, 'Please do it, you will help us. Write to the CEO, write.' Anyway, I said, 'I'll think about it.' And then the end result was that I didn't do it, because I thought, 'I'm wasting my time.' (Family 12, 78yr female carer for husband with non-malignant illness) *I thought what was quite fascinating, I don't know if you know about it, all hospitals have now got a REACH program, have you heard of the REACH program?..The REACH program is when the family or the patient is not happy with the treatment they're getting, it's how they're going to report. They can ask for help, and they'll get a doctor within half an hour and the senior person within an hour, and it's a good little piece of paper. But what I found fascinating in this particular ward was that the piece of paper was behind the patient on the wall, that the piece of paper was so small that with a magnifying glass you wouldn't see what was written on it…So it was as good as useless, being there, as good as useless (Family 12, 78yr female carer for husband with non-malignant illness)* *Dad's the type of person that avoids conflict or any kind of confrontation. If there's any words that need to be said, he shuts down completely, and he gets quite... But dad, I think because it's been three years of building conversations with the oncologist and the palliative care doctor, because they have fairly regular visits*

		outside of hospital time with both of those two, that dad now feels comfortable enough to ask basic questions. There's no probing questions, and not questions of what happens next. It's just we're here in the now. I think for dad it's the comfort factor that's allowed him to start to ask questions (Family 5, 50yr female carer for mother with malignancy) *Where do I draw the line to be their daughter and support, versus coming in and overstepping clinicians and saying, "I don't think you're doing this right. I think you should be doing this. Or can you explain to me why this hasn't happened this way?" I just feel a little bit like I'm not sure at what point mom and dad are going to think I'm being overbearing, rude, pushy, those kind of things, because they may perceive that it might impact the care that they get. If the staff think, "Oh, their daughter's a pain in the bum, asking too many questions," yeah, I don't want them to be in the position where they feel awkward about the conversations that I have (Family 5, 50yr female carer for mother with malignancy)* *Not at all. Not at all. And I think a lot of people in that age group wouldn't do that either…. Always there's this worry that somebody will mistreat your loved one because you're being a little bit overbearing. And I was just trying to get the balance right there as well (Family 9, 64yr female carer for father with non-malignant illness)*

		Bereaved Family data *Well, one group of people clearly had no idea what they were doing, and they had no respect for anything or anyone. This is going to sound terrible, but their communication skills were abhorrent. Like, they could not, some of them found it difficult to speak English. Like, it was that bad. Speaking in a different language in front of you, and yeah, didn't feel safe. They looked scruffy. When people look scruffy, you go, "Oh, I don't know if I really want you looking after my mother. I don't care where you're from, but look neat." That's a terrible thing to be saying that, but you want your nurse to look like a nurse (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)* *So it was more just I suppose I'd say feeling unsafe is a bit strong word, but I think it's true. We did feel a bit unsafe. Look after that first night if anything goes wrong, what's gonna happen? Is anybody going to notice? Is anybody going to know what to do. That was the sort of things I suppose…you know if anything really goes wrong a) is anyone really going to notice? B) Are they gonna care? And c) are they gonna do anything? Then I suppose the focus was on getting her get out of here asap (Bereaved family 4, 69yr female carer for friend with malignancy)* *I felt a lot of responsibility for my friend's welfare while she was in hospital. Probably more than somebody who wasn't actually on the staff and their job was to look after her. I felt the burden of responsibility that I had to make sure that she was okay, because*

		nobody else was (Bereaved family 4, 69yr female carer for friend with malignancy) *Because I knew in ICU, there was nothing that would escape anybody's eye, and if anything could happen. Whereas up on the ward, I felt like it was dangerous, that something might get missed, because the whole time I was there on guard and making sure that that was done, and why hadn't they done that and could they do that, and where was that. Nobody had been, he was in pain and needed more pain, whatever. That kind of thing. Because I was so worried about him being not abandoned, but basically left ... anything could go wrong kind of thing because you're not being constantly monitored. They must get that all the time. I mean, that must be a common thing. It's either people are never getting out of there or when people are released, people must be really trepidacious about what's going to happen (Bereaved family 7, 56yr female carer for husband with malignancy)* *Things like that are very, very, very common. There's no detail. He's actually read the file, and hasn't picked up that he's had a total laryngectomy. It would have been written, total laryngectomy (Bereaved family 12, 54yr male carer for father with malignancy)* *I know that definitely was the case for my mother-in-law. She felt like she couldn't speak up and say, "Actually, I don't think this is right," or "I don't think you've done this," you know…. she didn't feel like she could actually go and talk to a doctor…I think there's a number of factors to that. That's cultural, there's its, you know, it's*

		generational. So XXX's 65, 66, so comes from the generation of, you know, doctors are right, are always right, you never question them. Also, she's a pretty confident woman but still not very good at challenging men. So you've then got that aspect as well (Bereaved family 11, 33yr female carer for father-in-law with malignancy) *I did. I just knew that you'd get a few looks, but whatever. I don't care (Bereaved family 8, 56yr female carer for mother-in-law with malignancy)* *In the end, from my hassling, they'd left a towel of nappies in there. I felt like you become this sort of ... Like, I was always really polite and nice to them, I assure you, because it was dad's care. Sometimes, that's why dad would go, "No, don't bother them." My mother was the same in hospital. They're of the nature, you don't bother them, because they'll take it out on them. You know what I mean? (Bereaved family 9, 57yr female carer for father with malignancy)* *They just kind of shrink away to a shadow of themselves while they're there. They're frightened of the nurse. Often, especially with the elderly ones, they're frightened of the nurses. They think they're going to get in trouble from them if they question anything or if they do anything, or if you question anything, kind of thing. Which is very sad why they've got this fear of them (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness)*

		I think that if she'd ... part of her not wanting me to come in on any consultations was she was afraid that I would challenge and she was embarrassed. So I think that it was very much for me an example of that which is known, that people don't want to criticize the care they're getting for fear it will compromise that care and that they'll be seen as being difficult or challenging or asking too many questions. And I think that was very much Wife… And my sister is not backward in being forward but she was so vulnerable and so afraid for Patient that she didn't want to do anything that might compromise his care and she perceived giving feedback or being critical may do that (Bereaved family 6, 68yr female carer for brother-in-law with malignancy) *So, sometimes you felt like you were kind of ... it's a really tricky situation, I'm sure everybody says the same of being in that ... on a ward or wherever you are, trying to be as nice as you can to everybody and at the same time, trying to make sure ... try and get certain things to happen to help the situation for Patient X. So, you're always treading with delicate balance of being assertive, but being really nice to everybody, but when you really actually sometimes get completely pissed off with people, and really want to just say, as I eventually did, scream and yell and go what the bloody hell. But, you're all going out of your way to be nice and at one stage, Patient X, when he came back from ICU, and he was getting better, but he wasn't very happy I guess and he was being really quite snappy with some of the nurses and not saying thank you and being a bit abrupt and sort of ordering them around a bit*

		and being ... and I had to say to him, Patient X, you can't do that. If you're like that with people, they'll come and do their job that they have to do, but they're not going to spend a ... it'll be very hard for them to spend an ounce of extra energy on whatever you need when they don't have to. You've got to be nice to people. He always had, so it was very unusual. He was really sick, so ... but I was a bit shocked at how sort of snappy and sharp and short. I mean, I know nurses must be trained to deal with that, but still. In the end, you become that difficult man in the corner. It's not good. You need to be ... and he got it and he did change. He realized what he was doing, he just didn't realize I don't think (Bereaved family 7, 56yr female carer for husband with malignancy) New data Patient data *And also, the hospital constantly gets the medications wrong. That is terrible. I check every tablet I take, and they get it wrong. Then they tell me I don't take this. Then we get into screaming arguments. And then they bring up pharmaceuticals again. They say, "Yes, you do, but they didn't believe you." You know things like that or it's not on the computer, because somebody forgot to put it down. I find that absolutely off the tree. (Patient 10, 82yr female with non-malignant illness)* *…that's the other thing. Emergency department always lose your medication list. (Patient 10, 82yr female with non-malignant illness)*

		I go to hospital sometimes and I take my Webster-pak because its dead easy. You punch out, because I do a Webster-pak at home, I just punch out breakfast, I punch out bedtime. It's done and easy and I get my dosage, right? In hospitals they won't do the Webster-pak. Then we have to pack them into single bottles or whatever else. So then my wife counts, she's very good at maths. So she counts out the tablets. I'm going to be there for six days or five days or whatever else and they bring out my tablets and they haven't given me all my tablets…... I mean I'll still come out alive but, I don't understand it. (Patient 12, 65yr male with non-malignant illness) *Sometimes there was an issue with the medications initially, because I don't know whether it was a fault, that they were confused with the list of drugs that I gave them. But, sometimes some of the drugs weren't listed on the chart... had not been charted by the doctors. So, there was a lot of issues with that. (Patient 7, 59yr male with non-malignant illness)* *And I said, "Well, no, this is wrong. It should be this, this, and such and such, such. So, can you please fix it?" And then, they fixed that one and then there was another incident where there was the Diamicron. I used to take two tablets in the morning, so that controls the blood sugar. One of the drugs that controls blood sugar. And they weren't... they were only giving me one. And of course, my blood sugars were spiking up and I said, "Well, no, it's supposed to be two." So, one of the doctors from the ENT… he came and just asked me to write all the medications down, which I did. And then*

		even after the medications all written down, that I wrote down and handed to him, even some of them were left off and... so, yes it was a bit of a muck up there. (Patient 7, 59yr male with non-malignant illness) *I said, "Yes, but I told you what was prescribed to me and he's across the road. Oh my goodness, all you have to do is go across the road if you have to." And, in fact, then he sent his assistant over to see me and she told him what I was on and still it was very difficult to get the prescription from him. But it's not like they explain to you. They just leave you in the dark. They'll say, "Yeah, today, I'm going to sort it out," and nothing ever happens. (Patient 18, 71yr male with non-malignant illness)* *But now with everything going on computers, if a mistake is there, the mistake stays there. (Patient 11, 72yr female with malignancy)* *She shouldn't have had to spend an hour doing it, because my list was correct, but nobody believed me, because somebody had done it wrong on the computer. (Patient 10, 82yr female with non-malignant illness)* *They were all very, very nice and good at their jobs. Where it lacked is that unless you were always on the ball for your own case, there could be a lot of mistakes because if... and then they are put down on computers, you don't know what is written there so you'll have to constantly be on the ball. But if somebody's very ill, or very tired or*

		uneducated, it's not easy to be on the ball. (Patient 11, 72yr female with malignancy) *A lot of people... like I said, this elderly gentleman that was next to me. He wouldn't have a clue what he was taking. And a lot of other people wouldn't have a clue what they're taking. But, I'm very switched on, so to speak. As to what drugs I have to take, what treatment I require, and so yes. I'm very switched on in that regard (Patient 7, 59yr male with non-malignant illness)* *It's you, it's your pain, you own it. No one else owns it. If you want to get rid of it, well if you want to do something about it, well you can sit there and go, "Poor long suffering me"….. And the conversation still goes on. No one gives a damn. (Patient 12, 65yr male with non-malignant illness)* *You've just got to sort of look after yourself. Which I think you should, but then there's a lot of people who aren't capable of doing that. (Patient 13, 61yr female with non-malignant illness)* *In March this year I fell over and broke my left femur quite badly. When I was in hospital ... two days after I had surgery, it was a sort of a bruise under my left heel which after seven weeks longer in hospital had took away basically my left heel. It was just a bedsore….If I'd been rotated or my ankle would have been elevated or a couple of nurses just sort of stuck the bandage back on even though it was a bit wet ... Which the wound care for that was shocking. I have a wound on my right stump at the moment caused*

		from the same problem…. At the moment, I've got quite a problem to live the best life I can. I need to get rid of both bed ulcers because that does stop me moving around a lot. (Patient 13, 61yr female with non-malignant illness) *And they're treating a lot of people, and there were a lot of sick people there. They're treating those people, and those people are really sick. They need more help than me needing a bloody fork. It's easy to understand that. (Patient 10, 82yr female with non-malignant illness)* *Well, if the nurses weren't in such a hurry. If they had more time. Because you see, it's not just me. If I'm not dying, they're not going to rush to me. Okay, if I feel I can't breathe, and they happen to see it, yes they'll be there. If they can be. But if they've got a guy down the road who is dying, they've got to be there. And very often, it's more than one nurse that has to be there. It's not a one person thing. And there's more than one person who's doing that on the wards. And you have to understand that. (Patient 10, 82yr female with non-malignant illness)* *Whereas when you're in the ward… there's just not enough nurses….They walk in, they give you what they need to know, they give you a tablet and walk straight back out. There's no time to answer a question. You just really feel like a robot. Like a chicken in there in one of those chicken hatches. (Patient 13, 61yr female with non-malignant illness)*

		And also the other thing that I've noticed is certainly understaffed. I was on level 10, that's the both sides north and south, so I had about a couple months here in both units. So I felt that... That just concerned me…their workloads were enormous and I thought to myself, you know... and understaffed, grossly understaffed, grossly understaffed. (Patient 9, 75yr male with non-malignant illness) *Yeah, and also that the staffing levels weren't adequate. The nursing levels, the staff there were brilliant, in my book, and they tried their hearts out, but they didn't have their... They're overworked. Grossly overworked. (Patient 9, 75yr male with non-malignant illness)* *Of course, they're flat out. They're very busy and I know that. I understand that. So, you don't always get attention immediately but I totally respect and understand that because it's usually because they're busy, not because they're ignorant or don't want to do what you ask them. So, it's about lack of staff. That's what it's about and that's a huge problem, and I can see that (Patient 3, 80yr female with non-malignant illness)* Family data *Yes I did. For the most part I did. The lack of safety was, I thought, with medication being prescribed by the urology team, that he didn't need. And Dad had had two episodes of melaena in there, and had a massive drop in hemoglobin. And the team continued the input of*

		some oral aspirin, and I was at home here thinking "Oh, I'm not happy about that." Because, you know, he was transfused, had three units of blood and until I actually brought up the issue, this aspirin's still here, I felt a bit of danger in that regard. Not ultimate danger, but I just thought, "This is not ideal management." (Family 9, 64yr female carer for father with non-malignant illness) *My beef with this last admission, and I can't stop about this beef, was, I was impelled, I felt I had to be there from quarter to eight in the morning until after they'd finished dispensing the medications, because the medication dispensing is such a stuff-up, excuse my language, that they could kill a patient. They could kill a patient, easily…But basically, my concern was from the day go, the way they distribute the medication. I don't blame the nurses, it's the system, and it is horrendous…One nurse looking after five patients, she comes in with her computer and she starts dishing out pills. She dishes out one or two pills and then her buzzer rings or whatever, she runs away, and she comes back half an hour later. She has no idea, she can't remember what she dished out (Family 12, 78yr female carer for husband with non-malignant illness)* *His thyroid went up the hill. Because the thyroid pills are kept in the fridge, there was no fridge in the room which was fair enough, he was a four people room, everything was okay, but I could not get them to get these pills (Family 12, 78yr female carer for husband with non-malignant illness)*

		My bit about the pills was that they were never dished on time, in my last stay. They were never dished on time, I had to forever go chasing for them, and then I thought, 'Well, look, I am really getting paranoid about these pills.' But then I was walking for the bathroom one day, and I saw huge sign in the corridor where he was there, saying that transplant patients are allowed to medicate themselves to ensure they have their medication on time. This has set me off, completely and utterly! If they are allowed to medicate themselves, then there is a problem on the ward about medication and I'm not the only one complaining about it (Family 12, 78yr female carer for husband with non-malignant illness) *I said, 'He's not on Warfarin, why are you coming to give him a test for Warfarin?' She said, 'You don't know what you're talking about, he is on Warfarin.' I said, 'He hasn't been on Warfarin for years. He's on another blood thinner that doesn't require an INR test.' 'No, no, no, no, no, you don't know what you're talking about.' So I said, 'Stop here and then don't give him that test,' I saw the specialist in the corridor, I went running after him and I said to him, 'Have you stopped Xarelto and put him on Warfarin?' He looked at me as if I was totally mad. He said, 'Why would I do that and not tell you?' I said, 'Because that's what he's on.' So that's when he thought that I wasn't all there, he went and looked at the chart, and sure thing, someone at the public changed him from Xarelto to Warfarin. That could have ended up in a disaster (Family 12, 78yr female carer for husband with non-malignant illness)*

		I think that's where I felt that there might have been a few issues, so one issue was that Daughter 2 was given the wrong medication by someone who didn't really understand the medications. And this script had been handwritten, so they didn't see that the milligram dose was 25, they thought it was a 7, so gave 75 milligrams of a medication, which would have been a lethal dose, and if I hadn't been there to stop her, Daughter 2 would have died that night. Those were things that I thought, in these acute care settings where you've got drugs that are dangerous, perhaps it's having a casual pool of people that are really well-grounded in the area that they're going into so that they share the philosophies and are really across the medications and the issues for the patients (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness) Bereaved Family data *The other thing that happened was that she had a pulmonary embolism, was on clexane. And the night before the first chest tube went it, or was it the second one? I can't remember, one of them. The doctor had written on the chart to withhold the clexane, and she knew that. The nurse came on and he came to give her a quick her clexane .And she said, "No the doctor said not to give it I'm having the procedure tomorrow." And he argued with her and said, "no you've got to have it." So because she was sick, and thinking well maybe the doctors been back and changed the orders or*

		something. So she was sort of bullied into allowing her to have it. And then there was the real question the next day about whether the procedure could be done because it was meant to be withheld. And the Registrar said but I wrote on the chart to withhold it, he was quite cross. And I mean they did decide to do it anyway. So there was a general, that I think added to the fact that we didn't really feel safe (Bereaved family 4, 69yr female carer for friend with malignancy) *It's slower, it's not quicker, it's a lot more convenient for the doctors 'cause they can come into the computer without turning any pages, and having a look at what they wanna, but it doesn't make the system better. As far as care for the patient, it doesn't make it better for the patient, it makes it better for the doctor. That's all it does. And the hospital records – there's no paperwork. But as far as the patient goes, it doesn't help the patient (Bereaved family 12, 54yr male carer for father with malignancy)*
Domain: Addressing nutritional needs: Impact of good food, hot drinks, nutrition and supportive kitchen staff		
Nil	• The comfort provided by good food at the right temperature and in line with preferences is notable • Importance of nutrition to aide in wellbeing (including diabetic management) and recovery • The need to maintain weight whilst an inpatient	Patient data *The kitchen at the hospital is one of the most fabulous things. People do not realize what that kitchen does for the hospital. Their food is bloody good. It is. And people think I'm crazy. I put on a lot weight in hospital, because I eat a lot… They always give me bacon, even when it's not on the menu, because they know I*

	• Kind and empathetic kitchen staff make a positive impact on care experience • Assistance with accessing food items on the tray, when unable to manage independently, is valued	*like bacon, so they give it to me. (Patient 10, 82yr female with non-malignant illness)* *Now, morning and afternoon tea…. That is one of the most important things in life. Because what else is there? … They're the important things in life, because that cup of tea, or the cups of tea that you do order and not get, is about all you'll ever get. And that is important, because a lot of people ... I've heard people say in the morning, "I need a cup of tea when I first wake up." Well, you've got about as much luck of getting that as falling through the floor. No way. (Patient 10, 82yr female with non-malignant illness)* *My diet in the hospital is a big drama because I don't eat meat. I have to be on a dialysis diet and a diabetic diet so really getting down to not many very choices on the diet front. The food front. Then at breakfast time you might get a lukewarm cup of supposedly hot water and a tea bag, and I don't drink tea. Then you ask someone, could you have a coffee satchel. By the time they get back with the coffee satchel the hot water's cold. It just sort of ... it's a bad way to start the day…. It's just a shocker. I find that quite depressing actually. (Patient 13, 61yr female with non-malignant illness)* *Both of them were appalled at the food that I was served like minced chicken and stuff that just looked so unappetizing. It didn't matter how many people I told I didn't eat eggs ... "Don't give me egg sandwich or scrambled eggs - routinely they turned up…with diabetes, you have to have supper. What would arrive would be a*

		half an egg sandwich. Now, if I didn't have family to bring me in food, well, what? I can't eat that. Then I'd be hyper. (Patient 13, 61yr female with non-malignant illness) *I'm in a ward where there are 30 patients there, with severe bowel and gut, and stomach issues... And getting served meals that were frozen in June, and handed to you with two days to go until they expire.... It was ridiculous. I couldn't eat any of them. Bloody horrible. And when you're trying to repair a stomach... Try to get a stomach healthy again, being fed shit like that is ridiculous. (Patient 14, 45yr male with malignancy)* *I do not like the food, okay. I need to eat, and I do not want to be thrown on that Sustagen, the whole thing. But the food is not decent. I'm so sorry. It's cold. It's not hot, especially in the morning. You need a hot food really in the morning. It's so cold. (Patient 21, 50yr female with malignancy)* *It really is and it's good homemade stuff. I think over the years that different hospitals have sort of had the same thing all the time. This one here, all the sweets are a different thing. I can't complain about the food here. It's absolutely top class (Patient 22, 75yr female with non-malignant illness)* *Even the hospital food... because I didn't eat for months coming up to it and I lost nearly 30 kilos. And they'd come in and they'd turn around and say "Oh, we'll put you on this diet" and I saw a dietician come in. And then they give me a little menu, a secret little menu*

		with party pies and sausage rolls. Oh, I loved it! I think I put on 10 kilos. Every morning I was having my Weetbix and then at lunchtime it was party pies, and for dinner I was having all this other stuff, and all these people were "Oh, what do you got to eat tonight?" I'd say – oh party pies, It worked out really good. (Patient 1, 48yr male with malignancy) *This is going to sound petty, but that the food I was given was okay... was what I normally eat and what I wanted…it's things I prefer and I don't have much appetite…And, I'm only 55 kilos, so I need to maintain my weight if I can, because you lose a lot of protein and stuff, and I've always been fairly thin. I just need to keep my weight up. But when I'm in hospital, just the smell of food makes me feel nauseated so I have to be really careful with what I'm served (Patient 3, 80yr female with non-malignant illness)* *And it has to be there, and if she's not there, and you're in the bathroom or somewhere else ... I go through hell everyday doing that. And that's another thing, I don't want to have to do. (Patient 10, 82yr female with non-malignant illness)* *And this is why the people that know more about us ... are the people who bring the tea and coffee, morning and afternoon. They know their patients better than the nurses…Because they know what the patients want…And they come in and say, "Oh hello, Patient 10. How are you this morning? Oh, you weren't well this morning?" They know more about the patients than the nurses do, because the nurses are busy doing other things…And they're very*

		good people those people from the kitchen. (Patient 10, 82yr female with non-malignant illness) *even down to the women that come and take your order for your food. I think we forget about those people. Yeah. Like I might've been in the shower and they would come back. It's just those little things that, they come back to take my order. They could have just given me anything. I think we forget about those people, who I think are sort of a key part as well in your psychological….. You know, if you're getting the food that you like….I think we just take it for granted that they're just people who are taking your order and serving your meal, but I think they do a lot more than that. And I think they do have that empathy, and they care and they know that people in hospital that aren't always at their best manners themselves. (Patient 4, 54yr female with malignancy)* *... The nurse stood there and opened the packet so I could.. it says on my plate every time - Needs help with opening packages because of my strokes. Yet, I think one out of every second week, one person would help me. Then you're sitting there trying to open packets with your teeth, which is very undignified. (Patient 13, 61yr female with non-malignant illness)* Family data *I'll give you another example, from one to another one. It annoyed the daylights out of me, but it wasn't important. The dietician's aid*

		came in with a computer and with a menu to ask what you want to eat the next day. He wasn't eating anything, so it really didn't matter. She would come in, and if he had somebody attending to him, or there was a doctor in, she'd turn around and she'd walk away, and she would never come back. This ended up, out of his nine days, for three or four days he had no breakfast at all. No breakfast at all, I would have to go downstairs and buy something for him, to take his medication. The poor cleaner was going beside herself, she said, 'Why do you have to spend the money?'…And this kind of thing happened just about every day, but the breakfast was eventually fixed up, that was all right. But then when she came in to other three, and he was busy with somebody she couldn't talk to him, she would walk away, she would never come back and ask him what he wants. So he would end up with having something to eat, that he wouldn't eat anyway, because she didn't ask him what he wanted to eat. He was only eating soup, and he ended up with getting meat and anything else, you know... It wasn't important, but this was another annoying thing, because he wasn't eating, what if he would have been eating? (Family 12, 78yr female carer for husband with non-malignant illness) *Because even dad, with his menu, just filling out the menu, because there's not always anyone there to do that for him. A lot of people don't have families, like I was able to be there and say, "Well, you want this?" And too many choices, so he could have circled absolutely everything on the menu. And so just little things that sort of could go in knowing that history… because on the menu, there*

		was sandwiches, there was sweets, there was salads. Now, he likes those sorts of things, but sometimes it was a matter of his digestion as well. So when we found out he's got hiatus hernia, we now believe that a lot of what was happening at home was a result of that, that he couldn't swallow some of the food. So if he ordered a casserole and there were chunks of meat, yeah, and I would send it back. If there was a way that you could do that, that there was sort of likes and dislikes, somehow that that was set, because the menus would change. I think they were a week about, so like one week, he might have like a tuna mornay or something like that. But each day, I know that the kitchen staff work with the dietician to provide specific things, but I also wonder how gluten intolerant, diabetics, because sometimes the meals that are brought to them, and if they're an aged person, often it's the swallowing and things like that are the issue (Family 16, 59yr female carer for father with malignancy and non-malignant illness) *So, I would see that if there was some way that they could, and not just have sandwiches and sweets all the time, because dad, he's lost. He's now 62 kilograms. He's gone from a size 36 trousers to 32, and over a period of time, that's been happening now. He hasn't felt like eating, and I think, sometimes, that's the other thing. If they don't feel like eating, what else is available that they could have, and then have things like high protein diet? (Family 16, 59yr female carer for father with malignancy and non-malignant illness)*

		That first admission, they sent him home, because he lives with my sister, and sent home a high protein diet and what we could put in that to build his strength up, because I mean, he sits around a lot. So what could he have that would build his strength up? So, yes, if there was a way to do that, and it was sort of also when the meals that were delivered, so you have the PSAs or the personal services assistants delivering the meals, and they've only got a certain time to eat those meals, and then they come and collect the trays (Family 16, 59yr female carer for father with malignancy and non-malignant illness) *And so if you happen to be a person who takes time with a meal, and dad's quite slow at eating, that was the other thing. I'd get the tray and he'd say, "I'm not finished yet. Don't take it away." But I can leave the sweets and the cup of tea here but take the rest. "But I'm not finished with it yet." So it was across the board, so not just from when the menus were delivered, but through to how you can have that extra time to sort of finish off a meal (Family 16, 59yr female carer for father with malignancy and non-malignant illness)* *Or if you can't get your meal, often they would leave it on the tray instead of putting it in front of the person. If they can't get the meal, they come and collect the tray and the person's not had anything to eat. And that becomes a big problem nutritionally, and yes, so it didn't happen, very fortunately, with dad, it didn't happen, but then again, we were there between both of us. We have two brothers as well, but they don't live in Town X. They moved a long time ago. But*

		I just feel, sometimes, that if a person hasn't got somebody, how do they? We can be there at meal times (Family 16, 59yr female carer for father with malignancy and non-malignant illness) *One of the departments which I thought wasn't good, and I can... this is where I think the system was a problem, was when the dietician came round. Now, if I happened to be there, it was useful, because someone would come along and just say "Lunch is blah" And instead of Dad saying "Well, look I wouldn't eat that" or "I don't like that" or "What else have you got to offer?", he would just say "Yes, yes", and didn't know he had any choice. And it wasn't... but I know how the system runs. And I would say, "Look, Dad would never eat that, is this available?", oh yes, that's fine. Yes that's available. And Dad, in his age group, he wouldn't think that you could actually challenge the system. If someone said, "It's steak and vegetables for lunch," and that's what you're offered, you'd accept steak and vegetables. They would feel, look, you're lucky to have food and that's very important. And didn't realize he had some options, so the effect was all this food would come up, which he couldn't eat. He didn't feel like it, what was inappropriate for him. So just loads of meals wasted. It didn't matter for Dad, because Dad wasn't hungry, but for anyone else that needed the nutrition, it was seriously not good. (Family 9, 64yr female carer for father with non-malignant illness)* *She was so happy about the meals, and being given options. It was good because her condition did not restrict her diet. So she could*

		eat anything she wanted. So, she was quite happy about that (Family 3, 52yr female carer for mother with malignancy) *The different types of food, the hot food is always ... There is a range there but they may not like that kind of stuff, which Patient 15 normally has sandwiches…every time you have something to eat, then not long after they come around with the iPad and see what you want for the next meal… That system is pretty good…If you've got special needs, the special needs person will come around and see what meal you're allowed to have (Family 14, 49yr male carer for wife with malignancy)* Bereaved Family data *because also one of the things that they kept doing was giving if like I wasn't there to order her, especially towards the end to order her dinner, they kept ordering her stuff that she necessarily didn't like, which wasn't their fault because they didn't know what she was eating and what she wasn't eating. She wasn't eating nothing at the end. But that would have been good too. Like if I could've pre-ordered her food in that respect and maybe written it in that book or with her on the iPad and done it for her at my choice of time when I was with her because I would go of a nighttime then my aunty would go the morning time. So, maybe something like that, because that was one of the only other issues we had an issue with was*

		getting her something that she likes to eat (Bereaved family 10, 43yr female carer for mother with malignancy) *If I'm preparing meals for someone in a hospital and I come to this patient and all he's got on his plate is drink, like water and tea, and tea or coffee. I'm thinking, well there's something wrong here, why hasn't this guy got any food? But no, not in the case of my father, they actually gave him the tray with just food, with no food just drink. And when I asked the lady, "Where's the food?" "Oh he didn't order." That's...how can you respond to that?... And this happened at Hospital X constantly, where he couldn't get out of bed to go and get the food because the tray was at the foot of the bed or long...and he can't get up to get it. So his breakfast which was eight in the morning or nine in the morning and I would come at 11 and it's still sitting there, because no one bothered to give it to him (Bereaved family 12, 54yr male carer for father with malignancy)* *If I wasn't there everyday, because I would go everyday. If I didn't go everyday they would bring a tray and then they would come and take it. And that's another thing, the food's there, they would drop off the food, and then the patient might be napping or sleeping, and then fifteen minutes later they come and take them without being touched…And I've caught them a few times I would say, "What are you doing?" "Oh you wanna leave it?" I said, "Yeah you know what I mean, he's sleeping, leave it so he gets up and he can eat it, otherwise he's not gonna eat." "Oh, okay." That's the mentality. The mentality is just do their job. I don't wanna come back and get the*

		tray later, let's just take it now. They're not looking after the patient, they're just doing their job. They're not looking after a patient. Their job is not really about the patient. Their job is just to give them the food. Their job is not to actually look after them, if you know what I mean (Bereaved family 12, 54yr male carer for father with malignancy) *The main issue, and I knew this before we took him. Because I know a lot of people get so malnourished, they've got no energy, and they end up deteriorating to the point where that's where they pass. Because they haven't got the strength. So my main concern, and I knew when I took my father, that I would have to make sure he was well-fed and had all the nutrition that he needed (Bereaved family 12, 54yr male carer for father with malignancy)* *One, we never got a diet after the stent. We never got ... Like he said, "Oh, just keep on ..." What was it? The low ... God, now I can't remember. Low residue. Right? He didn't ... There was some printout somewhere that he'd emailed. I think this was even before the stent, because obviously dad's diet had to change, because he had no way to ... He had something like the size of a pencil, the tumor was so big (Bereaved family 9, 57yr female carer for father with malignancy)* *Food is really important when you're in a hospital, I think (Bereaved family 9, 57yr female carer for father with malignancy)*

		But, Hospital XX was very unsatisfactory actually. The dietician never quite got with the program or he never quite got to see us, so the food he was getting wasn't right and he wasn't eating. So, he wasn't eating enough, he was losing more weight (Bereaved family 7, 56yr female carer for husband with malignancy)
Domain: Comfort provided by easy access to medical and nursing specialists		
Nil	• Easy access to medical specialists provides comfort and reassurance • Access to a nurse specialist is important enabling prompt attention to any noted concerns, answers to questions, time for support and planning, comfort in relation to ongoing support on discharge home, continuity with the patient's care and needs and high levels of expertise	Patient data *Yes. I do have an amazing specialist and he would be there at 7:00 in the morning and 7:00 at night, so I'm very lucky in that I'm looked after and kept right up to date. (Patient 3, 80yr female with non-malignant illness)* *Oh, just a discussion that I've had with doctor X. He said just tell them that if you really need help with trouble just tell them that I said it's a-okay and they will just squeeze you in…but you've got to have that conversation with the specialist. You've got to have all these conversations. (Patient 12, 65yr male with non-malignant illness)* *A nurse specialist. It was the lady who is in charge of transplants…. Absolutely, important. Right, because you get attention I suppose, on your problems, your questions answered in one way, shape, or form. (Patient 12, 65yr male with non-malignant illness)*

		Well, for a start, I spent about two and a half hours with her. And she explained everything and she also said, "look, we can do this." She was just much more engaged. Much more caring. Treating me like a person, not like a unit in a process factory. (Patient 16, 60yr male with non-malignant illness) *Yes because Renal Nurse X will ring me to talk anytime in the day, at least once a week, whatnot and see how I'm going. And then she'll say "Have you been taking your resonium" and whatnot. I say "Yes, yes, I drink that bloody awful stuff, yes". …I've got her card with her mobile number and all. It doesn't matter what time of day or night (Patient 22, 75yr female with non-malignant illness)* *Yes, they were…. because the nurses from the PD clinic, the peritoneal dialysis clinic there, come and see you every day as well. They're so in... across your particular case, because I see them at least monthly. They are like angels. They're just absolutely tops in terms of nurses. So, they would come up daily and they'd always check with the staff on the ward. I don't know that that's so in all chronic disease but certainly renal dialysis at Hospital XX, we are incredibly lucky. (Patient 3, 80yr female with non-malignant illness)* *They are just... That's where you should be doing a study. They are just amazing. I'm blown away by what they do every day. They're the doctors really. Well my doctor says that, "There's no way I could practice renal... I could be a renal physician without these nurses.*

		They're the most important people in my life." (Patient 3, 80yr female with non-malignant illness) Family data *Access to the specialists that she'd probably need to speak to like doctors and specialists (Family 11, 61yr female carer for mother with malignancy)* *This to me, is well beyond. Let's not go any further, right now, Nurse X, the lung nurse that told you about me….She is incredible as to what she does for us…I dare not disturb her, but she is there for me and I know if I had to ring her 10 times a day, she'd be happy for me to do so. I'm not the type of person to do it, I'll only call when I have to. I will not disturb anybody…She does everything. Just being there, on the other line of the phone, is helpful…It's the access, it's her friendliness, it's her treating you as an equal. She comes in as a breath of fresh air. My husband doesn't like any services, my husband has got a thing about it, he does not like all these people coming in and out. Hates it, we really don't access any services, he won't have any services, but Nurse X is a breath of fresh air. She is very knowledgeable, she knows when he's off and when he's not off, and she's so pleasant, I would say that she is probably too nice. Too nice! She asks permission if it's okay to call me. She can call me 24/7, if I can bother her for eight hours a day, she can call me 24/7! But she asks me if it's*

		convenient, we SMS eachother if it's convenient. She's the nicest person, she's very knowledgeable, and she's down-to-earth. She knows what she's doing…And this is the type but look, not everybody has her type of personality, not everybody has the background of her experience. You know, somehow rather in life you have to click with people. Sometimes you take a dislike to somebody, for a reason that you don't know. Some people are nicer than others, that's all….It's a life saver, it's a life saver. It's a life saver because I was only saying to a friend earlier today, all these services are available Monday to Friday, but come Saturday, Sunday, there's nothing, and everything that goes wrong always goes wrong on Saturday, Sunday!..You know, so having access to a nurse like Nurse X is very important. We also have Nurse XX, but we haven't had to access her as much. Nurse XX is the nurse practitioner for cardio…She's also very nice, she's also very nice. These people that come, they're really very nice…Yes, oh no, multiple, multiple. These days everybody seems to be happy with SMS…That's the fastest, but there is email, absolutely. And there are people that are - they're making themselves accessible.I'm old-fashioned, to me you work 9-5 and you don't bother anybody at 5:10. I'm a hospital trained person! Like a puppy dog, you know! You do the right thing. And they talk to each other, which is very important, and they also have access to the specialist, which is very important. I mean, now that we've got all this help, we don't access to the specialists so easily any more, but the specialists have come up in the world, they've got more hospitals and more patients to

		attend to, and all of that (Family 12, 78yr female carer for husband with non-malignant illness) *She was placed under the care of just ... Cardiologist is just outstanding, they're all outstanding. Cardiologist 2 is amazing-amazing. And then a nurse, a clinical nurse specialist, was also overseeing Daughter 2's care, Clinical Nurse Specialist X, and she ... I actually put her name forward for nurse of the year because she was amazing. She would come in on her days off. You know, people don't see necessarily what ... I suppose ... Excuse me. (became teary) (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness)* *As patients and their families, we see things differently, we see the team from a different perspective, and we experience such overwhelming kindness in some people that it just changes the way that you see the world, and it's really life-changing. And so Clinical Nurse Specialist X, who was just such a great clinician but also ... She just went so far above and beyond her call of duty in a sense, in that she would come in every day. She was coming in every day to check on Daughter 2, and her ... I don't know. Her dedication to her job, her competence and the way that she just enabled us to all feel so comfortable because she was onto everything. If there was any little thing, she was across it straight away, not in an overbearing way, in the most appropriate and life-giving way.*

		(Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness) *It didn't matter if it was the meals, if it was just the physio. You know, it didn't matter what aspect of her care, she was across it. And if there were any concerns, we felt that she was the person that would advocate or would notice things that were perhaps not quite right. And if there was anything that Daughter 2 needed, she would tell the team and then she would go back home for her day off. You know, that's the level of care. It was just phenomenal (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness)* *Yeah, from dispensing the Keytruda, which is given for 30 minutes, so everything is explained. So, you are never in the dark, and questions are answered. People made themselves available. Nurses gave me their email addresses, their numbers. So, I'm able to reach them, or I'm able to thank them. I'm able to update them (Family 3, 52yr female carer for mother with malignancy)* *... so I can't be at the hospital all day every day, so I miss all of those important conversations, so it's good I suppose that I have had Breast cancer nurse's number to call her and find out what's going on, but I haven't been there when mom may have gotten information or yeah, I only know what Breast cancer nurse's telling me, I don't know what's actually going on (Family 6, 30yr female carer for mother with malignancy)*

		She's so friendly and she's informative. I've got her mobile number and if I phone her at any point, I know that she'll tell me exactly what's going to be done. She takes the time… At the slightest thing, you don't want to call an ambulance. You just want a little more information. Most doctors turn their phones off, which that's understandable. But you just need a point of contact. You don't want to spend 10 minutes on the phone to hospital XXX. Or any hospital. You've got to go through press this number or push that number. You just need to speak to somebody ASAP and if you've got a mobile number, that's going to be answered…Peace of mind. Yeah (Family 14, 49yr male carer for wife with malignancy) Bereaved Family data *Whereas, when dad had the colostomy, those stoma nurses were amazing. Like, they were amazing. They would come and see dad every day. Dad really liked them. He wanted to go for a run to Hospital XX to do the outpatient thing with the stoma nurse. He really liked them. They were really positive. Nurses, they're fantastic (Bereaved family 9, 57yr female carer for father with malignancy)*

Appendix 11: Joint display tables for Research Question 1

Research question 1: What are the domains of care that are most important to inpatients with palliative care needs and their families?

Domain: Effective communication and shared decision making				
Systematic Review (Study 1a)[1]	**Meta-synthesis (Study 1b)[2]**	**Semi-structured interviews (Study 2)[3]**	**Data convergence**	**Meta- inference**
Patient and carer data • Honest communication • Ability to prepare for life's end • Ensuring availability of someone to listen • Being aware of what to expect about physical condition • Appropriate treatment and tests • Not being placed on life support with little hope for recovery • Having the opportunity to nominate their preferred decision maker • Honest and clear information to enable a shared understanding • Need for layman's language • Communication delivered with compassion	***Patient and carer data*** • Honest and clear information to enable a shared understanding, noting the need for layman's language and communication delivered with compassion • Adequate information throughout a hospitalisation, inclusive of family members, to support decision making, decrease stress and prevent surprises	***Patient and carer data*** • Compassionate communication that was honest, clear and used layman's language • Active listening • Adequate information provision • Engaging both patients and families in care planning • Being fully present and focused on the patient's current situation • Connecting with the patient • Acknowledging and tapping into the patient's own knowledge in relation to their health condition • Adequate information throughout a hospital admission to assist decision making and development of	Confirmed and enhanced understanding achieved.	Effective communication and shared decision making are key for optimal palliative care in the hospital setting and include the following elements: 1. Communication that is honest, clear, uses layman's language, demonstrates understanding of the current situation and is delivered in a compassionate, connected and mindful way (including sitting at eye level and near to the person) 2. Communication that enables a shared understanding and feels unpressured by time 3. Communication that works with a patient's/ family's own knowledge and expertise about their condition and ensures hearing impairments are managed effectively 4. Listening to the patient and family member and using this information to guide clinical assessments and care planning, especially in relation to symptoms, being mindful of the fact patients and family

• Adequate information throughout a hospitalization, inclusive of family members, to support decision-making, decrease stress and prevent surprises • To be engaged in care planning, inclusive of advance care planning, to remove the burden for decisions from family members		trust and confidence in the team • Depth of information from their health care team • Time and compassion from the doctors leading their care • Consistency of messaging and accurate documentation across teams and departments • Availability of a team member to pull complex information together • To be positive and maintain hope within the context of living with a serious illness • Cross-cultural awareness to prevent misunderstanding and negativity		members might want to meet separately with clinicians at times 5. Communication that maintains positivity and hope within the context of their illness 6. Communication that focuses on the bigger picture in relation to their care, not just the immediate day to day issues 7. Accurate documentation of communications held with patients, families and across teams and departments 8. Difficult conversations should be led by a senior clinician and held directly with patients, as appropriate 9. Acknowledgment and support for the requirements within cross cultural communication to prevent misunderstanding and negativity across patient, family and clinician groups 10. Regular updates throughout an admission about the patient's current condition and plan of care 11. Consistent messages across teams and departments with a lead clinician to pull complex information together and a key contact who can address any noted concerns 12. Clinicians should explain what is likely to happen with the patient's physical condition over time, to enable planning 13. When the patient is close to death, clinicians should be explicit about the fact the patient may die within the next few days/a week to enable important conversations and preparations as much as possible 14. When the patient is close to death, clinicians should check with family members about whether they are wanting explicit information about the physical changes that
Patient only additions: Nil	***Patient only additions:*** • to be engaged in care planning, inclusive of advance care planning, to remove the burden for decisions from family members	***Patient only additions:*** Nil		

				occur as a patient nears death (e.g., breathing and circulatory changes) 15. To be engaged in care planning and supported in making decisions in line with personal needs to be able to live as well as possible 16. Discussion of patient choices with family members should be supported informally or more formally through advance care planning processes, advance care directives, and nomination of preferred decision makers
Carer only additions: • Availability of medical staff to talk to as required • Opportunity to participate in a family conference to review the patient's illness • Having a sense of control over their loved one's care • To receive straightforward information about prognosis, tests, treatments and future options for care	***Carer only additions:*** • Having the necessary information as end-of-life decision making is affected by medical complexity, emotional and financial factors • Discussions with medical teams • Availability of a family meeting	***Carer only additions:*** • Opportunities for patients and families to speak separately with clinicians • Asking directly about patients' preferences • Being mindful of patients with cognitive impairments when providing information to them without a carer present • When a patient is close to dying, clinicians to be explicit about likely prognosis and for practical information about physical changes one may expect		

Domain: Expert care				
Systematic Review **(Study 1a)[1]**	**Meta-synthesis** **(Study 1b)[2]**	**Semi-structured interviews** **(Study 2)[3]**	**Data convergence**	**Meta- inference**
Patient and Carer data: *Physical care* • Being kept clean *Symptom management* • Symptom relief • Effective pain management *Integrated care* • Effective discharge planning • Clinicians being knowledgeable about the specific condition of the patient	***Patient and Carer data:*** *Physical care* • Good nursing care including maintaining hygiene *Symptom management* • Regular, person centred pain assessment and management • Rapid response when analgesia is required *Integrated care* • Staff working as a team	***Patient and Carer data:*** *Physical care* • Providing physical care in a compassionate, empathetic and willing way • Responsiveness is critical *Symptom management* • Effective symptom management including accurate assessment and responsive attention • Prompt, individualised assessment and management of pain and breathlessness *Integrated care* • Handing over complex care needs between shifts to enable good care and prevent continual repeating of needs by patients • Clinicians being knowledgeable about their specific condition • Clinicians working as a team between and across departments	Confirmed and enhanced understanding achieved.	Expertise in care is critical for an optimal palliative care experience in the hospital setting and is focused around four areas: physical care; symptom management; integrated care; and technical competence. Key elements to enable optimal care in relation to expertise include: 1. Excellence in physical care 2. That the clinician is knowledgeable about their specific health care needs within the context of their broader health issues, enabling them to accurately assess the current situation and related care requirements to achieve a good clinical outcome (not being focused purely on one component of care or one organ system only) 3. That the clinical team pays attention to a person's holistic health care needs, inclusive of their physical, social, emotional and spiritual wellbeing 4. Identification of when a patient is in their last days of life and ensuring their comfort

		- Effective discharge planning *Other* - Access to technical competence (Eg. cannulation) - Working with senior staff given complexity of needs		5. Regular assessment and rapid management of any symptoms causing discomfort or distress, especially in relation to pain and breathlessness 6. Responsive attention to any forms of distress identified for a patient who is imminently dying, with medication orders available for nursing staff to act immediately (not have to wait for medical review) 7. To see that clinicians are working together in relation to the patient's care, both within the ward environment and across different teams and/or departments and also with primary care providers or lead clinicians from other hospitals 8. To ensure their complex care needs are accurately handed over in depth between shifts to enable good care and prevent continual repeating of needs by patients, and where possible to roster the same nurse to a patient to support continuity in care 9. To enable access to multidisciplinary expertise to help patients be as well as they can be, with specific noting of the need for increased access to physiotherapy support, and a key clinician to support people with dementia, whilst in hospital 10. Efficient discharge planning and management with specific noting of timely provision of paperwork, accurate medication management with this information also provided for the GP, physical supports such as a
Patient only additions: *Physical care* - Receiving good care when family members were not present *Integrated care* - Clinicians working together as a team in relation to their care	***Patient only additions:*** *Physical care* - Maintaining independence *Symptom management* - Clinician demonstrating they cared about a patient's symptoms - Sufficient pain assessment and management for a person with a known opioid dependency - Management of vomiting - Management of restless legs *Integrated care* - Teamwork enabling safer care and better outcomes	***Patient only additions:*** *Physical care* - Informing patients if a delay in care will occur *Symptom management* - Effective communication in relation to symptom assessment and management - Clinicians being mindful of clarity of message with symptom management, as multiple drug names can be confusing for this population of patients who are unwell and may have some cognitive effects from illness or related pharmacology - For patients to understand that asking for medication, assists the clinical team to understand analgesic requirements - To explore why patients may be reluctant to take analgesia and the impact of		

		their prior life experience with opioids • Manage breathlessness in the hospital setting with difficulty noted when fans, fresh air or cooling may not be easy to access *Integrated care* • Being able to access advice from departments outside of their admitted location • Availability of medical history and care plan within the Emergency Department		wheelchair and/or wardsperson to assist with getting to the car and integration to primary care supports as required 11. Effective integration with specialist palliative care services both in relation to when they are consulted, how their service is described to families (to enable understanding of their expertise and role) and how their advice is integrated into care planning 12. That the clinician is an expert in procedures such as cannulation (insertion and care) or management of a pleural effusion 13. Ability to discuss and appropriately deactivate an implanted cardiac device in a timely way 14. Access to senior medical and nursing clinicians with high levels of expertise (email / mobile phone numbers) enabling prompt attention to any noted concerns, answers to questions, time for support and planning, comfort in relation to ongoing support on discharge home and continuity of care
Carer only additions: *Physical care* • How well nurses cared for their loved one *Symptom management* • Management of agitation • Regular, person-centred pain assessment and management • Enabling a rapid response when analgesia is required *Integrated care* • Ensuring the deceased died in the right place	***Carer only additions:*** *Physical care* • Ability to manage specialist nursing requirements *Symptom management* • Rapid and effective management of breathlessness *Integrated care* • Provision of care to the whole person physically, emotionally and/or spiritually • Clarity about physician in charge	***Carer only additions:*** *Physical care* • Sufficient nursing levels to enable adequate physical care, noting a willingness to assist under clinical guidance *Symptom management* • Use of critical thinking to ensure a comprehensive and accurate assessment and management plan • Efficient hospital processes for rapid medication provision • Integration of non-pharmacological care to relieve distress		

	• Multidisciplinary care that included social worker and pastoral care input	*Integrated care* • Timely integration with specialist palliative care providers *Other* • Access to competent care of an implantable device		

Domain: Respectful and compassionate care				
Systematic Review (Study 1a)[1]	**Meta-synthesis (Study 1b)[2]**	**Semi-structured interviews (Study 2)[3]**	**Data convergence**	**Meta- inference**
Patient and Carer data: • Preservation of dignity • Clinicians being respectful • Clinicians being compassionate and supportive	***Patient and Carer data:*** • Treated with compassion, respect and with a focus on dignity • Staff anticipating needs • Staff being responsive	***Patient and Carer data:*** • Feeling welcomed • Treated with care, respect and dignity • Clinicians anticipating patient/family needs • Being responsive • Demonstrating cheerfulness and care • Clinicians being compassionate and supportive • Respectful and compassionate tone of communication • Clinicians to connect with each patient • Simple acts of care and kindness • Friendliness, a nice manner and common courtesy • Being treated as a human being • Clinicians being empathetic, honest and trustworthy • Clinicians and ancillary staff being friendly with a	Confirmed and enhanced understanding achieved.	A respectful and compassionate approach to care is critical to an optimal experience in hospital for people with palliative care needs, and their families. Key elements of care that assist in this include: 1. Clinicians who provide care in a compassionate, empathetic, personalised, kind, friendly, supportive and willing way, who are professional and appear happy to be at work 2. Clinicians who are honest and trustworthy, who are knowledgeable, can anticipate needs and are confident, efficient, attentive, responsive and mindful in their care delivery 3. Clinicians who connected to their particular situation and circumstances, were unhurried, non-judgmental and acknowledged them as a unique human being 4. Preservation of dignity described in relation to physical care, consideration of quality of life, and through the tone of communication used (particularly noting the need for use of names and not terms such as 'darling', and not talking down to the patient or family member)

		nice manner and showing common courtesy • Being cared for by someone who appears happy to be at work • Care being less mechanical and more compassionate		5. Feeling welcomed and deserving of a hospital admission, and where they may have experienced multiple admissions, to be acknowledged by clinicians and ancillary staff, assisting a feeling of homeliness 6. Kind and empathetic kitchen staff and diet aides who return to talk with patients about dietary choices if they are not available on their first visit (asleep, at a procedure, in the bathroom etc) 7. Gentleness and kindness from ancillary staff, particularly noting the impact of cleaners, catering staff and those working in hospital cafes 8. Checking in with family members when their loved one is dying (prognosis of days only), even when there are no clinical tasks to be completed, to show kindness, support and care and to understand if they have any concerns at this time 9. Talking with patients when unconscious and after death, in relation to their care provision
Patient only additions:	***Patient only additions:*** • Feeling welcomed and deserving of a hospital admission • Staff demonstrating cheerfulness and care	***Patient only additions:*** • Minimising patients' feeling powerless		
Carer only additions: • Doctors taking a personal interest in their loved one Presence of family • Ability to have physical touch	***Carer only additions:*** • Clinicians that are helpful, empathic, affectionate, appreciative, comforting, gentle, considerate and capable • Individualised care valuing the patient and their family	***Carer only additions:*** • Respectful care that is not judgmental or stigmatising		

Domain: Trust and confidence in clinicians				
Systematic Review **(Study 1a)**[1]	**Meta-synthesis** **(Study 1b)**[2]	**Semi-structured interviews** **(Study 2)**[3]	**Data convergence**	**Meta- inference**
No specific additional detail provided.	Not stated within data set.	***Patient and Carer data:*** • Communication that builds trust and confidence and does not feel defensive • Clinicians being attentive, responsive and mindful in their care delivery • Achieving a good clinical outcome (feeling better), feeling safe and that everything that could be done was being done • A confident, competent and efficient clinician • A strong, caring, compassionate and professional approach to care	Confirmed and enhanced understanding achieved.	Trust and confidence is noted quantitatively as important for patients with palliative care needs, and their families. However, when integrated with qualitative data, this concept remains important as an outcome from care but not as an element of care provision. Therefore, the approaches to care enabling trust and confidence in the clinical team are important, and primarily link to effective communication, respectful and compassionate care and competent clinical care but this aspect remaining a domain of importance is not required.
		Carer only additions:		

		- Importance of a team that as a collective enable required care		
Domain: Family involvement in care provision				
Systematic Review **(Study 1a)[1]**	**Meta-synthesis** **(Study 1b)[2]**	**Semi-structured interviews** **(Study 2)[3]**	**Data convergence**	**Meta- inference**
Patient and Carer data: Not evident from quantitative data.	***Patient and Carer data:***	***Patient and Carer data:*** • Company and family connection provide comfort and emotional healing • To be respected and welcomed as partners in care • Family role in assisting understanding of information provision; • Hospital staff and processes to be supportive of family involvement through enabling access for visits at any time, comfort when staying overnight (to enable rest) and more explicit guidance in relation to timing of medical ward rounds.	Confirmed and enhanced understanding achieved.	Family involvement in care provision was not ranked highly in quantitative data but, when mixed with qualitative data, is confirmed as an important element for optimal hospital based palliative care. Data integration across both qualitative datasets enabled an understanding of the following elements of importance with specific reference to care throughout a hospital admission and at the time of and immediately after a loved one's death: 1. Family inclusion to advocate for optimal care and help patients understand complex information provision given they are so unwell and their cognition can be affected by illness or various medications 2. Family inclusion to provide comfort, emotional healing and ongoing sharing as part of a long-term partnership 3. More supportive hospital processes to enable family members to fully participate including:
Patient only additions:	***Patient only additions:*** • Company and family connection, including family support, is indispensable in providing comfort and emotional healing	***Patient only additions:*** • Involvement of a partner enables the ongoing sharing as part of a long-term partnership		

Carer only additions:	***Carer only additions:*** • To be recognised and respected for their expertise as ‘carer’ and welcomed as a partner in care • To be involved both in care provision and care planning • To value their role as patient advocates	***Carer only additions:*** • Clear process for communicating with a senior member of the team, to enable regular updates about the care plan, required • After a person’s death on the ward not to feel rushed to leave and for timely, accurate death certificate completion • Need for information about what happens after a person’s death in relation to death certification and removal of the body • Follow up contact from a clinician who had been connected to their loved one’s care to check in with them and offer information about additional supports		• understanding the timing of medical ward rounds (to prevent having to sit all day waiting) • supporting them to be part of the team, respecting their knowledge of their loved one’s care needs (enhancing patient safety) and inviting them to participate in care if they are wanting to • enabling access for visits at any time • comfort when staying overnight (to enable rest) and consideration of the carer’s wellbeing 4. A clear process for communicating with a senior member of the healthcare team, in charge of the care plan 5. Opportunity for a family conference to guide care planning at complex points of care 6. Explicit information and guidance, on admission about: • how to best manage parking costs • availability of Wi-Fi • supported accommodation options for those who are from rural locations • access to carer’s payments • access to subsidies for clinical equipment required for transition home (E.g. Incontinence pads) 7. Supportive care and processes at the time of a patient’s death (respectful care of the body; not feeling rushed; timely and accurate death certification completion) 8. Supportive information provision (verbal and written) about processes of care (death certification, removal of body)

				9. A follow up contact (call or email), conducted in a compassionate and kind manner, by a clinician connected to their loved one’s care to check in with the family and provide information about options for counselling or other supports (with routine bereavement letters from a separate service noted to be less supportive and feeling somewhat tokenistic)

Domain: Adequate environment for care				
Systematic Review (Study 1a)[1]	**Meta-synthesis (Study 1b)[2]**	**Semi-structured interviews (Study 2)[3]**	**Data convergence**	**Meta- inference**
Patient and Carer data: No specific additional detail provided.	***Patient and Carer data:*** Data presented came either from a patient or a carer only, as presented below.	***Patient and Carer data:*** • Restful environment that was quiet and enabled sleep to aide recovery • Being thoughtful of room lighting • Cleanliness, specifically in relation to infection control • Access to a window to enable a connection to the day/night cycle, feel connected to the world, to feel warmth from sunlight and to prevent feeling claustrophobic within their environment • Ensuring a comfortable temperature • Being in a shared room for company and helpfulness of fellow patients • Being in a private room to avoid being disturbed by noise, having to tolerate different smells/odours and feeling quite confronted by other people's illnesses • Not having frequent bed changes	Confirmed and enhanced understanding achieved.	Initial understanding about the elements of importance in relation to an inpatient with palliative care needs and their family was unclear from quantitative data. However, such elements were more clearly described within qualitative datasets and when integrated, the domain of environment being important, is confirmed and it is clear that there are three key areas of consideration in relation to this domain: 1) Structural factors – patient focused (Eg. bed area, window access, shared rooms); 2) Structural factors – family focused (comfort, privacy and access to food / drinks); and 3) Cleanliness to support infection control. Integrated data provides the following elements for consideration: 1. That the bed area is restful to enable sleep and recovery including the need for quiet, appropriate lighting and temperature

	Patient only additions: • Concept of space was personal in relation to private and shared rooms • Positive impact of community-based hospitals in preference to tertiary hospitals, which was attributed to a nicer atmosphere, feeling closer to home, more accessible parking and an increased feeling of safety	***Patient only additions:*** • Ensuring adequate ventilation (particularly for people with breathlessness), particularly in the bathroom to assist with ability to shower • More practical audio-visual control for the TV (not to be handheld) • Emergency access to toiletries for unplanned admissions • Enabling comfort when in the Emergency department • Managing infection risks, especially for those who are immunosuppressed		2. Access to a window to enable a connection to the day/night cycle, to feel connected to the world, to feel warmth from sunlight and to prevent feeling claustrophobic within their environment 3. Prevention of frequent bed changes as patients try to develop a sense of belonging within their space and feel disorientated when moved regularly (the loss of personal items when moved was also noted) 4. To consider comfort when waiting in the emergency department given patients are so unwell through the provision of a bed to wait in (rather than a chair only) 5. To consider practical supports such as emergency access to toiletries for unplanned admissions and more practical audio-visual controls for the TV (not to be handheld if possible) 6. Consideration of supports for people with breathlessness, including the provision of fans, cooling air and adequate ventilation in bathrooms specifically to assist with showering 7. To consider the implications of a shared room with positives noted in relation to the company and helpfulness of fellow patients but challenges noted in relation to being disturbed by noise, having to tolerate different smells/odours, feeling quite confronted by other people's illnesses, discomfort with mixed gender wards and lack of privacy for both care and important conversations 8. Access to seating and preferably a place to lie at night for carers, alongside the patient's bed, as well as simple kitchen items (water, ice, microwave) 9. A dedicated space or room to enable private conversations to be held, a break
	Carer only additions: • Organisational characteristics including hospital rules and processes need to make sense and shouldn't detract from optimal patient care • Environmental characteristics including the need for privacy, cleanliness and quiet. • Space for cultural practices such as congregating family members, chanting or other	***Carer only additions:*** • Discomfort with mixed gender wards • Shared rooms limit ability for privacy and important conversations • Private room required when someone was imminently dying • Dedicated space for carers to enable comfort, rest and private conversations • Access to nutritious and affordable meals		

	important rituals is also important			from caring or for quality family time away from the bedspace (inclusive of the patient) 10. Access to affordable meals onsite for carers (a suggestion of subsidised hospital cafeteria access for this population of people) 11. A private room for someone who is very close to dying to enable privacy for meaningful conversations and space for families to be present 12. Cleanliness, specifically in relation to infection control and managing the unique requirements of those who are immunosuppressed in a timely and efficient way

Domain: Financial affairs				
Systematic Review (Study 1a)[1]	**Meta-synthesis (Study 1b)[2]**	**Semi-structured interviews (Study 2)[3]**	**Data convergence**	**Meta- inference**
Patient and Carer data: Data pertaining to this domain was noted by carers only	***Patient and Carer data:*** Data presented came either from a patient or a carer only, as presented below.	***Patient and Carer data:*** • Supportive health system in Australia where a lot of healthcare is provided at little or no cost • Improved processes and supports required in relation to hospital parking costs, supported accommodation for those requiring this, access to carer's payments and subsidies for relevant clinical equipment required to enable transition home	Unclear	Data integration across studies showed the fact this specific area of care is closely tied to the access (or not) to universal health care. Therefore, the need to understand elements of importance for patients and carers in Australia was identified. The outcome from such data showed financial affairs as a stand-alone domain of importance in Australia was not required. However, the need for proactive information about broader financial supports

				was confirmed and from the Australian context, was notably linked to supporting family involvement in care provision. This is noted within the domain for family involvement in care provision in relation to: Explicit information and guidance, on admission about: • how to best manage parking costs • availability of Wi-Fi • supported accommodation options for those who are from rural locations • access to carer's payments • access to subsidies for clinical equipment required for transition home (E.g. Incontinence pads)
	Patient only additions: • Concern about hospital and living expenses for family members, given a lengthy hospitalization	***Patient only additions:***		
Carer only additions: • Impact of a patient's illness on finances • Having financial affairs in order	***Carer only additions:*** • Proactively supporting patients and families with information about financial supports to enhance comfort and decrease stress	***Carer only additions:***		

Domain: Maintenance of sense of self / self-identity				
Systematic Review (Study 1a)[1]	**Meta-synthesis (Study 1b)**[2]	**Semi-structured interviews (Study 2)**[3]	**Data convergence**	**Meta- inference**
Patient and Carer data: This domain was not evident from quantitative data.	***Patient and Carer data:*** Data presented came only from patients as presented below.	***Patient and Carer data:*** Data presented came only from patients as presented below.	Confirmed and enhanced understanding achieved.	Quantitative data did not inform an understanding of the importance of this domain. However, once patients were spoken to, their need to maintain their role, meaning and identity was strongly confirmed. Of note, this domain was purely informed by patient data. Following data integration across qualitative data sets the resulting elements of importance were described: • To be supported and encouraged to maintain independence and live as well as they can, within the context of illness, minimising feelings of being powerless and burdensome • To isolate illness from life and engage in meaningful activity on a day to day basis to assist wellbeing, even whilst in hospital, suggesting the following would assist them in this: Access to reading materials (papers/magazines) or puzzles/games, access to information about what is available across the hospital and encouragement for patients to get out of bed and engage in an activity • To feel a sense of control and avoid becoming institutionalised noting the importance of access to technology to
	Patient only additions: • Profound impact of a terminal illness • The need to maintain independence • The need to live well • The need to maintain a focus on work	***Patient only additions:*** • To maintain wellness, within the context of their illness • To isolate their illness from their full life – not to become their diagnosis • Physiotherapy to help patients be as well as they can be • To support their sense of self and connections with others, enabling a sense of control and avoiding becoming institutionalized • To enable access to technology to support social connections • To support making decisions about their care, in line with their personal needs to be able to live as well as possible		

		• To take control of their daily routine with a focus on physical activity and doing tasks they are able to do • Being acknowledged within the hospital, when they have experienced multiple admissions, likening this to feeling in a more homely environment • Access to beauty treatments for those who require it • To engage in meaningful activity on a day to day basis to assist in their wellbeing; • Access to reading materials (papers/magazines) or puzzles/games, access to information about what is available across the hospital and encouragement for patients to get out of bed and engage in an activity • Humour • Support gained from own spiritual beliefs		support social connections, to beauty treatments for those who require it (waxing and hair for example) and the need to maintain a focus on work where able
	Carer only additions: Nil	***Carer only additions:*** Nil		

Domain: Minimising burden				
Systematic Review **(Study 1a)**[1]	**Meta-synthesis** **(Study 1b)**[2]	**Semi-structured interviews** **(Study 2)**[3]	**Data convergence**	**Meta- inference**
Patient only additions: • Ensuring one is not a physical or emotional burden	Not evident from qualitative data in this study.	***Patient only additions:*** • Noted feelings of being burdensome on family members or friends but did not describe needing to minimise this per se • Focus on limiting time required to care by actively trying to delineate between 'carer' time and time being husband and wife	Unclear	It is possible minimising burden remains an area of importance, however data integration in relation to this remains unclear. Qualitative data suggests assisting patients with maintenance of independence and enabling supportive care packages may be important for quality care experiences. The elements of care most likely to support this aspect of burden sit within the domain noted as maintaining sense of self / self-identity.

Domain: Maintenance of patient safety and prevention of harm				
Systematic Review (Study 1a)[1]	**Meta-synthesis (Study 1b)**[2]	**Semi-structured interviews (Study 2)**[3]	**Data convergence**	**Meta- inference**
Not evident from quantitative data	***Patient and Carer data:***	***Patient and Carer data:*** • Need to feel their care is safe and well managed without needing continual oversight, given they are so unwell • Clinical team being knowledgeable about specific health care needs within the context of their broader health issues (not focused purely on one component of care / organ) • Medication management was discussed by participants with a focus on accuracy in prescription and administration, with particular concerns noted in relation to: translation of complex medication regimes in the home setting to the hospital setting (and vice versa), accuracy in timing of administration and managing an error in the computer system once entered • Understaffing adversely affects optimal care through lack of assistance with	Confirmed and enhanced understanding achieved.	Data integration enables the patient voice to be added to this dataset. Their views resonate strongly with those of carers. However, increased understanding of two keys areas informing optimal hospital based palliative care emerged from data integration with these being the need for: • Care to be safe and well managed without them needing to continually have oversight of the care (including risks of over-investigation and/or overtreatment), given the patient is so unwell • Accuracy in medication prescription and administration, with particular noting of translation of complex medication regimes in the home setting to the hospital setting (and vice versa), accuracy in timing of administration and managing an error in the computer system once entered

		simple tasks, shallow communication, care that feels mechanical, task orientated and not responsive to needs • Difficult to speak up when unhappy about care due to concerns about repercussions		
		Patient only additions: • Lack of pressure injury prevention impacts living as well as possible		
	Carer only additions: • Hospitalisation did not always provide improved care compared with the care they provided at home • Sub-optimal care impacts adversely on patient safety affecting care outcomes and leading to patient harm. Patient safety at the end-of-life was perceived to have been compromised by: poor communication; not considering a palliative approach; not considering a patient's unique care needs; families not feeling aware of how to best support the patient; poor nursing care and lack of timely attention • Support to 'speak up' about care to ensure patient	***Carer only additions:*** • Complexity felt in advocating for their loved one without upsetting staff and being seen as a 'difficult' family member		

	safety without repercussions			
Domain: Preparation for death				
Systematic Review **(Study 1a)[1]**	**Meta-synthesis** **(Study 1b)[2]**	**Semi-structured interviews** **(Study 2)[3]**	**Data convergence**	**Meta- inference**
Not evident from quantitative data	***Carer only additions:*** • Being prepared for the patient's death to ensure they were able to say goodbye and to assist with their bereavement	***Carer only additions:*** • Being prepared for the patient's death to ensure they were able to say goodbye and to assist with their bereavement • Clinicians being explicit about prognosis when a patient is imminently dying • Clinicians checking with family members about whether they are wanting explicit information about physical changes as a person nears death	Confirmed	Data integration confirmed the importance of carers feeling well informed about a person's impending death so as to enable the opportunity to have important conversations and be as prepared as possible. However, on analysis, this was related to effective communication and therefore does not need to remain as a stand-alone domain of importance.

Domain: Duty of care extending to the family after patient death				
Systematic Review (Study 1a)[1]	**Meta-synthesis (Study 1b)**[2]	**Semi-structured interviews (Study 2)**[3]	**Data convergence**	**Meta- inference**
Not evident from quantitative data	***Carer only additions:*** • Family members to be followed up after a patients' ICU death to prevent them feeling disconnected and rushed away from the hospital at such a profound time	***Carer only additions:*** • Respectful care of the body after death • Not feeling rushed to leave the ward • Timely, accurate death certificate completion • Need for information about what happens after a person's death in relation to death certification and removal of the body • Follow up contact from a clinician who had been connected to their loved one's care to check in with them and offer information about additional supports. The provision of a bereavement letter from a service separate to those connected to their care felt less supportive and somewhat tokenistic	Confirmed and enhanced understanding achieved.	Data integration confirmed the earlier understanding about carers not wanting to feel rushed away from the ward at the time of death. However, analysis is extended with specific reference to the care of a person at the time and immediately following their death. This is confirmed as important but does not require a stand-alone domain and has been integrated with family involvement in care provision and elements of care needed in relation to this.

Domain: Enabling patient choice at the end-of-life				
Systematic Review (Study 1a)[1]	**Meta-synthesis (Study 1b)[2]**	**Semi-structured interviews (Study 2)[3]**	**Data convergence**	**Meta- inference**
Not evident from quantitative data	***Carer only additions:*** • Need to follow established Advance Care Directives • Need for legalised euthanasia for critically ill patients	***Carer only additions:*** • Need to ask directly about patients' preferences	Unclear	There was not much data overall in relation to this domain and so integration remains unclear. Therefore, the need for this to remain as a stand-alone domain of importance is currently disputed and further research is needed.

Domain: Nutrition				
Systematic Review (Study 1a)[1]	**Meta-synthesis (Study 1b)[2]**	**Semi-structured interviews (Study 2)[3]**	**Data convergence**	**Meta- inference**
Not evident from quantitative data	Not evident from qualitative data in this study	***Patient and Carer data:*** • Provision of good food at the right temperature and in line with preferences • Adequate nutrition to aide in wellbeing (including diabetic management) and recovery • Maintaining weight whilst an inpatient • Kind and empathetic kitchen staff making a positive impact on care experience • Assistance with accessing food items on the tray, when unable to manage independently	Unclear	The data in relation to nutrition is a new finding from Study 3 only. However, the indication is strong within this dataset and so this will remain integrated across elements of importance noted from this full research project. Aspects of support in relation to nutrition are twofold and relate to both respectful and compassionate care and excellence in physical care: 1. Kind and empathetic kitchen staff and diet aides who return to talk with patients about dietary choices if they are not available on their first visit (asleep, at a procedure, in the bathroom etc) 2. Provision of good food at the right temperature, in line with preferences, that aides in wellbeing and a sense of comfort (E.g. A hot cup of tea or coffee in the morning) as well as timely assistance with accessing food items on the tray, when unable to manage independently 3. Attention to the patient’s nutrition to maintain weight throughout an admission and assist in management of chronic conditions (Eg. Diabetes) and overall recovery/wellbeing

Domain: Access to senior clinicians				
Systematic Review (Study 1a)[1]	**Meta-synthesis (Study 1b)[2]**	**Semi-structured interviews (Study 2)[3]**	**Data convergence**	**Meta- inference**
Not evident from quantitative data	Not evident from qualitative data in this study	***Patient and Carer data:*** • Easy access to medical specialists enabling comfort and reassurance • Access to a nurse specialist enabling prompt attention to any noted concerns, answers to questions, time for support and planning, comfort in relation to ongoing support on discharge home, continuity with the patient's care and needs and high levels of expertise	Unclear	Data pertaining to access to senior clinicians did not surface until Study 3. However, the indication for this was clear from this qualitative data set and so this element of care is noted in response to this research question investigating what elements of care are important for people with palliative care needs in the hospital setting and noted as: 1. Access to senior medical and nursing clinicians with high levels of expertise (email / mobile phone numbers) enabling prompt attention to any noted concerns, answers to questions, time for support and planning, comfort in relation to ongoing support on discharge home and continuity of care

References

1. Virdun C, Luckett T, Davidson PM, et al. Dying in the hospital setting: A systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. *Palliative Medicine* 2015; 29: 774-796.

2. Virdun C, Luckett T, Lorenz K, et al. Dying in the hospital setting: A meta-synthesis identifying the elements of end-of-life care that patients and their families describe as being important. *Palliative Medicine* 2016; 31: 587-601.

3. Virdun C, Luckett L, Davidson P, et al. Hospital patients' perspectives on what is essential to enable optimal palliative care: a qualitative study. *Palliative Medicine* 2020; Submitted for review Feb 27, 2020.

Appendix 12: Key points of importance for optimal palliative care in the hospital setting from the perspectives of inpatients (combining datasets from systematic reviews [Studies 1a and 1b][1, 2] and Study 2[3])

Domain: Effective communication and shared decision making	Key points noted within the systematic review (Study 1a) and meta-synthesis (Study 1b) work: 'SR points'	23. Honest communication; 24. Ability to prepare for life's end; 25. Ensuring availability of someone to listen; 26. Being aware of what to expect about physical condition; 27. Appropriate treatment and tests; 28. Not being placed on life support with little hope for recovery; 29. Having the opportunity to nominate their preferred decision maker; 30. Honest and clear information to enable a shared understanding; 31. Need for layman's language; 32. Communication delivered with compassion; 33. Adequate information throughout a hospitalization, inclusive of family members, to support decision-making, decrease stress and prevent surprises; 34. To be engaged in care planning, inclusive of advance care planning, to remove the burden for decisions from family members
	Additional points noted from Study 2: 'New points'	35. Communication that is mindful at time of discussion 36. To connect with and listen to the patient 37. To link into the patient's own knowledge and expertise relating to their condition 38. To maintain positivity and hope within the context of their illness 39. To be well informed across an admission building trust and assurance 40. Increased depth of information provided from medical team 41. Consistency of messaging across teams and departments 42. Accurate documentation 43. Availability of a lead clinician to pull complex information together 44. To acknowledge and support the requirements for cross cultural communication to prevent misunderstanding and negativity across patient and staff population groups
Domain: Expert care (good physical care, symptom management and integrated care) **Physical care, Symptom management, Integrated care, Other**	SR points	Physical care 45. Being kept clean 46. Receiving good care when family members were not present 47. Maintaining hygiene 48. Maintaining independence Symptom management 49. Symptom relief 50. Regular, person-centred pain assessment and management 51. Enabling a rapid response when analgesia is required 52. Effective pain management 53. Clinicians demonstrating they cared about a patient's symptoms 54. Sufficient pain assessment and management for a person with a known opioid dependency 55. Management of vomiting 56. Management of restless legs Integrated care 57. Effective discharge planning 58. Clinicians need to be knowledgeable about the specific condition of the patient 59. Clinicians working together as a team in relation to their care 60. Staff working as a team
	New points	Physical care 61. Providing physical care in a compassionate, empathetic and willing way

		62. Informing patients if a delay in care will occur Symptom management 63. Effective communication in relation to symptom assessment and management 64. Staff being mindful of clarity of message with symptom management, as multiple drug names can be confusing for this population of patients who are unwell and may have some cognitive effects from illness or related pharmacology 65. For patients to understand that asking for medication, assists the clinical team to understand analgesic requirements 66. To explore why patients may be reluctant to take analgesia and the impact of their prior life experience with opioids 67. Need for managing breathlessness in the acute care setting and the difficulty in managing this when fans, fresh air or cooling may not be easy to access Integrated care 68. Handing over complex care needs between shifts to enable good care and prevent continual repeating of needs by patients 69. Clinicians working as a team between and across departments 70. Being able to access advice from departments outside of their admitted location 71. Availability of medical history and care plan within the Emergency Department Other: 72. An expert to insert an intravenous cannula 73. Appropriate management of intravenous cannula 74. An expert to drain pleural effusions 75. Working with senior staff given complexity of needs 76. Managing issues with rotational intern programs in rural and remote setting for this population 77. To accurately assess a person with palliative care need's current situation and related requirements 78. Clinical competence of the nursing staff 79. Timely response to requests for care, especially for people with breathlessness
Domain: Adequate environment for care	SR points	
	New points	80. Restful environment that was quiet and enabled sleep to aide recovery; 81. Being thoughtful of room lighting; 82. Cleanliness, specifically in relation to infection control; 83. Ensuring adequate ventilation (particularly for people with breathlessness), particularly in the bathroom to assist with ability to shower; 84. Access to a window to enable a connection to the day/night cycle, feel connected to the world, to feel warmth from sunlight and to prevent feeling claustrophobic within their environment; 85. Ensuring a comfortable temperature; 86. Being in a shared room for company and helpfulness of fellow patients; 87. Being in a private room to avoid being disturbed by noise, having to tolerate different smells/odours and feeling quite confronted by other people's illnesses; 88. Not having frequent bed changes; 89. Enabling comfort when in the Emergency department 90. Managing infection risks, especially for those who are immunosupressed 91. More practical audio-visual control for the TV (not to be handheld); 92. Emergency access to toiletries for unplanned admissions;
Domain: Family involvement in care provision	SR points	93. Company and family connection, including family support, is indispensable in providing comfort and emotional healing

	New points	94. Family in assisting understanding of information provision; 95. Involvement of a partner in information provision so as to enable the ongoing sharing as part of a longterm partnership; 96. Hospital staff and processes to be supportive of family involvement through enabling access for visits at any time, comfort when staying overnight (to enable rest) and also more explicit guidance in relation to timing of medical ward rounds.
Domain: Financial affairs	SR points	97. Concern about hospital and living expenses for family members, given a lengthy hospitalization
	New points	98. Increased information about broader supports that may be available to assist a person living with a chronic and complex illness; 99. Information provision about supported parking options; 100. Consideration and support for those living in a remote location where care is required in a metropolitan centre;
Domain: Maintenance of sense of self / self-identity	SR points	101. Profound impact of a terminal illness 102. The need to maintain independence 103. The need to live well 104. The need to maintain a focus on work
	New points	105. To maintain wellness, within the context of their illness 106. To isolate their illness from their full life – not to become their diagnosis 107. Physiotherapy to help patients be as well as they can be 108. To support their sense of self and connections with others, enabling a sense of control and avoiding becoming institutionalized 109. To enable access to technology to support social connections 110. To support making decisions about their care, in line with their personal needs to be able to live as well as possible 111. To take control of their daily routine with a focus on physical activity and doing tasks they are able to do 112. Being acknowledged within the hospital, when they have experienced multiple admissions, likening this to feeling in a more homely environment 113. Access to beauty treatments for those who require it 114. To engage in meaningful activity on a day to day basis to assist in their wellbeing; 115. Access to reading materials (papers/magazines) or puzzles/games, access to information about what is available across the hospital and encouragement for patients to get out of bed and engage in an activity 116. Humour 117. Support gained from own spiritual beliefs
Domain: Minimising burden	SR points	118. Ensuring one is not a physical or emotional burden for family members
	New points	
Domain: Respectful and compassionate care	SR points	119. Preservation of dignity 120. Clinicians being compassionate 121. Clinicians being supportive 122. Feeling welcomed and deserving of a hospital admission 123. Treated with care, respect and with a focus on dignity 124. Staff anticipating needs 125. Staff being responsive 126. Staff demonstrating cheerfulness and care
	New points	127. Treatment provision being equal amongst all patients 128. Respectful and compassionate tone of communication 129. Connecting with the patient and not talking about personal aspects of social life 130. Being treated as a human being 131. Clinicians being empathetic, supportive, honest and trustworthy

		132. Staff being friendly with a nice manner and showing common courtesy 133. Ensuring a patient is comfortable before leaving the room 134. Being cared for by someone who appears happy to be at work 135. Care being less mechanical and more compassionate 136. Minimising patients' feeling powerless
Domain: Trust and confidence in clinicians	SR points	
	New points	137. Communication that builds trust and confidence including the way a clinician talks to a patient, honest and understandable information provision and ensuring a patient is fully informed about their care 138. Clinicians being attentive, responsive and mindful in their care delivery 139. Achieving a good clinical outcome (feeling better) 140. A confident, competent and efficient clinician 141. A strong, caring, compassionate and professional approach to care
Domain: Maintenance of patient safety and prevention from harm	SR points	
	New points	142. Accurate medication prescription and administration 143. Managing an error within the electronic record 144. Pressure injury prevention and management 145. The need to feel care is safe and patient's don't have to have continual oversight of their care at all times, whilst so unwell 146. Adequate staffing to enable required care and assistance in a responsive way, opportunity for deeper communication and less task-oriented care provision
Domain: Addressing nutritional needs	SR points	
	New points	147. Provision of good food at the right temperature and in line with preferences 148. Adequate nutrition to aide in wellbeing (including diabetic management) and recovery 149. Maintaining weight whilst an inpatient 150. Kind and empathetic kitchen staff making a positive impact on care experience 151. Assistance with accessing food items on the tray, when unable to manage independently
Domain: Comfort provided by easy access to medical and nursing specialists	SR points	
	New points	152. Easy access to medical specialists enabling comfort and reassurance 153. Access to a nurse specialist enabling prompt attention to any noted concerns, answers to questions, time for support and planning, comfort in relation to ongoing support on discharge home, continuity with the patient's care and needs and high levels of expertise

Note – highlighted points have been described in earlier published work but were not confirmed within Study 2.

References

1. Virdun C, Luckett T, Davidson PM, et al. Dying in the hospital setting: A systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. *Palliative Medicine* 2015; 29: 774-796.

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Appendix 13: Country vignettes (n= 15) - An overview of what is occurring in relation to national approaches to quality measurement of palliative care

United Kingdom:

England

A comprehensive strategy for quality end-of-life care across England was first released in 2008[1] and since this time England has continued to progress the sophistication of what they are able to provide in relation to end-of-life care. The Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020[2] identifies ‘evidence and information’ as one of eight of the foundations fundamental to making progress on the ambitions. This is now the policy framework for palliative and end of life care in England, so data and intelligence continue to receive prominence. However, England’s ability to measure the quality of end-of-life care, across all care settings, at a national level is limited (Wee 2016, pers. comm.,13 Dec). Currently, ‘measurement’ at national level revolves around death registration data, allowing monitoring of the proportion of people who die at home, in care homes, in hospices and in hospitals. It is recognised that this does not represent ‘quality’ but is data that is routinely available and was the focus when the first national strategy was published in 2008.[1] Wee (2016, pers. comm.,13 Dec) confirmed discussions are now underway to shift this focus to start looking at indicators that are more likely to measure, and drive improvements, in quality of end of life care. Wee (2016, pers. comm.,13 Dec) outlined there is an exploration of indicators such as proportion of time spent out of hospital in the last 3-6 months of life, number of people who have 3 or more emergency admissions to hospital in the last 3 months of life and others yet to be determined. All such work is yet to be checked for validity and reliability. Barriers to this work include the lack of a national data collection system and legal and regulatory constraints following the Health and Social Care Act 2012.[3]

Recent changes to the hospital regulation system in England have seen end-of-life care added as a ‘core service’.[4] Regulation relies on local data submission to the inspection team (including patient experience data) and an inspection visit at which time all areas noted as ‘core’ are specifically reviewed. Inspections of core services are supported by guidance written by experts with the end-of-life guidance focusing predominately on structural and process indicators of quality.[5] This has enabled a national spotlight on end-of-life care provision within acute hospitals as evidenced in a recent publication outlining the state of care in English hospitals.[6] Importantly, NHS England has committed to a further five years of their national care of dying people in hospitals audit (Wee 2017, pers.comm., 4 Mar). The last national audit included an organisational review of structures, policies and processes as well as an audit of the medical records of all adults who died within a specified time period, based on the five Priorities for Care of the Dying Person as outlined in a 2014 report - One chance to get it right: Improving people’s experience of care in the last few days and hours of life.[7] Although a voluntary program, 97% of acute hospitals participated in that audit which reported in 2016 (Wee 2017, pers.comm., 4 Mar) thereby providing comparative opportunities for quality of end-of-life hospital care across England.

Furthermore, a national palliative care clinical data set for specialist palliative care services was published in late 2016 with a focus on outcome data and the ability to describe the complexity of a service's casemix.[8] Outcome data measures are based on the integrated palliative care outcome scale (IPos)[9] with examples including: Has pain affected you / Has the patient been affected by pain - over the past 3 days?; Have you had / has the patient had as much information as s/he wanted - over the past 3 days (inpatient) or 1 week (community-based)?. At this time, the implementation of such data collection and analysis is voluntary with a recent pilot study confirming the data set as both useful and acceptable to service providers.[8] At local service levels, a range of quality indicators are used to drive improvements, with these predominantly focusing on processes of service delivery. For example, it may include the proportion of people who have advance care plans or DNACPR decisions documented (Wee 2016, pers. comm.,13 Dec).

Policy frameworks and national quality standards[1, 2, 10-14] clearly support the need to measure the impact of service delivery and quality of end-of-life care. In addition to policy guidance, the National End of Life Care Intelligence Network team is preparing an Atlas of Variation for End of Life Care, scheduled to be published in 2017 (Wee 2016, pers. comm.,13 Dec). This will enable comparisons across Clinical Commissioning Groups (of which there are 211 across England) across over 20 variables being finalised at present. Most of the data obtained to inform this work is linked with death registration data.

England has a depth of understanding of the needs for measuring quality to drive system-wide improvements in relation to end-of-life care and is currently working on this area closely. There is clear recognition of the need to do this within both generalist and specialist palliative care sectors. However, they are currently hindered by a complex health system that does not have a universal data collection method (aside from the death registration data).

Expert contributor:

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Scotland

In 2014, legislation was passed in Scotland to integrate health and social care services. These services are now managed locally by newly established Integrated Joint Boards who are responsible for commissioning all palliative care services (Meade 2017, pers. comm.,22 March). In line with this, health and social care outcomes have been written with an accompanying set of integration indicators.[15] Two of these indicators have direct relevance for end-of-life care: Proportion of last 6 months of life spent at home or in community setting; Expenditure on end of life care. This work is currently under review, awaiting finalisation. In response to this work, three charities who work within end-of-life care provision in Scotland (Hospice UK, Marie Curie and Sue Ryder) have proposed an additional measure focusing on anticipatory care planning.[16] It is hoped this additional measure would add depth to the understanding of the experience of care for patients and families and thereby afford a greater insight into the quality of care provided and also provide additional information about access to palliative care. The proposed indicator is accessible from current data recording systems and is written with both main and sub-indicator measures: Main- Of those who died in the last year, upon death how many had an anticipatory care plan such as a KIS (Key Information Summary); 1. Length of time KIS held prior to death, 2. Primary diagnosis, as recorded on KIS and 3. How many times was KIS accessed/updated in last year (including in acute and out of hospital settings).[16]

In addition to the above, the Scottish government has recently released a national framework for action on palliative and end-of-life care for 2016-2021.[17] This document notes the fact that it is not currently possible to describe the availability and quality of current end-of-life care services across Scotland and that this makes it difficult to focus improvement efforts or service developments accordingly. Furthermore, this framework articulates the need to develop quality indicators that can be embedded into routine clinical processes and practices and that they must align with existing performance and health frameworks to inform improvement actions at a national level. They note the need to use such data to inform service design, delivery, monitoring, quality improvement and benchmarking. A focus on data that captures people's 'experience' of care is noted. In accordance with this framework, the Scottish Partnership for Palliative Care (SPPC) has proposed the introduction of a single, system-wide national survey of bereaved informal carers as an indicator to allow a level of quality of care for those terminally ill and end of life to be measured.[18]

Expert contributor:

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Marie Curie

United Kingdom:

Wales

The Welsh government have shown considerable focus on palliative and end-of life care with three significant reports guiding current practice: 1) The Sugar Report (2009);[19] 2) Together for Health - Delivering End of Life Care. A Delivery Plan up to 2016 for NHS Wales and its Partners;[20] 3) Palliative and End of Life Care Delivery Plan (2017).[21] The current plan outlines the measurement focus being to develop patient reported quality outcome measures as a priority with a focus on symptom management, evaluation of specialist palliative care service access and delivery and family evaluation of care received. In addition to these patient and family reported measures, a focus will also be provided on data within GP palliative care registers, availability of advance care plans and the proportion of patients who are cared for in their stated place of preference. The plan provides key themes for care with each theme noting a delivery aspiration, key priorities for action and assurance measures. Systems to enable the collection and analysis of data to inform the priority areas lies at each service level (mainly at Trust level, which refers to an overarching governance structure over several smaller services). Overall a threefold approach to data collection and reporting is noted: 1) a peer review process for specialist palliative care services; 2) review of data available within information systems and 3) health board reports.

Expert contributor:

Veronica Snow

Lead Professional

South West Wales Cancer Network

United Kingdom:

Northern Ireland

A comprehensive five year strategy for palliative and end-of-life care for Northern Ireland, ‘Living Matters;Dying Matters (LMDM)’, was released in 2010.[22] This strategy included an action plan with 25 recommendations, noting quality outcomes and possible data sources for use to track implementation and opportunities for ongoing improvements. A Regional Implementation Board was established to take forward the implementation of the strategy across Northern Ireland and report regularly to the Department of Health on progress against its recommendations (Dawson 2017, pers.comm., 12 May). Implementation of this strategy was also supported by the Transforming Your Palliative and End of Life Care programme (2013 – 2015).[23] An independent review of the implementation of the LMDM strategy[22] noted considerable progress facilitated by both strong leadership and evident partnership working (Dawson 2017, pers.comm., 12 May). Although quality indicators are not noted specifically within the strategy, mechanisms for data collection such as local registers and availability of population needs data are documented. The LMDM strategy[22] has been confirmed as appropriate for current working and has been framed within a new programme, Palliative Care in Partnership (Dawson 2017, pers.comm., 12 May). A revised action plan has been developed and governance structures to oversee implementation are in place via a Regional Palliative Care Programme Board (Northern Ireland level) and Palliative Care Locality Boards (at local commissioning group level) (Dawson 2017, pers.comm., 12 May).

Expert contributor:

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Primary Care Directorate

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Sweden

Email communication with Axelsson (2016, pers. comm., 21 Nov) confirmed the infrastructure to enable national data collection and analysis for end-of-life care, the Swedish Registry of Palliative Care, was established in Sweden in 2005. Since 2011, two thirds of all deaths in Sweden have been entered into this system, irrespective of location of death. 30 data items are collected by professional staff from the patient's medical record complemented by their own caring experience and entered accordingly. These 30 items include questions such as: How long before death did the person lose the ability to express his/her will and take part in decisions concerning the content of medical care?; Do the medical records include a documented decision by the physician responsible to shift treatment/care to end-of-life care?; Did the person receive information about imminent death, i.e. an individually tailored and informed conversation with a physician that is documented in the medical records about being in the final stage of life and about care being focused on quality of life and symptom relief?; Was the place of death in line with the person's last stated wishes? Data analysis and reporting is available via the Government's health website (www.palliative.se) in real time.

Axelsson (2016, pers. comm., 21 Nov) outlined further progression in quality measurement for end-of-life care in Sweden occurred in 2012 when the National Board of Health and Welfare published national guidelines for optimal end-of-life care[24] and specified nine quality indicators. Eight of these indicators are provided by the Swedish Registry of Palliative Care. The nine quality indicators are listed in Appendix 3.

Rigorous analysis of the data contained within the Swedish Registry of Palliative Care has occurred with the research team noting improvements in symptom management, prescription of 'as required' key medications, increasing the proportion of patients dying in their preferred location and an increase in bereavement visits offered to the nominated next of kin.[25]

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Australia

Australia has strong policy support at both national[26] and state / territory levels[27-33] (excepting Tasmania and Northern Territory who do not have current policies in place) for quality provision of end-of-life care, regardless of setting of care. Most policies outline the need for a continuous quality improvement approach to end-of-life care service design, delivery and management but this is not mandated for either specialist or generalist service providers. Indicators for use are not provided.

Australia has two significant national quality improvement programmes available for specialist palliative care service providers, supported by national funding. Neither are mandated for use but both are referenced within many State/Territory plans and are therefore strongly encouraged. Firstly, the Palliative Care Outcome Collaboration (PCOC)[34] was established in 2005 with the aim of embedding standardised clinical assessment tools and point of care data collection into daily clinical practice to both inform care planning and provision as well as quality review and improvements. Data are routinely collected, analysed and systematically fed back to services through regular reporting. Reporting enables individual services to review their practice over time (individual service data) as well as providing systems level data through benchmarking results. PCOC also provides support in running quality improvement initiatives for services at local, regional and national levels – using point of care, patient recorded data to drive improvements across the sector.[35] 115 specialist palliative care services (approximately 85% of inpatient units and 65% of community services) participate in PCOC with several additional services working towards participation (Clapham 2017, pers. comm., 14 Feb). PCOC has developed 20 benchmarks, listed in Appendix 3, and runs national benchmarking workshops to support collaborative improvement opportunities.

Secondly, the National Standards Assessment Program (NSAP) was piloted in 2008 and implemented nationally from 2009 focusing on processes of service delivery and governance. NSAP maps specialist palliative care service performance against the National Palliative Care Standards[36] to achieve the overall goal of improving patient care.[36, 37] NSAP is administered by Palliative Care Australia (PCA), who provide online and telephone resources, audit tools, and data entry and reporting support to participating services. In addition, PCA prepares an annual report and provides information about opportunities for system-level improvement.[38] There are 188 specialist palliative care services registered for NSAP with representation across all Australian states and territories. Services complete a self-assessment every 2-3 years followed by focusing on their identified key areas for improvement. 311 self-assessment cycles have been completed with some services now commencing their 5th cycle of improvement work (Palliative Care Australia 2017, pers. comm. 6 Mar).

Significant work is also underway by the Australian Commission on Safety and Quality in Health Care in relation to quality end-of-life care within the hospital setting.[39-43] This work aims to support the delivery of safe and high-quality end-of-life care by generalist care providers caring for people at the end-of-life who are in hospital. One of the key mechanisms for doing this is through the National Safety and Quality Health Service (NSQHS) Standards.[44] Since 2013 all public and private hospitals need to be assessed against the NSQHS Standards when they are accredited. The first edition of the NSQHS Standards did not have an explicit focus on end-of-life care, although some items about advance care planning were included.[44] Following this a specific paper was written focusing on the safety and quality of end-of-life care in acute hospitals[40] and a consensus statement for recommended practice released.[41] The second edition of the NSQHS Standards[39] will be released in late 2017 with a notable increase in quality items referring to optimal end-of-life care. Therefore, once implemented within the NSQHS Standards, a mandatory review of the quality of end-of-life hospital care will be required for generalist providers, and this new focus will also support mandatory data collection and analysis for hospital end-of-life care. Acknowledging the complexity of measuring such care, the Commission has recently released a rapid review of the literature to inform development of indicators and is currently examining how these can be further developed to support safety and quality improvement for end-of-life care in hospitals.[43]

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New Zealand

New Zealand has a strong focus on outcome measurement in health as outlined in their recently released national health strategy,[45] accompanying roadmap for change[46] and healthy ageing strategy.[47] The importance of measurement of quality end-of-life care is also noted in an earlier (2001) palliative care strategy.[48] However, the focus of such measurement in relation to end-of-life care is predominantly on specialist palliative care services rather than all providers working within end-of-life care. Another important report released in 2012 is ‘Measuring What Matters’,[49] providing health care providers with a framework for the development of quality measurement for end-of-life care based within an improvement theory, ‘managing for outcomes’. This theory provides an approach to planning service delivery in line with clear expectations and goals at both intermediate and long-term levels. Linking outcomes with key attributes of service delivery, this approach ensures careful thought about measurement and evaluation from the outset to drive ongoing service developments, improvements and to determine value for investment. Indicators are not provided within any papers or strategies to date, however; a national conversation was held on February 17, 2017, to progress such work (Grundy, 2016, pers. comm,. 14 Feb). Of note, New Zealand has a national indicator database for health called ‘Health Quality Measures New Zealand’. Currently this database does not include any indicators for end-of-life care and predominantly focuses on information from linked datasets. However, this system is about to consider an indicator about Advance Care Planning and possibly provides a useful infrastructure for wider end-of-life care measurement (Grundy, 2016, pers. comm,. 1 Nov).

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France

France has official indicators to measure the provision of palliative care and the accessibility of specialised palliative care services. These indicators were developed by the Department of Health in 2008, and are collected nationally every 2 years (Morin, 2016, pers. comm,. 19 Nov). To date, there are no national indicators to measure the quality of end-of-life care nor any national policy to support such work although recent meetings have been held to progress such work (De La Tour, 2016, pers. comm,. 16 Nov). However, there are mandated criteria used routinely as part of hospital accreditation focused specifically on the 'care and rights of people at the end of life' (criterion 13a)[50] delivered in a safe manner. Developed and implemented by the National Health Authority and governed by national laws, this criterion asks services to be accredited against the areas shown below (translated with assistance from Silove, 2017, pers.comm., Feb 15): Haute Autorite de sante [50], p60-61.

E1	E2	E3
Anticipate	Implement	Evaluate and Improve
An organisation enabling evaluation and management of the needs of the patients at the end of their lives.	Care projects for patients and their families are established and implemented. Professionals concerned benefit from multidisciplinary and multi-professional palliative care training. In relevant sectors, multidisciplinary meetings are put into place to discuss patients.	A multi-professional evaluation is carried out on the treatment of patients at end of life, together with relevant bodies (ethics committee or equivalent, user relationship committee, medical commission, treatment commission, etc.).

	In relevant sectors measures to support health caregivers are put in place especially in crisis situations.	
Methods for collecting information on the wishes of the patient and, if applicable, storing instructions of advance directives, are defined.	The healthcare players involved are notified of the legal provisions regarding patient rights and end of life.	The areas of activity that are most involved begin the process of analysing situations in which there is unreasonable insistence to treat, and of establishing ways of limiting or stopping these treatments.
Adult patients receive written information about their right to agree to or refuse treatment to maintain life or resuscitation treatment, and about their right to draw up advance instructions.	The action of support associations and their volunteers is facilitated.	An improvement action plan is implemented.

In addition to this specific end-of-life care standard, there are also standards focusing on patient needs and pain management, both with clear relevance to optimal end-of-life care. Therefore, national hospital accreditation is inclusive of end-of-life care. However, specific national indicators to assist service providers to measure quality in line with these accreditation requirements are not currently available.

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Canada

Canada notes the need for measurement of end-of-life care to ensure quality of service provision in key strategy documents, but does not have national indicators for use.[51-53] Provincial governments and local quality initiatives are evident but these mostly focus on specialist palliative care provision.[53] A national initiative that ended in 2014, ‘The Way Forward: A roadmap for an integrated palliative approach to care',[54] commenced early thinking and work in relation to quality measurement and released a national framework for integrating a palliative approach to care, that is now being utilized in many provinces (Baxter, 2017, pers. comm,. 21 Feb). However, actual indicators are not stipulated or mandated at this point.[54]

In 2002 and then updated in 2010, Canada published national palliative care norms of practice.[52] Measures to accompany this document or an implementation strategy to align with this work, are not evident. However, most specialist palliative care programs are based on the national norms of practice (Baxter, 2017, pers. comm,. 21 Feb). More recently another document has been published by the Canadian Cancer Society[53] focusing on specialist palliative care and outlines the need for change, inclusive of the need for national standards and measurement. Nationally, end-of-life care is devolved to provincial/territorial implementation and discussion at this level about development of quality indicators is underway in some of these regions (Baxter, 2016, pers. comm,. 16 Dec).

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Belgium

Belgium does not have a national policy for end-of-life care but has legislated the right to palliative care at the end-of-life for all patients, irrespective of care setting in 2002. There is also a legal obligation that every hospital has a palliative support team. There is no current policy on quality monitoring within palliative care (Menten, 2016, pers. comm,. 21 Nov). However, significant research in the Flemish region has been completed in this area by an international research team with a focus on quality measurement of specialist palliative care services.[55] As a result, a comprehensive national quality indicator set for specialised palliative care is available, developed through a consensus process with professionals. Currently 39 palliative care teams in Flanders (31% of all Flemish teams) are using the indicators for quality monitoring and improvement (Leemans, 2016, pers. comm,. 22 Nov). Services use the indicators and accompanying questionnaires to measure the quality of their care (through the perspective of patients, family members and professional caregivers) and a research team provides personalised feedback reports with team level data in addition to mean scores of other teams working within a similar structure (Leemans, 2016, pers. comm,. 22 Nov). The final minimal indicator set for palliative care consists of 5 indicators about the physical aspects of care; 6 about the psychosocial aspects of care; 13 about information, communication, and care planning; 5 about type of care; and 2 about continuity of care (31 measures in total – 14 process indicators and 17 outcome indicators). Appendix 3 outlines these indicators. In addition to this, quality indicator sets have been developed for different disease trajectories focusing on structures and processes of care. An additional quality indicator set was developed for aged care settings and within this set, two indicators focus on end-of-life care: place of death and presence of a care pathway at the end-of-life (Leemans, 2016, pers. comm,. 22 Nov). Therefore, there is significant research work underway but this is not mandated for use in clinical practice at this time. Besides these guided initiatives no comprehensive data are available on local initiatives in Flanders or in the Walloon part of Belgium.

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Netherlands

In the Netherlands there are no mandatory quality indicators for palliative care nor policy guidance to support such work. However, there is currently a major national quality improvement program in which a set of quality indicators are being used for evaluation purposes. Launched in 2012 by the Dutch Ministry of Health, this four year programme focuses on five key objectives across generalist health care settings: Patients die at their preferred place; Patients and relatives feel they are in control regarding palliative care; Patients and relatives see palliative care as being coordinated; Patients and relatives feel care to be concordant with their needs, preferences and values; Patients and relatives receive care for their needs in the physical, psychosocial and spiritual domains.[56] The data collection and analysis for this program is based on three measurement instruments: (1) numerical rating scales for six symptoms (pain, fatigue, breathlessness, constipation, sadness and anxiety), (2) the Consumer Quality Index Palliative Care - patient version and (3) the version for bereaved relatives.[56] The development of the consumer quality index tools is well documented across three published articles.[57-59] Of note, these tools ask patients and bereaved family members to describe actual experience alongside noting how important respondents feel such care aspects are (patient version with 56 items and family version with 64 items). The tools provide information to inform 33 patient focused quality indicators and 10 bereaved family quality indicators with 14 process indicators and 29 outcome indicators. These quality indicators are shown in Appendix 3.

Data collection and analysis is driven by the national quality improvement program which will end in 2017. Numerical rating scales are implemented by clinical staff, asking for patient scores at the same time on three consecutive days. The results are sent to the research team for analysis and reporting. The Consumer Quality Index (patient version) is administered by a trained interviewer whereas the bereaved family version is sent via post for completion. All results are returned to the research team for analysis and reporting. Such data collection is completed prior to an improvement intervention and after the intervention (pre and post test) to assist in understanding how to drive improvement across the healthcare sector within end-of-life care.[56]

Finally, it is relevant that at the moment a national quality framework for palliative care is being developed by, amongst others, the comprehensive cancer center in The Netherlands. This framework will be launched in 2017 and will involve quality criteria and norms. However, at the moment it is not clear whether this framework will become mandatory.

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Singapore

In recent years, Singapore has developed strong policy support for provision and measurement of quality end-of-life care. Their national strategy in 2011[60] focuses predominantly on specialist palliative care providers, with 1 of its 10 improvement goals outlining a need to establish national guidelines, a minimum dataset and an accreditation system for palliative care services. This strategy also notes that hospitals are accredited by the 'Joint Commission International' which includes an end-of-life care standard.[61] On reviewing the JCI standard it is evident that high level statements are provided without explicit indicators noted. For example: The hospital supports the patient's right to assessment and management of pain and respectful compassionate care at the end of life; Care of the dying patient optimizes his or her comfort and dignity. Therefore, accreditation within the hospital system does require a focus on end-of-life care but exact indicators or tools to assist in this are not evident. In response to the national strategy, the National Guidelines for Palliative Care (NGPC) were developed and recently released[62] with an accompanying interpretation guide.[63] These provide specific focus on quality improvement and encourage links to a number of tools that could assist services in their quality measurement including: tools used by the Palliative Care Outcome Collaboration - Australia (PCOC),[34] Toolkit of Instruments to Measure End of Life Care (TIME) – United States,[64] The National Assessment Program Family Evaluation of Palliative Care - Australia (NSAP FEPC)[38] and Quality of Care at End of Life Measure 0208 – Family Evaluation of Hospice Care (FEHC) – National Quality Forum, United States.[65]

In addition, the NGPC and interpretation guide comes with a Self- Assessment Workbook, which allows palliative care services to perform a self-audit of their services as part of a quality improvement process.[66] The self-audit, performed 2 yearly with members of the multidisciplinary team within the service, allows staff to come together to identify gaps and agree on priority areas for improvement. Services are also encouraged to send the self-audit results to Singapore Hospice Council, the umbrella body governing all palliative care services in Singapore. In return, the self-audit results of individual organisations are benchmarked against the consolidated results of all services (including hospitals and community hospice services) and reflected back to individual organisations. The first round of self-assessments have been completed by 11 services (out of a possible 15) representing approximately 73% participation nationally.

There are also future plans to embark on national quality improvement training and projects linking palliative care services across hospitals and the community (Unpublished data: Report of the Guidelines Implementation Workgroup Jan 2016).

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Switzerland

Switzerland released a national strategy for palliative care in 2010[67] prompting the development of National guidelines for Palliative Care.[68] Subsequently an updated strategy, 2013-2015,[69] with an accompanying framework for palliative care in Switzerland[70] were published. These documents note the need for quality review of specialist palliative care services but not for generalist care providers at this time, with the later strategy noting this as an area for focus in coming years. For this reason, a national platform for data collection to support quality measurement in palliative care is under discussion with hopes this will be established in 2017.

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Präsidentin Palliative CH**Taiwan**

Taiwan does not have a national policy for end-of-life care but they are governed by two regulations affecting quality of death: The Natural Death Act (passed in 2000) and the Patient Self-determination Act (passed in 2015, for implementation from 2018) as outlined by email (Cheng 2016, pers. comm., 7 Nov). The Natural Death Act supports patients in decisions about resuscitation and/or futile treatments. It also provides medical personnel with a legal basis to make medical decisions in accordance with a patient's living will. Furthermore, the Patient Self-determination Act entitles patients to decline medical treatments according to their own will. Advance care planning and directives are advised for every patient wishing to apply this law. It is felt these laws enable an improvement in end-of-life care (Cheng 2016, pers. comm., 7 Nov).

Many service providers caring for people with cancer in Taiwan, use a quality measurement tool called the 'Good Death Scale' (Cheng 2016, pers. comm., 7 Nov). It is composed of five questions covering the domains of biological, psychological, social and spiritual needs of the patients. Examples of some of the questions included in this tool include: Has the patient known the fact that he/she is dying?; Could the patient accept his/her illness well?; Has the patient arranged everything according to his/her own will?;

Was the timing appropriate for the patient to pass away?; How about the physical condition of the patient at that time? This is completed by staff after a patient's death, however, this is not yet routinely used or reported on nationally (Cheng 2016, pers. comm., 7 Nov).

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United States

The United States does not have a national policy in relation to end-of-life care. However, specific work in relation to quality measurement of end-of-life care has progressed in recent years with 25 endorsed indicators for use nationally by either specialist or generalist end-of-life care providers (Prins 2016, pers. comm., 19 Nov).[65] These indicators are developed by external organisations and submitted to the National Quality Forum (NQF), a not for profit organisation established in 1999 to ensure patient safety and health care quality, for endorsement and ratification. Quality measurement using NQF indicators is in some instances linked to payment and reporting by federal government and private organisations. Indicators endorsed by the NQF are seen as the gold standard of measurement (Prins 2016, pers. comm., 19 Nov). Work to endorse indicators for end-of-life care commenced in the United States in 2012, where 14 measures were endorsed. Continued work has led to the current 25 endorsed indicators for end-of-life care (12 process and 13 outcome) outlined in Appendix 3.

In addition to the above, there is a considerable amount of work happening at local / regional levels to enable quality measurement of end-of-life care resulting in several tools developed and used within the US and in other countries. Indeed, some of these tools form part of the NQF endorsed suite of indicators. Some of this work includes:

- American Academy of Hospice and Palliative Medicine: Measuring What Matters[71]
- The Carolina's Centre for Medical Excellence: PEACE measures[72]
- National Palliative Care Research Centre: Compilation of assessment tools for use[73]
- Brown University: Toolkit of Instruments to Measure End of Life Care (TIME)[64]

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The following provides an overview of key points in relation to quality measurement of end-of-life care by participating countries

Country	Key points from informants and online searching
Australia	National policy support for quality measurement of end-of-life care.[26] Two significant national specialist palliative care provider quality improvement programs: – The Palliative Care Outcomes Collaboration (PCOC);[34] and the National Standards Assessment Program (NSAP).[37] PCOC reports against 20 national benchmarks, using standardised point of care data and provides opportunities for collaborative improvements across the sector. NSAP supports services to self-assess their care provision in line with the national standards. Services may use PCOC data in addition to many other sources of evidence to inform their multidisciplinary self-assessment, conducted biannually. Work is underway to provide greater focus on end-of-life care within national hospital accreditation, including the development and trialling of relevant indicators.
Belgium	2002 legislation detailing the right to palliative care for all who need it, irrespective of care setting.[74] No national policy for end-of-life care. Research in the Flemish region has occurred in relation to quality measurement of specialist palliative care services.[55] This has led to the availability of a 31 item national quality indicator set developed through a consensus process with health professionals. 31% of all Flemish specialist palliative care teams use these indicators (not mandated for use) with centralised support provided by the research team for reporting. Some relevant disease specific quality indicator sets have also been developed for people with cancer, chronic obstructive pulmonary disease or Alzheimer's disease.[75]
Canada	National palliative care policy supports the need for measurement of care provision, but no quality indicators are provided.[51-53]

	Local work is underway with a predominant focus on specialist palliative care services.[53] Nationally, end-of-life care is devolved to provincial / territorial implementation and discussions are underway in some of these regions in relation to optimal approaches for quality measurement of service provision.
England	Comprehensive strategy guidance for end-of-life care available since 2008.[1] Current strategy identifies 'evidence and information' as one of eight foundations to enable progress.[2] Current ability to measure nationally is limited by available data (death registration only), lack of a national data collection system and legal and regulatory constraints.[3] End-of-life care recently added as a 'core service' for review by the hospital regulation system.[4] This relies on local data submission and site visit reporting. Recent commitment made to continue national care of dying people in hospitals audit for an additional five years. National palliative care clinical data set for specialist palliative care services published in late 2016[8] with a focus on outcome measurement based on the palliative care outcome scale.[9] Range of tools and indicators used at local service levels to drive improvement with a predominant focus on processes of service delivery.
France	National indicators to measure availability of palliative care and access to specialist palliative care services available since 2008, but no indicators of quality of care provision have been developed. No current national palliative care policy. Mandatory quality elements available for use in hospital accreditation, focused on the 'care and rights of people at the end of life'.[50] However, national quality indicators mapped to these are not yet available.
Netherlands	No national policy for end-of-life care, but a national palliative care quality framework (including quality criteria and norms) is under development, and due to be launched in 2017.

	A major national quality improvement program is underway (2012– 17) with a set of quality indicators (n=43) used for evaluation purposes[56] of end-of-life care in general healthcare settings. Three measurement tools used to inform national quality indicators: numerical rating scales for six symptoms, consumer quality survey for patients and another for bereaved relatives.[56]
New Zealand	National policy support evident for quality measurement of end-of-life care.[45-47] Focus for measurement is predominantly on specialist palliative care providers. Policy guidance for a framework called 'managing for outcomes'[49] – an approach linking outcomes with key attributes of service delivery to drive development, improvement and evaluation. National meeting held in February 2017 to discuss development of national indicators.
Northern Ireland	A comprehensive five year strategy for palliative and end-of-life care for Northern Ireland, 'Living Matters;Dying Matters (LMDM)', was released in 2010.[22] This strategy has been confirmed as appropriate for current working and informs a new program across the country called 'Palliative Care in Partnership'. Quality indicators are not noted specifically within the LMDM strategy, however, mechanisms for data collection such as local registers and availability of population needs data are documented.
Scotland	Since the integration of health and social care services in 2014 'integrated joint boards' responsible from commissioning palliative care services have been established. Health and social care outcomes and integration indicators have been written in line with the above change and are awaiting review and finalisation.[15] Two have direct relevance for end-of-life care. Three large charities working in end-of-life care have proposed one additional indicator for use nationally and await feedback from the current national review into proposed indicators for health and social care.

	Recent release of a national framework for palliative and end-of-life care[17] noting the clear need to develop quality indicators to inform improvement efforts. A particular focus on capturing 'experience' of care is noted. The Scottish Partnership for Palliative Care have proposed the introduction of a national survey for bereaved informal carers.[18]
Singapore	National policy available with a focus on specialist palliative care providers and outlining a proposal for their accreditation.[60] National standards for palliative care available[62] with an accompanying interpretation guide[63] with specific focus provided on quality improvement and linkage to a number of data collection tools for local service providers' consideration. Hospital accreditation includes an end-of-life care standard.[61] Indicators are not mapped to this standard at this time.
Sweden	The Swedish Registry of Palliative Care was established in 2005, providing a national data collection infrastructure. Since 2011, two thirds of all deaths in Sweden (irrespective of location of care) have been entered into the system. 30 data items are entered following medical record review alongside professional caregiver experience. National guidelines for optimal end-of-life care were published in 2012[24] and specified nine quality indicators. Eight of these indicators are provided by the national data registry. Data analysis has occurred with research noting improvements based on this quality measurement approach.[25]
Switzerland	National strategy, guidelines and framework for palliative care available.[68-70] Focus in recent years has been on specialist palliative care with acknowledgements made of the need to move to a greater review of generalist care providers in coming years. Current work underway discussing a national platform for data collection to support quality measurement in palliative care with hopes this will be established in 2017.

Taiwan	National policy not available but two regulations exist in relation to quality of death – The Natural Death Act (passed in 2000) and the Patient Self-determination Act (passed in 2015 for implementation in 2018). These acts provide for patients and clinicians to: determine appropriate care options in relation to resuscitation and/or futile treatments; receive care in line with their living will; decline medical treatments. Many services caring for people with cancer use the 'Good Death Scale', completed after a patient's death. However, this is not routinely used nor reported on nationally.
United States	No national policy available. Established a not for profit organisation in 1999, the National Quality Forum (NQF), to ensure patient safety and health care quality. NQF have endorsed 25 clinical indicators available nationally for either specialist or generalists working in end-of-life care.[65] Quality measurement using NQF endorsed measures is, in some instances, linked to payment and reporting requirements. Considerable work underway at local / regional levels leading to the development of several tools used across the US and in other countries.
Wales	Three significant reports have guided palliative and end-of-life care service development since 2009.[19-21] Current policy guidance focuses on developing patient reporting quality outcome indicators as a priority. Systems for data collection and analysis exist at the service level. There is a threefold approach to data collection and reporting: 1) peer review of specialist palliative care services; 2) review of data available in current information systems; 3) health board reports.

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Appendix 14: Availability of national policies, standards and/or indicators to ensure quality palliative care across 15 countries

Rank / Country	National policy supports use of quality indicators for end-of-life care	National standards available for end-of-life care	National quality indicators available for use by specialist palliative care providers	National quality indicators available for use by generalist palliative care providers	Use of quality indicators for end-of-life care mandatory for specialist palliative care providers	Use of quality indicators for end-of-life care mandatory for generalist palliative care providers
1. United Kingdom: England	✓ [1]	✓ [2, 3] Guidelines available	X	X	X	X (Hospital accreditation notes EOL care[4-7])
1. United Kingdom: Scotland	✓ [8]	X Guidelines[9]	X	X (under review)	X	X
1. United Kingdom: Wales	✓ [10]	X Guidelines[11]	X	X	X	X
1. United Kingdom: Northern Ireland	✓ [12]	X Guidelines[13]	X	X	X	X
2. Sweden	✓ [14]	X Guidelines[14]	X	✓	X	X
3. Australia	✓ [15]	✓ [16]	✓	X	X	X
4. New Zealand	✓ (focused on specialist palliative care)[17, 18]	✓ [19]	X	X	X	X
5. France	X	X Guidelines[20]	X	X	X	X (Hospital accreditation notes EOL care[21])
6. Canada	✓	X Principles and Norms of practice[22]	X	X	X	X
7. Belgium	X	X Guidelines[23]	✓	X	X	X
8. Netherlands	X	X Guidelines[24]	✓	✓	X	X

8. Singapore	✓ (focused on specialist palliative care)[25]	✓[26, 27]*	X	X	X	X (Hospital accreditation notes EOL care[28])
8. Switzerland	✓[29] (expired)	X Guidelines[30]	X	X	X	X
8. Taiwan	X	X	X	X	X	X
8. United States	X	X Guidelines[31]	✓	✓	X (Some payment incentives linked to indicator use)	X (Some payment incentives linked to indicator use)
Totals	**10/15**	**4/15**	**4/15**	**3/15**	**0/15**	**0/15**

*Singapore's standards are called 'guidelines' but written in a very similar way to standards from Australia and New Zealand and therefore have been classified as standards for this study

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Appendix 15: Type of indicators available for national use to measure quality of palliative care listed by country of origin, mapped to the domains from the Clinical Practice Guidelines for Quality Palliative Care and linked to a key measurement domain

Indicators listed by participating country in alphabetical order. ***Participating countries with national indicators available are:*** ✓ ***Australia (20 benchmarks available for specialist palliative care providers);*** ✓ ***Belgium (31 indicators available for specialist palliative care providers);*** ✓ ***The Netherlands (43 indicators available for generalist and specialist palliative care providers);*** ✓ ***Sweden (9 indicators available for generalist providers) and*** ✓ ***The United States (25 indicators available for generalist and specialist palliative care providers).***	**Type of Indicator (structure / process / outcome)**	**Clinical Practice Guidelines for Quality Palliative Care, Third Edition[1] Domains (Text box noting full domain headings at conclusion of this table)**	**Key area indicator measures (allocated by research team)**
Australia – 20 benchmarks for use by specialist palliative care providers			
Benchmark 1: 90% of patients must have their episode commence on the day of, or the day following date ready for care.*	Process	Domain 1	Service access
Benchmark 2: 90% of patients are in the unstable phase for 3 days or less.	Outcome	Domain 2	Resolution of unstable phase
Benchmark 3.1: At least 90% of patients with absent or mild PCPSS pain at the beginning of their phase of palliative care have absent or mild PCPSS pain at the end of the phase.*	Outcome	Domain 2	Pain
Benchmark 3.2: At least 60% of patients with moderate or severe PCPSS pain at the beginning of their phase of palliative care have absent or mild PCPSS pain at the end of the phase.*	Outcome	Domain 2	Pain
Benchmark 3.3: At least 90% of patients with absent or mild SAS pain at the beginning of their phase of palliative care have absent or mild SAS pain at the end of the phase.*	Outcome	Domain 2	Pain
Benchmark 3.4: At least 60% of patients with moderate or severe SAS pain at the beginning of their phase of palliative care have absent or mild SAS pain at the end of the phase.*	Outcome	Domain 2	Pain
Benchmark 3.5: At least 90% of patients with absent or mild fatigue at the beginning of their phase of palliative care have absent or mild fatigue at the end of the phase.	Outcome	Domain 2	Fatigue
Benchmark 3.6: At least 60% of patients with moderate or severe fatigue at the beginning of their phase of palliative care have absent or mild fatigue at the end of the phase.	Outcome	Domain 2	Fatigue
Benchmark 3.7: At least 90% of patients with absent or mild breathing problems at the beginning of their phase of palliative care have absent or mild breathing problems at the end of the phase.	Outcome	Domain 2	Dyspnoea
Benchmark 3.8: At least 60% of patients with moderate or severe breathing problems at the beginning of their phase of palliative care have absent or mild breathing problems at the end of the phase.	Outcome	Domain 2	Dyspnoea
Benchmark 3.9: At least 90% of patients with absent or mild family / carer problems at the beginning of their phase of palliative care have absent or mild family / carer problems at the end of the phase.	Outcome	Domain 4	Family problems
Benchmark 3.10: At least 60% of patients with moderate or severe family / carer problems at the beginning of their phase of palliative care have absent or mild family / carer problems at the end of the phase	Outcome	Domain 4	Family problems
Benchmark 4.1: Case-mix adjusted Pain as rated by the clinician using the problem severity	Outcome	Domain 2	Pain

Benchmark 4.2: Case-mix adjusted Other symptoms as rated by the clinician using the problem severity	Outcome	Domain 2	General symptom management
Benchmark 4.3: Case-mix adjusted Family / carer as rated by the clinician using the problem severity	Outcome	Domain 4	Family problems
Benchmark 4.4: Case-mix adjusted Psychological / spiritual as rated by the clinician using the problem severity	Outcome	Domains 3 and 5	Psychological / spiritual / religious care for the patient
Benchmark 4.5: Case-mix adjusted Pain as rated by the patient using the Symptom Assessment Scale	Outcome	Domain 2	Pain
Benchmark 4.6: Case-mix adjusted Nausea as rated by the patient using the Symptom Assessment Scale	Outcome	Domain 2	Nausea
Benchmark 4.7: Case-mix adjusted Breathing problems as rated by the patient using the Symptom Assessment Scale	Outcome	Domain 2	Dyspnoea
Benchmark 4.8: Case-mix adjusted Bowel problems as rated by the patient using the Symptom Assessment Scale	Outcome	Domain 2	Bowel management
Belgium – 31 indicators available for specialist palliative care providers (Ca = caregiver, Ph = physician, Pa = patient, Fc = family carer)			
Nominator: number of patients who were subjected to a general symptom assessment on a validated scale Denominator: total number of patients for whom this indicator was measured (Ca)	Process	Domains 1 and 2	General symptom management
Nominator: number of patients whose symptom burden was mostly or completely under control in the final week of life Denominator: total number of patients for whom a palliative care service was involved for at least 3 days (Ph)	Outcome	Domain 2	General symptom management
Nominator: number of patients who were subjected to a pain assessment, with or without pain scale Denominator: total number of patients for whom this indicator was measured (Ca)	Process	Domain 2	Pain
Nominator: number of patients who, after treatment, experienced significant improvement in pain Denominator: total number of patients treated for pain (Pa)	Outcome	Domain 2	Pain
Nominator: number of patients whose shortness of breath was relieved within 48 hours after admission or starting palliative care Denominator: total number of patients with shortness of breath (Ca)	Outcome	Domain 2	Dyspnoea
Nominator: number of patients who indicated that the caregivers regularly assessed how they were feeling Denominator: total number of patients for whom this indicator was measured (Pa)	Process	Domains 2, 3, 4, 5 and 6	Indicators covering multiple categories
Nominator: number of family carers who indicated that the caregivers regularly talked to them about what it meant to them to care for their ill next of kin Denominator: total number of family carers who cared for their ill next of kin (Fc)	Process	Domains 3, 4, 5 and 6	Family support
Nominator: number of family carers who indicated that the caregivers regularly asked how they were feeling Denominator: total number of family carers for whom this indicator was measured (Fc)	Process	Domains 2, 3, 4, 5 and 6	Family support
Nominator: number of family carers who were given as much assistance as necessary with the care process Denominator: total number of family carers who needed assistance with the care process (Fc)	Process	Domain 4	Family support
Nominator: number of patients with a score of 5 or more on a scale of 0 to 10 for quality of life Denominator: total number of patients for whom this indicator was measured (Pa)	Outcome	Domains 2, 3, 4, 5 and 6	Quality of life measure

Nominator: number of patients who indicated that the caregivers most of the times or always respected their personal wishes and that they could most of the time or always plan their day and decide about the care provided Denominator: total number of patients for whom this indicator was measured (Pa)	Outcome	Domain 4	Respect for patient autonomy
Nominator: number of patients who received the right amount of information about their diagnosis Denominator: total number of patients for whom this indicator was measured (Pa)	Outcome	Domain 4	Information provision - patient
Nominator: number of patients who received the right amount of information about the course of the disease Denominator: total number of patients for whom this indicator was measured (Pa)	Outcome	Domain 4	Information provision - patient
Nominator: number of patients who received the right amount of information on palliative care options Denominator: total number of patients for whom this indicator was measured (Pa)	Outcome	Domain 4	Information provision - patient
Nominator: number of patients who indicated that they most of the time or always received clear and comprehensible and never or sometimes contradictory information Denominator: total number of patients for whom this indicator was measured (Pa)	Outcome	Domain 4	Information provision - patient
Nominator: number of family carers who received the right amount of information about the patient's condition and treatments Denominator: total number of family carers for whom this indicator was measured (Fc)	Outcome	Domain 4	Information provision - family
Nominator: number of family carers who received the right amount of information about the patient's approaching death Denominator: total number of family carers for whom this indicator was measured (Fc)	Outcome	Domains 4 and 7	Information provision - family
Nominator: number of family carers who felt they had adequate support after the patient's death (inclusive evaluation meeting) and were informed of the possibilities of after-care. Denominator: total number of family carers for whom this indicator was measured (Fc)	Outcome	Domains 3, 4, 5, 6 and 7	Indicators covering multiple categories
Nominator: number of patients about whom multidisciplinary consultations took place at least once a week about their care objectives Denominator: total number of patients for whom the palliative care service was involved for at least 1 week (Ca)	Process	Domain 1	Evident MDT care
Nominator: number of patients about whom a conversation about their care preferences took place between the caregivers and family carers in the first week after admission or start of palliative care Denominator: total number of patients for whom this indicator was measured (Ca)	Process	Domains 1, 4 and 8	Treatment preference discussion and/or documentation – families
Nominator: number of patients with whom the physician discussed the care objectives Denominator: total number of patients for whom this indicator was measured (Ph)	Process	Domain 4	Discussion about care objectives
Nominator: number of patients who were in touch with their family physician on a weekly basis in the last 3 months before death (personally or by telephone) Denominator: total number of patients for whom this indicator was measured (Ph)	Process	Domain 1	Family physician contact for patient

Nominator: number of patients (or representatives) who were asked how they felt about end of life decisions and euthanasia Denominator: total number of patients for whom this indicator was measured (Ca)	Process	Domain 8	Treatment preference discussion and/or documentation - patients
Nominator: number of patients who got a positive response to (all) their request(s) for a treatment or an end-of-life decision Denominator: number of patients who requested a treatment or an end-of-life decision (Fc)	Process	Domains 4 and 8	Indicators covering multiple categories
Nominator: number of patients who scored 5 or more on a scale of 0 – 10 for the quality of death according to family carers Denominator: total number of patients for whom this indicator was measured (Fc)	Outcome	Domain 7	Quality of death measure
Nominator: number of patients who scored 5 or more on a scale of 0 – 10 for the quality of death according to physicians Denominator: total number of patients for whom this indicator was measured (Ph)	Outcome	Domain 7	Quality of death measure
Nominator: number of patients whose palliative care started at least 2 weeks before death Denominator: total number of patients for whom this indicator was measured (Ph)	Outcome	Domain 1	Service access
Nominator: number of patients admitted more than once to the emergency room since admission or start of palliative care Denominator: total number of patients for whom this indicator was measured (Ph)	Outcome	Domain 1	Acute care use
Nominator: number of patients admitted to the intensive care unit since admission or start of palliative care Denominator: total number of patients for whom this indicator was measured (Ph)	Outcome	Domain 1	Acute care use
Nominator: number of patients whose caregivers were given the care objectives and resuscitation status during or after admission or starting palliative care Denominator: total number of patients for whom this indicator was measured (Ca)	Process	Domains 1 and 8	Discussion about care objectives
Nominator: number of patients for whom the prognosis, psychosocial symptoms, functional status, symptom burden and documentation about care wishes were entered in the file within 48 hours after admission or starting palliative care Denominator: total number of patients for whom this indicator was measured (Ca)	Process	Domain 1	Evident MDT care
Netherlands – 43 indicators available for generalist and specialist palliative care providers			
A. Management of pain and other physical symptoms A1. Percentage of patients with moderate to severe pain*	Outcome	Domain 2	Pain
A2. Percentage of patients with fatigue*	Outcome	Domain 2	Fatigue
A3. Percentage of patients with shortness of breath*	Outcome	Domain 2	Dyspnoea
A4. Percentage of patients with constipation*	Outcome	Domain 2	Bowel management
A5. Extent to which patients receive support for their physical symptoms (pain, fatigue, shortness of breath, and constipation)	Outcome	Domain 2	General symptom management
A6. Extent to which patients receive help with physical care	Process	Domain 2	Physical care

B. Care for psychosocial well-being B1. Percentage of patients with anxiety*	Outcome	Domain 3	Psychological / spiritual / religious care for the patient
B2. Percentage of patients who feel depressed*	Outcome	Domain 3	Psychological / spiritual / religious care for the patient
B3. Extent to which patients receive support when they feel anxious or feel depressed	Process	Domain 3	Psychological / spiritual / religious care for the patient
B4. Extent to which patients receive attention from their caregivers	Process	Domains 3 and 4	Indicators covering multiple categories
B5. Extent to which patients are satisfied with the counseling aspects of ''politeness'' and ''being taken seriously''	Outcome	Domain 4	Respectful care
B6. Extent to which patients experience respect for their autonomy	Outcome	Domains 4 and 8	Respect for patient autonomy
B7. Extent to which patients experience respect for their privacy	Outcome	Domains 1 and 4	Respectful care
B8. Extent to which direct relatives considered that the patient had the opportunity to be alone	Process	Domains 1, 3 and 5	Indicators covering multiple categories
C. Care for spiritual well-being C1. Extent to which patients indicate that caregivers respect their life stance	Outcome	Domain 5	Respectful care
C2. Extent to which patients indicate that they have access to a counselor for spiritual problems	Process	Domain 5	Psychological / spiritual / religious care for the patient
C3. Extent to which relatives indicate that the patient had access to a counselor for spiritual problems	Process	Domain 5	Psychological / spiritual / religious care for the patient
C4. Extent to which relatives indicate that the patient received support with preparations for saying goodbye	Process	Domains 3, 4, 5, 6 and 7	Preparation for death
C5. Extent to which patients indicate that they feel that life is worthwhile	Outcome	Domains 3 and 5	Indicators covering multiple categories
C6. Percentage of relatives who indicate that the patient died peacefully*	Outcome	Domains 2, 3, 4, 5, 6 and 7	Quality of death measure
C7. Percentage of relatives who indicate that the patient had accepted her/his approaching death*	Outcome	Domains 3, 5 and 7	Preparation for death
C8. Extent to which relatives indicate that there was attention and respect for the psychosocial and spiritual well-being of the patient	Outcome	Domains 3, 4 and 5	Psychological / spiritual / religious care for the patient
D. Generic aspects D1. Extent to which patients in the last month before their death were in the location of their preference	Outcome	Domains 1 and 7	Location of preference

D2. Percentage of patients who died in the location of their preference*	Outcome	Domains 1 and 7	Location of preference
D3. Extent to which patients know who the contact person is for the care	Process	Domain 1	Integrated / coordinated care and care expertise
D4. Extent to which patients receive information about the expected course of the illness	Process	Domain 4	Information provision - patient
D5. Extent to which patients receive information about the advantages and disadvantages of various types of treatments	Process	Domain 4	Information provision - patient
D6. Extent to which patients indicate that they receive understandable explanations	Outcome	Domain 4	Information provision - patient
D7. Extent to which patients indicate that they receive contradictory information	Outcome	Domain 4	Information provision - patient
D8. Presence of documentation concerning the desired care and treatment at the end of life*	Process	Domains 4 and 8	Treatment preference discussion and/or documentation - patients
D9. Extent to which relatives indicate that the patient was asked about her/his opinions with regard to end-of-life decisions	Outcome	Domains 4 and 8	Respect for patient autonomy
D10. Extent to which patients experience expertise and continuity	Outcome	Domain 1	Integrated / coordinated care and care expertise
D11. Percentage of patients who receive medical aid soon enough	Process	Domain 1	Service access
E. Care for psychosocial and spiritual well-being of relatives E1. Extent to which, according to the direct relatives, attention was paid to their own psychosocial and spiritual well-being	Outcome	Domains 2, 3, 4, 5 and 6	Family support
E2. Extent to which the direct relatives felt that they were treated well in all respects by the caregivers	Outcome	Domains 2, 3, 4, 5 and 6	Family support
E3. Extent to which, according to the direct relatives, their autonomy was respected	Outcome	Domain 4	Respect for family member's autonomy
E4. Extent to which the direct relatives had the opportunity to be alone with their relative	Outcome	Domains 1 and 4	Indicators covering multiple categories
F. Generic (in the care for relatives) F1. Extent to which direct relatives received information that was understandable and unambiguous at the time of the patient's death	Outcome	Domains 4 and 7	Information provision - family
F2. Extent to which direct relatives received information about the advantages and disadvantages of various types of treatment	Outcome	Domain 4	Information provision - family

F3. Extent to which direct relatives perceived the expertise of caregivers and the continuity of care	Outcome	Domain 1	Integrated / coordinated care and care expertise
G. Aftercare G1. Extent to which direct relatives felt supported by the caregivers immediately after the patient's death	Outcome	Domain 7	Bereavement
G2. Extent to which direct relatives were informed about the possibilities of aftercare	Process	Domain 7	Bereavement
G3. Extent to which a final conversation or discussion was held to evaluate the care and the treatment	Process	Domains 1 and 7	Indicators covering multiple categories
Sweden – 9 indicators available for generalist providers			
1. Coverage in the Swedish Registry of Palliative Care, ie the proportion of all deaths that are registered.	Process	Domain 1	Coverage in a registry of palliative care
2. Two or more admissions to hospital during the last month in life - not covered by the register	Process	Domain 1	Acute care use
3. Proportion with pressure ulcers at death (Norton grade 2-4)	Outcome	Domain 2	Pressure ulcers
4. Proportion with individualized prn parenteral anxiolytic medication	Process	Domain 2	Psychological / spiritual / religious care for the patient
5. Proportion with individualized prn parenteral opioid medication	Process	Domain 2	Pain
6. Proportion with a documented discussion between physician and patient about the transition to EOL care	Process	Domains 1 and 7	Discussion about care objectives
7. Proportion with systematic pain assessment	Process	Domain 2	Pain
8. Proportion with systematic symptom assessment.	Process	Domain 2	General symptom management
9. Proportion with documented assessment of oral health	Process	Domain 2	Oral health
United States – 25 indicators available for generalist and specialist palliative care providers			
Comfortable Dying: Pain Brought to a Comfortable Level Within 48 Hours of Initial Assessment* Numerator Statement: Patients whose pain was brought to a comfortable level (as defined by patient) within 48 hours of initial assessment. Denominator Statement: Patients who replied "yes" when asked if they were uncomfortable because of pain at the initial assessment.	Outcome	Domain 2	Pain
Proportion of patients who died from cancer receiving chemotherapy in the last 14 days of life*	Process	Domain 1	Receiving chemotherapy in last 14 days of life
Proportion of patients who died from cancer admitted to the ICU in the last 30 days of life*	Outcome	Domain 1	Acute care use
Proportion of patients who died from cancer not admitted to hospice*	Process	Domain 1	Service access
Proportion of patients who died from cancer admitted to hospice for less than 3 days*	Outcome	Domain 1	Service access

Patients Treated with an Opioid who are Given a Bowel Regimen* Percentage of vulnerable adults treated with an opioid that are offered/prescribed a bowel regimen or documentation of why this was not needed	Process	Domain 2	Bowel management
Hospitalized Patients Who Die an Expected Death with an ICD that Has Been Deactivated Percentage of hospitalized patients who die an expected death from cancer or other terminal illness and who have an implantable cardioverter-defibrillator (ICD) in place at the time of death that was deactivated prior to death or there is documentation why it was not deactivated	Process	Domains 1 and 7	ICD deactivation
Patients Admitted to ICU who Have Care Preferences Documented* Percentage of vulnerable adults admitted to ICU who survive at least 48 hours who have their care preferences documented within 48 hours OR documentation as to why this was not done.	Process	Domains 1 and 8	Treatment preference discussion and/or documentation - patients
Patients with Advanced Cancer Screened for Pain at Outpatient Visits* Percentage of adult patients with advanced cancer who have an assessment of pain with a standardized quantitative tool at each outpatient visit.	Process	Domain 2	Pain
Hospice and Palliative Care -- Pain Screening* Percentage of hospice or palliative care patients who were screened for pain during the hospice admission evaluation / palliative care initial encounter.	Process	Domain 2	Pain
Hospice and Palliative Care -- Pain Assessment* Percentage of hospice or palliative care patients who screened positive for pain and who received a clinical assessment of pain within 24 hours of screening.	Process	Domain 2	Pain
Hospice and Palliative Care -- Dyspnea Treatment* Percentage of patients who screened positive for dyspnea who received treatment within 24 hours of screening.	Process	Domain 2	Dyspnoea
Hospice and Palliative Care -- Dyspnea Screening* Percentage of hospice or palliative care patients who were screened for dyspnea during the hospice admission evaluation / palliative care initial encounter.	Process	Domain 2	Dyspnoea
Hospice and Palliative Care – Treatment Preferences Percentage of patients with chart documentation of preferences for life sustaining treatments.	Process	Domains 1 and 8	Treatment preference discussion and/or documentation - patients
Beliefs and Values - Percentage of hospice patients with documentation in the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/caregiver did not want to discuss.*	Process	Domain 5	Psychological / spiritual / religious care for the patient
CAHPS® Hospice Survey (family experience with care) – Hospice Team Communication Numerator Statement:	Outcome	Domain 4	Information provision - family

CMS calculates CAHPS Hospice Survey measures using top-box scoring. The top-box score refers to the percentage of caregiver respondents that give the most positive response. Details regarding the definition of most positive response are noted in Section S.6 below. Denominator Statement: The measure's denominator is the number of survey respondents who answered the item. The target population for the survey is primary caregivers of hospice decedents. The survey uses screener questions to identify respondents eligible to respond to subsequent items. Therefore, denominators will vary by survey item (and corresponding multi-item measures, if applicable) according to the eligibility of respondents for each item.			
CAHPS® Hospice Survey (family experience with care) – Getting Timely Care (numerator / denominator description provided above)	Outcome	Domain 1	Service access
CAHPS® Hospice Survey (family experience with care) – Getting Emotional and Religious Support (numerator / denominator description provided above)	Outcome	Domains 3 and 5	Family support
CAHPS® Hospice Survey (family experience with care) – Getting Hospice Training (numerator / denominator description provided above)	Outcome	Domain 4	Family support
CAHPS® Hospice Survey (family experience with care) – Rating of the Hospice Care (numerator / denominator description provided above)	Outcome	Domain 1	Hospice evaluation
CAHPS® Hospice Survey (family experience with care) – Willingness to Recommend the Hospice (numerator / denominator description provided above)	Outcome	Domain 1	Hospice evaluation
CAHPS® Hospice Survey (family experience with care) – Treating Family Member with Respect (numerator / denominator description provided above)	Outcome	Domain 4	Respectful care
CAHPS® Hospice Survey (family experience with care) – Getting Help for Symptoms (numerator / denominator description provided above)	Outcome	Domain 2	General symptom management
Bereaved Family Survey (tool with 19 items) – measures = Numerator Statement: The numerator is comprised of completed surveys (at least 12 of 17 structured items completed), where the global item question has an optimal response. The global item question asks "Overall, how would your rate the care that [Veteran] received in the last month of life" and the possible answer choices are: Excellent, Very good, Good, Fair, or Poor. The optimal response is Excellent. Denominator Statement: The denominator consists of all inpatient deaths for which a survey was completed (at least 12 of 17 structured items completed), excluding: 1) deaths within 24 hours of admission (unless the Veteran had a previous hospitalization in the last month of life); 2) deaths that occur in the Emergency Department (unless the Veteran had a prior hospitalization of at least 24 hours in the last 31 days of life); 3) deaths that occur in the operating room; and 4) deaths due to suicide or accidents. Additional exclusion criteria include: 1) Veterans for whom a family member knowledgeable about their care cannot be identified (determined by the family member´s report); or contacted (no current contacts listed or no valid addresses on file); 2) absence of a working telephone available to the family member.	Outcome	Domains 1, 2, 3, 5 and 7	Indicators covering multiple categories

Information re the tool: The Bereaved Family Survey (BFS) is comprised of 19 items. Sixteen forced-choice items focus on specific aspects of care that the Veteran received at a VA inpatient facility during the last month of life. These items evaluate performance on areas of care including *communication, emotional and spiritual support, pain management, and personal care needs.*			
Family Evaluation of Hospice Care (tool with 54 questions for bereaved caregivers to complete)* Measure: Numerator Statement: The numerator is the sum total of the weighted incidence of problem scores occurring in response to 17 specific items on each survey. The 17 questions focus on the following aspects of hospice care: symptom management, communication, provision of information, emotional support and care coordination. Denominator Statement: The denominator represents the number of surveys with responses for at least 14 of the 17 questions required to compute the composite score in the FEHC survey.	Outcome	Domains 1, 2,3, 5 and 7	Indicators covering multiple categories

Domain headings from the United States Clinical Practice Guidelines for Quality Palliative Care, Third Edition: Domain 1: Structure and Processes of Care; Domain 2: Physical Aspects of Care; Domain 3: Psychological and Psychiatric Aspects of Care; Domain 4: Social Aspects of Care; Domain 5: Spiritual, Religious and Existential Aspects of Care; Domain 6: Cultural Aspects of Care; Domain 7: Care of the Patient at the End of Life; Domain 8: Ethical and Legal Aspects of Care

* This indicator was evident in the most recently published systematic review about quality indicators for end-of-life care[2]

References

1. National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care, Third Edition*. Pittsburgh, United States of America 2013.

2. De Roo ML, Leemans K, Claessen SJ, et al. Quality indicators for palliative care: update of a systematic review. *Journal of Pain and Symptom Management* 2013; 46: 556-572.

Appendix 16: Mapping of indicators from a recent systematic review [1] under headings correlating with domains* from the United States Clinical Practice Guidelines for Quality Palliative Care, Third Edition[2] as designated by the review

(Note – highlighted cells represent an exact match between the published review and national indicators found within this study)

Indicator cited in review[1] (326 indicators in total)	Indicator in use nationally (128 indicators in total) (or very similar matching)
1. Structure and processes of care	
10. Peruselli, 1997 The palliative care service responds rapidly to request for care. Process **Numerator**: Number of patients who received initial visits from a team member within 48 hours of request **Denominator**: Population served x 100 **Exclusion**: - **Performance standard**: 95%	**Australia** Benchmark 1: 90% of patients must have their episode commence on the day of, or the day following date ready for care. Process **United States** CAHPS® Hospice Survey (family experience with care) – Getting Timely Care Numerator Statement: CMS calculates CAHPS Hospice Survey measures using top-box scoring. The top-box score refers to the percentage of caregiver respondents that give the most positive response. Details regarding the definition of most positive response are noted in Section S.6 below. Denominator Statement: The measure's denominator is the number of survey respondents who answered the item. The target population for the survey is primary caregivers of hospice decedents. The survey uses screener questions to identify respondents eligible to respond to subsequent items. Therefore, denominators will vary by survey item (and corresponding multi-item measures, if applicable) according to the eligibility of respondents for each item. Outcome
14. Earle,2006 Proportion not admitted to hospice. Process **Numerator**: Patients who died from cancer without being admitted to hospice **Denominator**: Patients who died from cancer **Exclusion**: - **Performance standard**: <45%	**United States** Proportion of patients who died from cancer not admitted to hospice Process

15. Earle,2006 Proportion admitted to hospice for less than 3 days. Process **Numerator**: Patients who died from cancer and spent fewer than three days in hospice **Denominator**: Patients who died from cancer who were admitted to hospice **Exclusion**: - **Performance standard**: <8%	Proportion of patients who died from cancer admitted to hospice for less than 3 days Outcome
21 NEW Eagar, 2010 Time from referral to first contact Time from referral to first contact is calculated as the time in days between the referral date and the date of first contact or episode start date (whichever occurs first) and is calculated for all episodes of care and across all settings of care. Structure **Numerator/Denominator:** Percentage of patients that are contacted by a member of the clinical team (either face to face or by phone) within 48 hours of referral (including weekends) **Exclusion**: - **Performance standard:** 90%	**Australia** Benchmark 1: 90% of patients must have their episode commence on the day of, or the day following date ready for care. Process
23 NEW Quality Markers, 2009 QM for commissioners: Co-ordination of care across organisational boundaries: A locality-wide register of individuals approaching the end of life is maintained.	**Sweden** Coverage in the Swedish Registry of Palliative Care, ie the proportion of all deaths that are registered Process

Structure Proportion of deceased individuals who entered onto the locality-wide register **Numerator**: - **Denominator**: - **Exclusion**: - **Performance standard**: -	
29 NEW Quality Markers, 2009 QM for acute hospitals: They ensure that relevant information on patients approaching the end of life is entered into a locality-wide register (where available) or otherwise communicated to other health and social care professionals involved in the patient's care. Structure Proportion of deceased patients who were recorded in the locality-wide register (locality-wide registers for end of life care are to be piloted starting in 2009) **Numerator**: - **Denominator**: - **Exclusion**: - **Performance standard**: -	**Sweden** Coverage in the Swedish Registry of Palliative Care, ie the proportion of all deaths that are registered Process
1. Structure and processes of care	
37 Yabroff, 2004 Percentage of patients and family/caregivers within health facilities or systems that understand and are satisfied with provider communication about prognosis. Outcome	**Belgium** Nominator: number of patients who received the right amount of information about their diagnosis Denominator: total number of patients for whom this indicator was measured (Pa) Outcome

Numerator: - **Denominator**: - **Exclusion**: - **Performance standard**: -	Nominator: number of patients who received the right amount of information about the course of the disease Denominator: total number of patients for whom this indicator was measured (Pa) Outcome Nominator: number of patients who indicated that they most of the time or always received clear and comprehensible and never or sometimes contradictory information Denominator: total number of patients for whom this indicator was measured (Pa) Outcome Nominator: number of family carers who received the right amount of information about the patient's condition and treatments Denominator: total number of family carers for whom this indicator was measured (Fc) Outcome Nominator: number of family carers who received the right amount of information about the patient's approaching death Denominator: total number of family carers for whom this indicator was measured (Fc) Outcome **Netherlands** D4. Extent to which patients receive information about the expected course of the illness Process D6. Extent to which patients indicate that they receive understandable explanations Outcome

	United States CAHPS® Hospice Survey (family experience with care) – Hospice Team Communication Numerator Statement: CMS calculates CAHPS Hospice Survey measures using top-box scoring. The top-box score refers to the percentage of caregiver respondents that give the most positive response. Details regarding the definition of most positive response are noted in Section S.6 below. Denominator Statement: The measure's denominator is the number of survey respondents who answered the item. The target population for the survey is primary caregivers of hospice decedents. The survey uses screener questions to identify respondents eligible to respond to subsequent items. Therefore, denominators will vary by survey item (and corresponding multi-item measures, if applicable) according to the eligibility of respondents for each item. (Likely to also be questions about this in the US bereavement survey and FEPC)
38 Yabroff, 2004 Percentage of patients and family/caregivers within and among health facilities or systems that understand and are satisfied with provider communication about risks and benefits or treatment. Outcome **Numerator**: - **Denominator**: - **Exclusion**: - **Performance standard**: -	**Belgium** Nominator: number of patients who received the right amount of information on palliative care options Denominator: total number of patients for whom this indicator was measured (Pa) **Netherlands** D5. Extent to which patients receive information about the advantages and disadvantages of various types of treatments F2. Extent to which direct relatives received information about the advantages and disadvantages of various types of treatment
51 NEW Miyashita, 2008 (omitted in Sato, 2008)	**Belgium** Nominator: number of patients about whom multidisciplinary consultations took place at least once a week about their care objectives Denominator: total number of patients for whom the palliative care service was involved for at least 1 week

Decision making and preference of care: Discussion of strategy of care among physicians and nurses. Process **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization **Denominator:** All patients who died (retrospectively identified) **Exclusion: -** **Performance standard: -**	(Ca) **United States** Patients Admitted to ICU who Have Care Preferences Documented: Percentage of vulnerable adults admitted to ICU who survive at least 48 hours who have their care preferences documented within 48 hours OR documentation as to why this was not done. Process
52 NEW Miyashita, 2008 (and split up in 2 separate indicators, one for patient and one for family by Sato, 2008) Decision making and preference of care: Explanation of medical condition to patient. Process **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization **Denominator:** All patients who died (retrospectively identified) **Exclusion: -** **Performance standard: -**	**Belgium** Nominator: number of patients with whom the physician discussed the care objectives Denominator: total number of patients for whom this indicator was measured (Ph) **Netherlands** D8. Presence of documentation concerning the desired care and treatment at the end of life **United States** Hospice and Palliative Care – Treatment Preferences Percentage of patients with chart documentation of preferences for life sustaining treatments.
53 NEW Miyashita, 2008 (and split up in 2 separate indicators, one for patient and one for family by Sato, 2008) Family care: Explanation of medical condition to family. Process **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization	**Belgium** Nominator: number of family carers who received the right amount of information about the patient's condition and treatments Denominator: total number of family carers for whom this indicator was measured (Fc) Nominator: number of family carers who received the right amount of information about the patient's approaching death Denominator: total number of family carers for whom this indicator was measured (Fc)

Denominator: All patients who died (retrospectively identified) **Exclusion: -** **Performance standard: -**	**Netherlands** F1. Extent to which direct relatives received information that was understandable and unambiguous at the time of the patient's death F2. Extent to which direct relatives received information about the advantages and disadvantages of various types of treatment
54 NEW Miyashita, 2008 Family care: Explanation to family about course of disease until death. Process **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization **Denominator:** All patients who died (retrospectively identified) **Exclusion: -** **Performance standard: -**	**Belgium** Nominator: number of family carers who received the right amount of information about the patient's condition and treatments Denominator: total number of family carers for whom this indicator was measured (Fc) US – Hospice survey, FEPC and Bereavement surveys may all have information to assist this
55 NEW Miyashita, 2008 ; Sato, 2008 Family care: Explanation to family of patient's impending death. Process **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization **Denominator:** All patients who died (retrospectively identified) **Exclusion: -** **Performance standard: -**	**Belgium** Nominator: number of family carers who received the right amount of information about the patient's approaching death Denominator: total number of family carers for whom this indicator was measured (Fc) **Netherlands** F1. Extent to which direct relatives received information that was understandable and unambiguous at the time of the patient's death **US – Hospice survey, FEPC and Bereavement surveys may all have information to assist this**
61 Twaddle, 2007 Documentation of patient status	**Belgium** Nominator: number of patients for whom the prognosis, psychosocial symptoms, functional status, symptom burden and documentation about care wishes were

Percentage of all patients with documentation of prognosis, psychosocial symptoms, functional status, and overall symptom distress within 48 hours of admission. Process **Numerator**: - **Denominator**: - **Exclusion**: - **Performance standard**: 90%	entered in the file within 48 hours after admission or starting palliative care Denominator: total number of patients for whom this indicator was measured (Ca)
64 NEW Schenck, 2010 Structure and Process: Percent of patients who have comprehensive assessment completed within 5 days of admission. Process **Numerator:** Number of patients with all times<=5 **Denominator:** Total # of patients (Prognosis Time= Prognosis date-date of admission (Note: if Prognosis Time < 0, set = 0) Functional Status Time= Functional status screening date-date of admission Pain Time=Pain screening date-date of admission Dyspnea Time= Dyspnea screening date-date of admission Nausea Time= Nausea screening date-date of admission Constipation Time= Constipation screening date-date of admission Depression Time= Depression screening date-date of admission Anxiety Time= Anxiety screening date-date of admission Spiritual Time= Spiritual discussion date-date of admission Social Family Time= Family discussion date-date of admission) **Exclusion: -** **Performance standard: -**	**Belgium** Nominator: number of patients for whom the prognosis, psychosocial symptoms, functional status, symptom burden and documentation about care wishes were entered in the file within 48 hours after admission or starting palliative care Denominator: total number of patients for whom this indicator was measured (Ca) Process
68 Mularski, 2006	Patients Admitted to ICU who Have Care Preferences Documented Percentage of vulnerable adults admitted to ICU who survive at least 48 hours who have their care preferences documented within 48 hours OR documentation as to why this was not done.

Documentation of the goals of care, in the patient chart, within 72 hours. Process **Numerator**: Total number of patients in the ICU for > 72 hours with documentation of the goals of care **Denominator**: Total number of patients in the ICU for > 72 hours **Exclusion**: - **Performance standard**: -	Process
77 – 80 (covers community hospitals, care homes, SPC and then community) NEW Quality Markers, 2009 QM for community hospitals: They (all community hospitals which provide relevant services) nominate a key worker for each patient approaching the end of life if required. Process Audits of the proportion of patients approaching the end of life with a documented key worker **Numerator: -** **Denominator: -** **Exclusion: -** **Performance standard: -**	**Netherlands** D3. Extent to which patients know who the contact person is for the care Process
78 as above	
79 as above	
80 as above	
83 National Hospice and Palliative Care Organization (NHPCO), 2006 Brown University, 2006 Provide coordination of care (Family evaluation of hospice care) Questions: F1: How often did someone from the hospice team give confusing or contradictory information about the patient's medical treatment?	Family Evaluation of Hospice Care (tool with 54 questions for bereaved caregivers to complete) Measure = Numerator Statement: The numerator is the sum total of the weighted incidence of problem scores occurring in response to 17 specific items on each survey. The 17 questions focus on the following aspects of hospice care: symptom management, communication, provision of information, emotional support and care coordination.

F2: While under the care of hospice, was there always one nurse who was identified as being in charge of the patient's overall care? F3: Was there any problem with hospice doctors or nurses not knowing enough about the patient's medical history to provide the best possible care? Process **Numerator**: Sum of 1 response to survey instrument by family member of deceased patient **Denominator**: Number of items (=3) **Exclusion**: Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded **Performance standard**: -	Denominator Statement: The denominator represents the number of surveys with responses for at least 14 of the 17 questions required to compute the composite score in the FEHC survey.
84 Twaddle, 2007 Patient/family meeting Percentage of all cases with documentation that a patient/family meeting (i.e. meeting between patient/family and members of the health care team to discuss the patient's treatment preferences or the plans for discharge disposition) occurred during the first week of the hospital stay. Process **Numerator**: - **Denominator**: - **Exclusion**: - **Performance standard**: 90%	**Belgium** Nominator: number of patients about whom a conversation about their care preferences took place between the caregivers and family carers in the first week after admission or start of palliative care Denominator: total number of patients for whom this indicator was measured (Ca)
85 Peruselli, 1997	**US** CAHPS, FEPC, Bereavement

Satisfaction for patients and families is crucial to palliative care services, which considers clients to be their central focus. Outcome **Numerator**: Number of responses to questionnaire items answered "excellent" by both patient and family **Denominator**: Total number of responses x 100 **Exclusion**: - **Performance standard**: 75%	
88 NEW Grunfeld, 2008 Enrollment in palliative care within 6 months of death A high proportion may indicate poor quality care. Palliative care should be accessible to all patients and families with a cancer diagnosis, in a timely manner, throughout the entire duration of their disease. Process **Numerator:** Number of cases enrolled in palliative care within six months prior to death **Denominator:** All cases enrolled in palliative care **Exclusion: -** **Performance standard: -**	**Belgium** Nominator: number of patients whose palliative care started at least 2 weeks before death Denominator: total number of patients for whom this indicator was measured (Ph) Outcome
91 NEW Eagar, 2010 Time in the unstable phase Time in the unstable phase is calculated as the difference between the phase start date and the phase end date and is analyzed by episode type and then occurrence of the unstable phase during the episode. Outcome	**Australia** Benchmark 2: 90% of patients are in the unstable phase for 3 days or less.

Percentage of patients in their first palliative care phase remain in the unstable phase for less than 7 days **Numerator**: - **Denominator**: - **Exclusion**: - **Performance standard:** 85% Percentage of patients in a subsequent palliative care phase who remain in the unstable phase for less than 7 days **Numerator**: - **Denominator**: - **Exclusion**: - **Performance standard:** 90%	
92 $^{\text{NEW}}$ ELCQuA, 2011 Care for individuals is coordinated across organisational boundaries 24 hours a day, seven days a week. Outcome **Numerator:** Number of emergency admissions for patients in last 12 months of life **Denominator:** Total deaths for same time period **Exclusion**: - **Performance standard**: -	**Belgium** Nominator: number of patients admitted more than once to the emergency room since admission or start of palliative care Denominator: total number of patients for whom this indicator was measured (Ph) Outcome **Sweden** Two or more admissions to hospital during the last month in life - not covered by the register Process
Domain 2 Physical Aspects of Care	
96 Keay, 1994 If a patient had pain, this is followed to assess results of intervention and pain is reduced. Process/outcome **Numerator: -** **Denominator:-**	**Australia** Benchmark 3.1: At least 90% of patients with absent or mild PCPSS pain at the beginning of their phase of palliative care have absent or mild PCPSS pain at the end of the phase Benchmark 3.2: At least 60% of patients with moderate or severe PCPSS pain at the beginning of their phase of palliative care have absent or mild PCPSS pain at the end of the phase. Benchmark 3.3: At least 90% of patients with absent or mild SAS pain at the beginning of their phase of palliative care have absent or mild SAS pain at the end of the phase.

Exclusion: Intractable pain ever after consultation **Performance standard: >** 80%	Benchmark 3.4: At least 60% of patients with moderate or severe SAS pain at the beginning of their phase of palliative care have absent or mild SAS pain at the end of the phase All outcome **Belgium** Nominator: number of patients who, after treatment, experienced significant improvement in pain Denominator: total number of patients treated for pain (Pa) Outcome **United States** Comfortable Dying: Pain Brought to a Comfortable Level Within 48 Hours of Initial Assessment Numerator Statement: Patients whose pain was brought to a comfortable level (as defined by patient) within 48 hours of initial assessment. Denominator Statement: Patients who replied "yes" when asked if they were uncomfortable because of pain at the initial assessment. Outcome
102 Peruselli, 1997 Palliative care services must meet the physical, psychological, social and spiritual needs of patients. Outcome **Numerator:** Number of patients with score for pain control (STAS item) dropped after 8 days of care (if initial score >0)	**As above – measures looking for noted improvement in pain**

Denominator: Total patients x 100 **Exclusion: -** **Performance standard:** 75%	
104 Peruselli, 1997 Palliative care services must meet the physical, psychological, social and spiritual needs of patients. Outcome **Numerator:** Number of patients with global scores for pain (TIQ scale) dropped after 8 days of care (if initial score on the same scale > 25) **Denominator:** Total patients x 100 **Exclusion: -** **Performance standard:** 75%	**As above – measures looking for noted improvement in pain**
106 National Hospice and Palliative Care Organization (NHPCO), 2006 Brown University, 2006 Family evaluation of hospice care: Symptom management Questions: B1: While under the care of hospice, did the patient have pain or take medicine for pain? B2: How much medicine did the patient receive for his/her pain? Process **Numerator:** Those who received too much or too little help concerning pain **Denominator:** Those who experience pain **Exclusion:** Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded **Performance standard: -**	Family Evaluation of Hospice Care (tool with 54 questions for bereaved caregivers to complete) Measure = Numerator Statement: The numerator is the sum total of the weighted incidence of problem scores occurring in response to 17 specific items on each survey. The 17 questions focus on the following aspects of hospice care: symptom management, communication, provision of information, emotional support and care coordination. Denominator Statement: The denominator represents the number of surveys with responses for at least 14 of the 17 questions required to compute the composite score in the FEHC survey.

107 National Hospice and Palliative Care Organization (NHPCO), 2006 Comfortable dying Outcome **Numerator:** Patients whose pain was brought under control within 48 hours of admission to hospice **Denominator:** Patients who were uncomfortable because of pain on admission to hospice **Exclusion: -** **Performance standard: -**	Comfortable Dying: Pain Brought to a Comfortable Level Within 48 Hours of Initial Assessment Numerator Statement: Patients whose pain was brought to a comfortable level (as defined by patient) within 48 hours of initial assessment. Denominator Statement: Patients who replied "yes" when asked if they were uncomfortable because of pain at the initial assessment.
108 Twaddle, 2007 Pain assessment Percentage of all patients with documentation of pain assessment within 48 hours of admission. Process **Numerator: -** **Denominator: -** **Exclusion: -** **Performance standard: 90%**	**United States** Hospice and Palliative Care -- Pain Assessment Percentage of hospice or palliative care patients who screened positive for pain and who received a clinical assessment of pain within 24 hours of screening.
109 Twaddle, 2007 Use of a quantitative pain rating scale Percentage of patients with pain evaluated according to a numeric or other validated pain scale. Process	**Belgium** Nominator: number of patients who were subjected to a general symptom assessment on a validated scale Denominator: total number of patients for whom this indicator was measured (Ca) Process **Sweden**

Numerator: - **Denominator:** Patients reporting pain within 48 hours of admission **Exclusion: -** **Performance standard:** 90%	Proportion with systematic pain assessment Process **United States** Patients with Advanced Cancer Screened for Pain at Outpatient Visits Percentage of adult patients with advanced cancer who have an assessment of pain with a standardized quantitative tool at each outpatient visit. Process
110 Twaddle, 2007 Reduction or relief of pain Percentage of patients with pain relieved or reduced (i.e. pain score of 3 or less) within 48 hours of admission. Outcome **Numerator: -** **Denominator:** Patients reporting pain **Exclusion: -** **Performance standard: 90%**	**United States** Comfortable Dying: Pain Brought to a Comfortable Level Within 48 Hours of Initial Assessment Numerator Statement: Patients whose pain was brought to a comfortable level (as defined by patient) within 48 hours of initial assessment. Denominator Statement: Patients who replied "yes" when asked if they were uncomfortable because of pain at the initial assessment. Ouctome
120 NEW Schenck, 2010 Physical Aspects of Care: Percent of patients screened for pain during the admission visit. Process **Numerator:** Number of patients with pain time=0 **Denominator:** # of patients (Pain time = pain screening date – date of admission)	**United States** Hospice and Palliative Care -- Pain Screening Percentage of hospice or palliative care patients who were screened for pain during the hospice admission evaluation / palliative care initial encounter. Process

Exclusion: - **Performance standard: -**	
121 NEW Schenck, 2010 Physical Aspects of Care: For patients who screened positive for pain, the percent with clinical assessment within 1 day of screening. Process **Numerator:** Number of patients with (0<=Clinical Pain Time<=1) **Denominator:** Patients with pain (Clinical Pain Time= screening date – pain assessment date) **Exclusion: -** **Performance standard: -**	**United States** Hospice and Palliative Care -- Pain Assessment Percentage of hospice or palliative care patients who screened positive for pain and who received a clinical assessment of pain within 24 hours of screening Process
128 NEW Lorenz, 2009 Pain: IF a cancer patient has a cancer-related outpatient visit THEN there should be screening for the presence or absence and intensity of pain using a numeric pain score. Process **Numerator**: - **Denominator**: - **Exclusion**: - **Performance standard**: -	**United States** Patients with Advanced Cancer Screened for Pain at Outpatient Visits Percentage of adult patients with advanced cancer who have an assessment of pain with a standardized quantitative tool at each outpatient visit. Process
130 NEW Lorenz, 2009 Pain: IF a patient with cancer pain is started on a long-acting opioid formulation, THEN a short-acting opioid formulation for breakthrough pain should also be provided. Process	**Sweden** Proportion with individualized prn parenteral opioid medication Process

Numerator: - **Denominator**: - **Exclusion**: - **Performance standard**: -	
134 NEW Claessen, 2011 Management of pain and other physical symptoms: Percentage of patients with moderate to severe pain Pain is a common symptom in the palliative phase. The quality of both pharmacological and non-pharmacological interventions influences the severity of pain. Outcome **Numerator:** The number of patients with a pain score of 4 or above on the NRS (average over 3 days) **Denominator:** The total number of patients for whom this indicator is measured **Exclusion:** Comatose and deeply sedated patients **Performance standard: -**	**Netherlands** Percentage of patients with moderate to severe pain Outcome
135 NEW Eagar, 2010 Change in pain Change in pain is calculated by the difference in pain score from the beginning of a phase to the end of phase and is calculated using both PSS pain and SAS pain measures. Outcome Percentage of patients with absent or mild pain at the beginning of their phase of palliative care have absent or mild pain at the end of the phase **Numerator**: -	**Australia** Benchmark 3.1: At least 90% of patients with absent or mild PCPSS pain at the beginning of their phase of palliative care have absent or mild PCPSS pain at the end of the phase. Benchmark 3.2: At least 60% of patients with moderate or severe PCPSS pain at the beginning of their phase of palliative care have absent or mild PCPSS pain at the end of the phase. Benchmark 3.3: At least 90% of patients with absent or mild SAS pain at the beginning of their phase of palliative care have absent or mild SAS pain at the end of the phase.

Denominator: - **Exclusion**: - **Performance standard:** 90% Percentage of patients with moderate or severe pain at the beginning of their phase of palliative care have absent or mild pain at the end of the phase **Numerator**: - **Denominator**: - **Exclusion**: - **Performance standard**: 60%	Benchmark 3.4: At least 60% of patients with moderate or severe SAS pain at the beginning of their phase of palliative care have absent or mild SAS pain at the end of the phase.
137 Keay, 1994 Dyspnea, if present, is addressed and attempts are made to minimize dyspnea. Process **Numerator: -** **Denominator: -** **Exclusion:** Physicians not made aware of dyspnea **Performance standard:** 100%	**Australia** Benchmark 3.7: At least 90% of patients with absent or mild breathing problems at the beginning of their phase of palliative care have absent or mild breathing problems at the end of the phase. Benchmark 3.8: At least 60% of patients with moderate or severe breathing problems at the beginning of their phase of palliative care have absent or mild breathing problems at the end of the phase. Outcome **Belgium** Nominator: number of patients whose shortness of breath was relieved within 48 hours after admission or starting palliative care Denominator: total number of patients with shortness of breath (Ca) Outcome **United States** Hospice and Palliative Care -- Dyspnea Treatment Percentage of patients who screened positive for dyspnea who received treatment within 24 hours of screening.

140 National Hospice and Palliative Care Organization (NHPCO), 2006 Brown University, 2006 Family evaluation of hospice care: Symptom management Questions: B5: While under the care of hospice, did the patient have trouble breathing? B6: How much help in dealing with his/her breathing did the patient receive while under the care of hospice? Outcome **Numerator:** Those who received too much or too little help concerning shortness of breath **Denominator:** Those who experience shortness of breath **Exclusion:** Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded **Exclusion: -** **Performance standard: -**	Family Evaluation of Hospice Care (tool with 54 questions for bereaved caregivers to complete) Measure = Numerator Statement: The numerator is the sum total of the weighted incidence of problem scores occurring in response to 17 specific items on each survey. The 17 questions focus on the following aspects of hospice care: symptom management, communication, provision of information, emotional support and care coordination. Denominator Statement: The denominator represents the number of surveys with responses for at least 14 of the 17 questions required to compute the composite score in the FEHC survey.
141 Twaddle, 2007 Dyspnea assessment Percentage of all patients with documentation of dyspnea assessment within 48 hours of admission. Process **Numerator: -** **Denominator: -** **Exclusion: -** **Performance standard:** 90%	**United States** Hospice and Palliative Care -- Dyspnea Treatment Percentage of patients who screened positive for dyspnea who received treatment within 24 hours of screening. Hospice and Palliative Care -- Dyspnea Screening Percentage of hospice or palliative care patients who were screened for dyspnea during the hospice admission evaluation / palliative care initial encounter.
142	**Belgium**

Twaddle, 2007 Reduction or relief of dyspnea Percentage of patients with dyspnea relieved or reduced (i.e. score of 3 or less on a 10-point scale) within 48 hours of admission. Outcome **Numerator: -** **Denominator:** Patients reporting dyspnea **Exclusion: -** **Performance standard:** 90%	Nominator: number of patients whose shortness of breath was relieved within 48 hours after admission or starting palliative care Denominator: total number of patients with shortness of breath (Ca)
151 NEW Schenck, 2010 Physical Aspects of Care: Percent of patients who were screened for shortness of breath during the admission visit. Process **Numerator:** Number of patients with dyspnea time=0 (Dyspnea time = dyspnea screening date –date of admission) **Denominator:** # of patients **Exclusion: -** **Performance standard: -**	**United States** Hospice and Palliative Care -- Dyspnea Screening Percentage of hospice or palliative care patients who were screened for dyspnea during the hospice admission evaluation / palliative care initial encounter. Process
152 NEW Schenck, 2010 Physical Aspects of Care: For patients who screened positive for dyspnea, the percent who received treatment within 1 day of screening. Process **Numerator:** Number of patients with (0<=Dyspnea Treatment Time<=1 and dyspnea treatment="Y")	United States Hospice and Palliative Care -- Dyspnea Treatment Percentage of patients who screened positive for dyspnea who received treatment within 24 hours of screening. Process

Dyspnea Treatment time = date of treatment – dyspnea assessment date **Denominator:** # patients with dyspnea **Exclusion: -** **Performance standard: -**	
161 NEW Claessen, 2011 Management of pain and other physical symptoms: Percentage of patients with shortness of breath Shortness of breath often occurs in the palliative phase and can to a certain extent be influenced by pharmacological interventions (e.g. antibiotics, anticoagulants) and non-pharmacological interventions (e.g. oxygen administration, suction). Outcome **Numerator:** The number of patients with a shortness of breath score of 4 or above on the NRS (average over 3 days) **Denominator:** The total number of patients for whom this indicator is measured **Exclusion:** Comatose and deeply sedated patients **Performance standard: -**	**Netherlands** Percentage of patients with shortness of breath Outcome
162 Peruselli, 1997 Palliative care services must meet the physical, psychological, social and spiritual needs of patients. Outcome **Numerator:** Number of patients with global scores for constipation (TIQ scale) dropped after 8 days of care (if initial score on the same scale > 25) **Denominator:** Total patients x 100 **Exclusion: -** **Performance standard:** 75%	**Netherlands** Percentage of patients with constipation Outcome

166 Twaddle, 2007 Bowel regimen ordered in conjunction with opioid administration Percentage of patients receiving opioids who had an order for a bowel regimen written within 24 hours of order for the opioid. Process **Numerator: -** **Denominator: -** **Exclusion: -** **Performance standard:** 90%	**United States** Patients Treated with an Opioid who are Given a Bowel Regimen Percentage of vulnerable adults treated with an opioid that are offered/prescribed a bowel regimen or documentation of why this was not needed Process
171 NEW Schenck, 2010 Physical Aspects of Care: Percent of residents on opioids for whom a bowel regimen is established. Process **Numerator:** Number of patients with opioids=”Y” and bowel regimen=”Y” **Denominator: #** patients on opioids **Exclusion: -** **Performance standard: -**	**United States** Patients Treated with an Opioid who are Given a Bowel Regimen Percentage of vulnerable adults treated with an opioid that are offered/prescribed a bowel regimen or documentation of why this was not needed Process
173 NEW Lorenz, 2009 Pain: IF a patient with cancer pain is started on chronic opioid treatment THEN s/he should be offered either a prescription or non-prescription bowel regimen within 24 hours OR there should be documented contraindication to a bowel regimen. Process	**United States** Patients Treated with an Opioid who are Given a Bowel Regimen Percentage of vulnerable adults treated with an opioid that are offered/prescribed a bowel regimen or documentation of why this was not needed Process

Numerator: - **Denominator**: - **Exclusion**: - **Performance standard**: -	
184 NEW Claessen, 2011 Management of pain and other physical symptoms: Percentage of patients with constipation Constipation is a frequent and burdensome problem in the palliative phase and can be influenced particularly by pharmacological interventions (e.g. laxantia). Outcome **Numerator:** The number of patients with a constipation score of 4 or above on the NRS (average over 3 days) **Denominator:** The total number of patients for whom this indicator is measured **Exclusion:** Comatose and deeply sedated patients **Performance standard: -**	**Netherlands** Percentage of patients with constipation Outcome
185 Peruselli, 1997 Palliative care services must meet the physical, psychological, social and spiritual needs of patients. Outcome **Numerator:** Number of patients with global scores for fatigue (TIQ scale) dropped after 8 days of care (if initial score on the same scale > 25) **Denominator:** Total patients x 100 **Exclusion: -** **Performance standard:** 75%	**Australia** Benchmark 3.5: At least 90% of patients with absent or mild fatigue at the beginning of their phase of palliative care have absent or mild fatigue at the end of the phase. Benchmark 3.6: At least 60% of patients with moderate or severe fatigue at the beginning of their phase of palliative care have absent or mild fatigue at the end of the phase. **Netherlands** Percentage of patients with fatigue Outcome
191	**Netherlands**

NEW Claessen, 2011 Management of pain and other physical symptoms: Percentage of patients with fatigue Fatigue is one of the most common symptoms in cancer patients. Both pharmacological and non-pharmacological interventions (e.g. relaxation therapy) are appropriate treatment options. Outcome **Numerator:** The number of patients with a fatigue score of 4 or above on the NRS (average over 3 days) **Denominator:** The total number of patients for whom this indicator is measured **Exclusion:** Comatose and deeply sedated patients **Performance standard: -**	Percentage of patients with fatigue Outcome
192 Yabroff, 2004 Percentage of patients within and among health facilities or systems with evidence that symptom relief was achieved and unmet needs were met with appropriate response or resolved. Outcome **Numerator: -** **Denominator: -** **Exclusion: -** **Performance standard: -**	**Belgium** Nominator: number of patients whose symptom burden was mostly or completely under control in the final week of life Denominator: total number of patients for whom a palliative care service was involved for at least 3 days (Ph) **Netherlands** Extent to which patients receive support for their physical symptoms (pain, fatigue, shortness of breath, and constipation) **United States** CAHPS® Hospice Survey (family experience with care) – Getting Help for Symptoms (numerator / denominator description provided above) Outcome
194 Peruselli, 1997	**Belgium**

Palliative care services must meet the physical, psychological, social and spiritual needs of patients. Outcome **Numerator:** Number of patients with score symptom control other than pain (STAS item) of 0-1 during final week of life **Denominator:** Total patients x 100 **Exclusion: -** **Performance standard:** 75%	Nominator: number of patients whose symptom burden was mostly or completely under control in the final week of life Denominator: total number of patients for whom a palliative care service was involved for at least 3 days (Ph)
200 NEW van der Ploeg, 2008 This indicator suits domain 2,3,4 and 8. IF a vulnerable elder dies with a progressive incurable disease (for example metastatic cancer, or dementia) THEN there should be evidence within 6 months prior to death that they received a comprehensive assessment including: • Pain; • Anxiety, depression; • Vomiting and dyspnea; • Spiritual and existential concerns; • Caregiver burdens/need for practical assistance; • Wishes concerning medical treatment and care at the end of life; A discussion about and if possible the determination of a surrogate decision maker. Process **Numerator: -** **Denominator: -** **Exclusion: -** **Performance standard: -**	**Belgium** Nominator: number of patients about whom a conversation about their care preferences took place between the caregivers and family carers in the first week after admission or start of palliative care Denominator: total number of patients for whom this indicator was measured (Ca) Nominator: number of patients for whom the prognosis, psychosocial symptoms, functional status, symptom burden and documentation about care wishes were entered in the file within 48 hours after admission or starting palliative care Denominator: total number of patients for whom this indicator was measured (Ca)
201	**Sweden**

$^{\text{NEW}}$ Miyashita, 2008 Sato, 2008 Symptom control: Observation and care of mouth Process **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization **Denominator:** All patients who died (retrospectively identified) **Exclusion: -** **Performance standard: -**	Proportion with documented assessment of oral health
Domain 3: Psychological and Psychiatric Aspects of Care	
210 Saliba, 2004 IF a nursing home resident was conscious during any of the last 7 days of life and died an expected death THEN there should be medical record documentation about emotional distress (presence, absence, or inability to assess) in the last 7 days of life. Process **Numerator**:- **Denominator**: - **Exclusion**: - **Performance standard**: -	**Belgium** Nominator: number of patients with a score of 5 or more on a scale of 0 to 10 for quality of life Denominator: total number of patients for whom this indicator was measured (Pa) **Netherlands** Percentage of patients with anxiety Percentage of patients who feel depressed Extent to which patients indicate that they have access to a counselor for spiritual problems Extent to which relatives indicate that the patient had access to a counselor for spiritual problems **United States** Beliefs and Values - Percentage of hospice patients with documentation in the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/caregiver did not want to discuss.
212	**Netherlands**

Peruselli, 1997 Palliative care services must meet the physical, psychological, social and spiritual needs of patients. Outcome **Numerator**: Number of patients with score for patient anxiety (STAS item) of 0-1 during final week of life **Denominator**: Total patients x 100 **Exclusion**: - **Performance standard**: 75%	Percentage of patients with anxiety
National Hospice and Palliative Care Organization (NHPCO), 2006 Brown University, 2006 Family evaluation of hospice care: Symptom management Questions: B9: While under the care of hospice, did the patient have any feelings of anxiety or sadness? B10: How much help in dealing with these feelings did the patient receive? Outcome **Numerator**: Those who received too much or too little help concerning anxiety/sadness **Denominator**: Those who experience anxiety/sadness **Exclusion**: Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded **Performance standard**: -	Family Evaluation of Hospice Care (tool with 54 questions for bereaved caregivers to complete) Measure = Numerator Statement: The numerator is the sum total of the weighted incidence of problem scores occurring in response to 17 specific items on each survey. The 17 questions focus on the following aspects of hospice care: symptom management, communication, provision of information, emotional support and care coordination. Denominator Statement: The denominator represents the number of surveys with responses for at least 14 of the 17 questions required to compute the composite score in the FEHC survey.
218 NEW Miyashita, 2008 Sato, 2008	**Netherlands** Percentage of patients with anxiety

Psychosocial and spiritual concerns: Degree and content of patient's anxiety. Outcome **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization **Denominator:** All patients who died (retrospectively identified) **Exclusion: -** **Performance standard: -**	
221 NEW Claessen, 2011 Care for psychosocial well-being of patients: Percentage of patients with anxiety Anxiety is a common symptom for many patients in the palliative phase, as a reaction to their illness and the prospect of approaching death. Anxiety can be influenced by pharmacological and non-pharmacological interventions (e.g. psychosocial support). Outcome **Numerator:** The number of patients with an anxiety score of 4 or above on the NRS (average over 3 days) **Denominator:** The total number of patients for whom this indicator is measured. **Exclusion:** Patients with moderate to (very) severe cognitive impairments, young children, psychiatric and/or confused patients, and comatose and deeply sedated patients **Performance standard: -**	**Netherlands** Percentage of patients with anxiety
222 NEW Schenck, 2010 Psychological Aspects of Care: For patients who screened positive for depression, the percent who received further assessment, counseling or medication treatment.	**Netherlands** Extent to which patients receive support when they feel anxious or feel depressed Process

Process **Numerator:** Number of patients with depression further assessment="Y" **Denominator:** # patients with depression screening=Yes **Exclusion: -** **Performance standard: -**	
226 NEW Claessen, 2011 Care for psychosocial well-being of patients: Percentage of patients who feel depressed Depression is a common symptom in the palliative phase, and can be influenced most by non-pharmacological interventions (listening to them), and to a lesser extent by pharmacological interventions (e.g. antidepressants). Outcome **Numerator:** The number of patients with a feeling depressed score of 4 or above on the NRS (average over 3 days). **Denominator:** The total number of patients for whom this indicator is measured. **Exclusion:** Patients with moderate to (very) severe cognitive impairments, young children, psychiatric and/or confused patients, and comatose and deeply sedated patients **Performance standard: -**	**Netherlands** Percentage of patients who feel depressed
229 National Hospice and Palliative Care Organization (NHPCO), 2006 Brown University, 2006 Attend to family needs (Family evaluation of hospice care) Questions:	

E2: Did you have as much contact about your religious or spiritual beliefs as you wanted? E3: How much emotional support did the hospice team provide to you prior to the patient's death? E4: How much emotional support did the hospice team provide to you after the patient's death? Outcome **Numerator**: Sum of 1 response to survey instrument by family member of deceased patient **Denominator**: Number of items (=3) **Exclusion**: Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded **Performance standard**: -	
230 Yabroff, 2004 Percentage of patients within and among health facilities or systems with evidence for ongoing quality of life assessment reflected in the treatment plan. Process **Numerator**: - **Denominator**: - **Exclusion**: - **Performance standard**: -	**Belgium** Nominator: number of patients with a score of 5 or more on a scale of 0 to 10 for quality of life Denominator: total number of patients for whom this indicator was measured (Pa) Outcome **Netherlands** Extent to which patients indicate that they feel that life is worthwhile Outcome
235 Peruselli, 1997 Palliative care services must meet the physical, psychological, social and spiritual needs of patients.	**Australia** Benchmark 3.9: At least 90% of patients with absent or mild family / carer problems at the beginning of their phase of palliative care have absent or mild family / carer problems at the end of the phase.

Outcome **Numerator**: Number of patients with score for communication between patient en family (STAS item) dropped after 8 days of care (if initial score >0) **Denominator**: Total patients x 100 **Exclusion**: - **Performance standard**: 75%	Benchmark 3.10: At least 60% of patients with moderate or severe family / carer problems at the beginning of their phase of palliative care have absent or mild family / carer problems at the end of the phase
238 NEW Miyashita, 2008 Psychosocial and spiritual concerns: Patient's preference of daily living. Outcome **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization **Denominator:** All patients who died (retrospectively identified) **Exclusion: -** **Performance standard: -**	**Belgium** Nominator: number of patients who indicated that the caregivers most of the times or always respected their personal wishes and that they could most of the time or always plan their day and decide about the care provided Denominator: total number of patients for whom this indicator was measured (Pa) **Netherlands** Extent to which patients experience respect for their autonomy
239 Keay, 1994 Psychological or social support is documented in the patient's medical record Process **Numerator**: - **Denominator**: - **Exclusion**: Patient death within a few hours of being declared terminally ill; patient cognitively impaired *and* family or friends are not reasonably available **Performance standard**: > 80%	**Belgium** Nominator: number of patients who indicated that the caregivers regularly assessed how they were feeling Denominator: total number of patients for whom this indicator was measured (Pa) Nominator: number of family carers who indicated that the caregivers regularly talked to them about what it meant to them to care for their ill next of kin Denominator: total number of family carers who cared for their ill next of kin (Fc) Nominator: number of family carers who indicated that the caregivers regularly asked how they were feeling Denominator: total number of family carers for whom this indicator was measured

	(Fc) Nominator: number of patients for whom the prognosis, psychosocial symptoms, functional status, symptom burden and documentation about care wishes were entered in the file within 48 hours after admission or starting palliative care Denominator: total number of patients for whom this indicator was measured (Ca) **Netherlands** *B. Care for psychosocial well-being – 8 indicators listed under this heading* *E. Care for psychosocial and spiritual well-being of relatives – 4 indicators listed under this heading* **United States** CAHPS® Hospice Survey (family experience with care) – Getting Emotional and Religious Support (numerator / denominator description provided above)
Domain 4: Social aspects of care	
242 Lorenz, 2007 NEW van der Ploeg, 2008 Caregiver stress IF a VE is a caregiver for a spouse, significant other , or dependent who is terminally ill or has very limited function, THEN the VE should be assessed for caregiver financial, physical, and emotional stress, BECAUSE caregiver burden is substantial in these situations and associated with poor outcomes. Process **Numerator**: - **Denominator**: - **Exclusion**: - **Performance standard**: -	**Belgium** Nominator: number of patients who indicated that the caregivers regularly assessed how they were feeling Denominator: total number of patients for whom this indicator was measured (Pa) Nominator: number of family carers who indicated that the caregivers regularly talked to them about what it meant to them to care for their ill next of kin Denominator: total number of family carers who cared for their ill next of kin (Fc) Nominator: number of family carers who indicated that the caregivers regularly asked how they were feeling Denominator: total number of family carers for whom this indicator was measured (Fc) **Netherlands**

	E. Care for psychosocial and spiritual well-being of relatives – 4 indicators listed under this heading **United States** CAHPS® Hospice Survey (family experience with care) – Getting Emotional and Religious Support (numerator / denominator description provided above)
243 NEW Miyashita, 2008 Family care: Care strategy for family Process **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization **Denominator:** All patients who died (retrospectively identified) **Exclusion: -** **Performance standard: -**	**Belgium** Nominator: number of patients who indicated that the caregivers regularly assessed how they were feeling Denominator: total number of patients for whom this indicator was measured (Pa) Nominator: number of family carers who indicated that the caregivers regularly talked to them about what it meant to them to care for their ill next of kin Denominator: total number of family carers who cared for their ill next of kin (Fc) Nominator: number of family carers who indicated that the caregivers regularly asked how they were feeling Denominator: total number of family carers for whom this indicator was measured (Fc)
246 NEW Quality Markers, 2009 QM for primary care: They have mechanisms in place to assess and document the needs of carers of those approaching the end of life (Royal College of General Practicioners' Supporting Carers). Process Proportion of carers who have been referred to a carer's assessment and whose needs have been recorded	**Australia** Benchmark 3.9: At least 90% of patients with absent or mild family / carer problems at the beginning of their phase of palliative care have absent or mild family / carer problems at the end of the phase. Benchmark 3.10: At least 60% of patients with moderate or severe family / carer problems at the beginning of their phase of palliative care have absent or mild family / carer problems at the end of the phase **Belgium**

Numerator: - **Denominator**: - **Exclusion**: - **Performance standard**: -	Nominator: number of patients who indicated that the caregivers regularly assessed how they were feeling Denominator: total number of patients for whom this indicator was measured (Pa) Nominator: number of family carers who indicated that the caregivers regularly talked to them about what it meant to them to care for their ill next of kin Denominator: total number of family carers who cared for their ill next of kin (Fc) Nominator: number of family carers who indicated that the caregivers regularly asked how they were feeling Denominator: total number of family carers for whom this indicator was measured (Fc) **Netherlands** *E. Care for psychosocial and spiritual well-being of relatives* E1. Extent to which, according to the direct relatives, attention was paid to their own psychosocial and spiritual well-being
253 NEW Sato, 2008 Family care: Discussion with family about goals of care. Process **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization **Denominator:** All patients who died (retrospectively identified) **Exclusion: -** **Performance standard: -**	**Belgium** Nominator: number of family carers who received the right amount of information about the patient's condition and treatments Denominator: total number of family carers for whom this indicator was measured (Fc) Nominator: number of patients about whom a conversation about their care preferences took place between the caregivers and family carers in the first week after admission or start of palliative care Denominator: total number of patients for whom this indicator was measured (Ca) Nominator: number of patients whose caregivers were given the care objectives and resuscitation status during or after admission or starting palliative care Denominator: total number of patients for whom this indicator was measured (Ca) **Netherlands**

	F. Generic (in the care for relatives) F1. Extent to which direct relatives received information that was understandable and unambiguous at the time of the patient's death F2. Extent to which direct relatives received information about the advantages and disadvantages of various types of treatment **United States** CAHPS® Hospice Survey (family experience with care) – Hospice Team Communication CAHPS® Hospice Survey (family experience with care) – Treating Family Member with Respect
Domain 5: Spiritual, Religious and Existential Aspects of Care	
255 NEW Miyashita, 2008 Sato, 2008 Psychosocial and spiritual concerns: Patient's religion. Outcome **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization **Denominator:** All patients who died (retrospectively identified) **Exclusion: -** **Performance standard: -**	**United States** Beliefs and Values - Percentage of hospice patients with documentation in the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/caregiver did not want to discuss. CAHPS® Hospice Survey (family experience with care) – Getting Emotional and Religious Support (numerator / denominator description provided above)
256 NEW Schenck, 2010 Spiritual Aspects of Care: Percent of patients with chart documentation of a discussion of spiritual concerns. Outcome	**United States** Beliefs and Values - Percentage of hospice patients with documentation in the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/caregiver did not want to discuss.

Numerator: Number of patients with spiritual discussion = "Y" **Denominator:** Total number of patients **Exclusion: -** **Performance standard: -**	
258 NEW Claessen, 2011 Care for spiritual well-being of patients: Percentage of relatives who indicate that the patient died peacefully If patients die peacefully, this can indicate that in this respect their spiritual needs were met. Outcome **Numerator:** The number of relatives who indicate that their relative died peacefully **Denominator:** The total number of relatives among whom this quality indicator was measured **Exclusion: -** **Performance standard:**	**Netherlands** Percentage of relatives who indicate that the patient died peacefully
259 NEW Claessen, 2011 Care for spiritual well-being of patients: Percentage of relatives who indicate that the patient had accepted her/his approaching death. If patients accept their approaching death, this can indicate that their spiritual needs were met. Outcome **Numerator:** The number of relatives who indicate that their relative had accepted approaching death **Denominator:** The total number of relatives among whom this quality indicator was measured **Exclusion: -**	Netherlands Percentage of relatives who indicate that the patient had accepted her/his approaching death

Performance standard:	
Domain 6: Cultural Aspects of Care (1 indicator) – no matches	
Domain 7: Care for the imminently dying patient (26 indicators)	
261 Earle, 2006 Proportion receiving chemotherapy in the last 14 days of life. Process **Numerator**: Patients who died from cancer and received chemotherapy in the last 14 days of life **Denominator**: Patients who died from cancer **Exclusion**: - **Performance standard**: < 10%	**United States** Proportion of patients who died from cancer receiving chemotherapy in the last 14 days of life
262 Earle, 2006 Proportion with more than one emergency room (ER) visit in the last 30 days of life. Process **Numerator**: Patients who died from cancer and had > 1 ER visit in the last 30 days of life **Denominator**: Patients who died from cancer **Exclusion**: - **Performance standard**: < 4%	**Belgium** Nominator: number of patients admitted more than once to the emergency room since admission or start of palliative care Denominator: total number of patients for whom this indicator was measured (Ph)
263 NEW Grunfeld, 2008 Frequency of ER visits High number of emergency room visits near death may indicate poor quality care.	**Belgium** Nominator: number of patients admitted more than once to the emergency room since admission or start of palliative care Denominator: total number of patients for whom this indicator was measured (Ph)

Outcome **Numerator:** Number of cases with more than 1 ER visit in the last 30 days **Denominator:** entire cohort **Exclusion: -** **Performance standard: -** **Numerator:** Number of ER visits in the last 30 days averaged across entire cohort **Denominator: -** **Exclusion: -** **Performance standard: -** **Numerator:** Sum of ER visits across entire cohort **Denominator:** The sum of available days (i.e., days out of hospital) across entire cohort) **Exclusion: -** **Performance standard: -**	
264 Earle, 2006 Proportion with more than one hospitalization in the last 30 days of life. Process **Numerator**: Patients who died from cancer and had > 1 hospitalization in the last 30 days of life **Denominator**: Patients who died from cancer **Exclusion**: - **Performance standard**: < 4%	**Sweden** Two or more admissions to hospital during the last month in life - not covered by the register
265 Earle, 2006 Proportion admitted to the ICU in the last 30 days of life. Process	**United States** Proportion of patients who died from cancer admitted to the ICU in the last 30 days of life

Numerator: Patients who died from cancer and were admitted to the ICU in the last 30 days of life **Denominator**: Patients who died from cancer **Exclusion**: - **Performance standard**: < 4%	
NEW Grunfeld, 2008 ICU stays near the end of life Hospital stays in the terminal period of cancer may indicate poor quality care. Outcome **Numerator:** Number of cases with one or more ICU admissions in the last 30 days **Denominator:** Entire cohort **Exclusion: -** **Performance standard: -**	**Belgium** Nominator: number of patients admitted to the intensive care unit since admission or start of palliative care Denominator: total number of patients for whom this indicator was measured (Ph)
267 NEW Grunfeld, 2008 Enrollment in palliative care within 3 days of death A high proportion may indicate poor quality care. Palliative care should be accessible to all patients and families with a cancer diagnosis, in a timely manner, throughout the entire duration of their disease. Process **Numerator:** Number of cases enrolled in palliative care within three days prior to death **Denominator:** All cases enrolled in palliative care **Exclusion: -** **Performance standard: -**	**Belgium** Nominator: number of patients whose palliative care started at least 2 weeks before death Denominator: total number of patients for whom this indicator was measured (Ph) **United States** Proportion of patients who died from cancer admitted to hospice for less than 3 days
273	**Belgium**

Keay,1994 Follow-up bereavement counseling is offered by the physician. Process **Numerator**: - **Denominator**: - **Exclusion**: - **Performance standard**: -	Nominator: number of family carers who felt they had adequate support after the patient's death (inclusive evaluation meeting) and were informed of the possibilities of after-care. Denominator: total number of family carers for whom this indicator was measured (Fc) **Netherlands** Extent to which direct relatives felt supported by the caregivers immediately after the patient’s death Extent to which direct relatives were informed about the possibilities of aftercare Extent to which a final conversation or discussion was held to evaluate the care and the treatment
274 National Hospice and Palliative Care Organization (NHPCO), 2006 Brown University, 2006 Inform and communicate about patient (Family evaluation of hospice care) Questions: D5: How often did the hospice team keep you or other family members informed about the patient’s condition? D7: Would you have wanted more information about what to expect while the patient was dying? Process **Numerator**: Sum of 1 response to survey instrument by family member of deceased patient **Denominator**: Number of items (=2) **Exclusion**: Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded **Performance standard**: -	**United States** Family Evaluation of Hospice Care (tool with 54 questions for bereaved caregivers to complete) Measure = Numerator Statement: The numerator is the sum total of the weighted incidence of problem scores occurring in response to 17 specific items on each survey. The 17 questions focus on the following aspects of hospice care: symptom management, communication, provision of information, emotional support and care coordination. Denominator Statement: The denominator represents the number of surveys with responses for at least 14 of the 17 questions required to compute the composite score in the FEHC survey.

275 National Hospice and Palliative Care Organization (NHPCO), 2006 Brown University, 2006 Provide information about symptoms (Family evaluation of hospice care) Questions: B4: Did you want more information than you got about the medicines used to manage the patient’s pain? B8: Did you want more information than you got about what was being done for the patient’s trouble with breathing? Process **Numerator**: Sum of 1 response to survey instrument by family member of deceased patient **Denominator**: Number of items (=2) **Exclusion**: Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded **Performance standard**: -	**United States** Family Evaluation of Hospice Care (tool with 54 questions for bereaved caregivers to complete) Measure = Numerator Statement: The numerator is the sum total of the weighted incidence of problem scores occurring in response to 17 specific items on each survey. The 17 questions focus on the following aspects of hospice care: symptom management, communication, provision of information, emotional support and care coordination. Denominator Statement: The denominator represents the number of surveys with responses for at least 14 of the 17 questions required to compute the composite score in the FEHC survey.
277 NEW Quality Markers, 2009 QM for primary care: They collate information of the quality of care provided to individuals after their death for audit purposes (e.g. using a tool such as the After Death Analysis from the Gold Standards Framework). Process Proportion of carers and family members who receive support following the death of a patient **Numerator**: -	**Belgium** Nominator: number of patients who scored 5 or more on a scale of 0 – 10 for the quality of death according to family carers Denominator: total number of patients for whom this indicator was measured (Fc) Nominator: number of patients who scored 5 or more on a scale of 0 – 10 for the quality of death according to physicians Denominator: total number of patients for whom this indicator was measured (Ph) **Netherlands** Percentage of relatives who indicate that the patient died peacefully

Denominator: - **Exclusion**: - **Performance standard**: -	**United States** Bereaved Family Survey (tool with 19 items) – measures = Numerator Statement: The numerator is comprised of completed surveys (at least 12 of 17 structured items completed), where the global item question has an optimal response. The global item question asks "Overall, how would your rate the care that [Veteran] received in the last month of life" and the possible answer choices are: Excellent, Very good, Good, Fair, or Poor. The optimal response is Excellent. Denominator Statement: The denominator consists of all inpatient deaths for which a survey was completed (at least 12 of 17 structured items completed), excluding: 1) deaths within 24 hours of admission (unless the Veteran had a previous hospitalization in the last month of life); 2) deaths that occur in the Emergency Department (unless the Veteran had a prior hospitalization of at least 24 hours in the last 31 days of life); 3) deaths that occur in the operating room; and 4) deaths due to suicide or accidents. Additional exclusion criteria include: 1) Veterans for whom a family member knowledgeable about their care cannot be identified (determined by the family member´s report); or contacted (no current contacts listed or no valid addresses on file); 2) absence of a working telephone available to the family member. Family Evaluation of Hospice Care (tool with 54 questions for bereaved caregivers to complete) Measure = Numerator Statement: The numerator is the sum total of the weighted incidence of problem scores occurring in response to 17 specific items on each survey. The 17 questions focus on the following aspects of hospice care: symptom management, communication, provision of information, emotional support and care coordination. Denominator Statement: The denominator represents the number of surveys with responses for at least 14 of the 17 questions required to compute the composite score in the FEHC survey.
280 $^{\text{NEW}}$ Quality Markers, 2009 QM for primary care:	**Netherlands** Percentage of patients who died in the location of their preference

They have mechanisms in place to assess and document the needs of those approaching the end of life (e.g. use of the Gold Standards Framework or equivalent), and to discuss, record and, (where appropriate) communicate the wishes and preferences of those approaching the end of life (advance care planning). Outcome Proportion of patients who die in their preferred place for care **Numerator**: - **Denominator**: - **Exclusion**: - **Performance standard**: -	
[281] [NEW] Quality Markers, 2009 QM for primary care: They collate information of the quality of care provided to individuals after their death for audit purposes (e.g. using a tool such as the After Death Analysis from the Gold Standards Framework). Outcome Proportion of individuals who die in their preferred place **Numerator**: - **Denominator**: - **Exclusion**: - **Performance standard**: -	**Netherlands** Percentage of patients who died in the location of their preference
[282] [NEW] Quality Markers, 2009 QM for district/community nursing services. They have mechanisms in place to assess and document the needs of those approaching the end of life (e.g. use of the Gold Standards Framework or equivalent), and to discuss, record and, (where appropriate) communicate the wishes and preferences of those approaching the end of life (advance care planning). Outcome	**Netherlands** Percentage of patients who died in the location of their preference

Proportion of patients who die in their preferred place for care **Numerator**: - **Denominator**: - **Exclusion**: - **Performance standard**: -	
283 NEW Claessen, 2011 Generic aspects: Percentage of patients who died in the location of their preference Patients have the right to die wherever they wish. The patient's wishes therefore prevail. Outcome **Numerator**: The number of relatives who indicate that the patient died in the location of his/her preference **Denominator**: The total number of relatives among whom this quality indicator was measured **Exclusion**: - **Performance standard**: -	**Netherlands** Percentage of patients who died in the location of their preference
Domain 8: Ethical and legal aspects of care (45 indicators)	
288 NEW Miyashita, 2008 Sato, 2008 Decision making and preference of care: Patient's preference of place of care. Outcome **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization **Denominator:** All patients who died (retrospectively identified)	**Belgium** Nominator: number of patients about whom a conversation about their care preferences took place between the caregivers and family carers in the first week after admission or start of palliative care Denominator: total number of patients for whom this indicator was measured (Ca) Nominator: number of patients who got a positive response to (all) their request(s) for a treatment or an end-of-life decision Denominator: number of patients who requested a treatment or an end-of-life decision (Fc)

Exclusion: - **Performance standard: -**	**Netherlands** Extent to which patients in the last month before their death were in the location of their preference Percentage of patients who died in the location of their preference Presence of documentation concerning the desired care and treatment at the end of life **Sweden** Proportion with a documented discussion between physician and patient about the transition to EOL care **United States** Hospice and Palliative Care – Treatment Preferences Percentage of patients with chart documentation of preferences for life sustaining treatments
289 NEW Miyashita, 2008 Sato, 2008 Decision making and preference of care: Patient's insight of disease. Outcome **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization **Denominator:** All patients who died (retrospectively identified) **Exclusion: -** **Performance standard: -**	**Netherlands** Percentage of relatives who indicate that the patient had accepted her/his approaching death
291	**Belgium**

291 NEW Miyashita, 2008 Sato, 2008 Family care: Family's preferences or expectations. Outcome **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization **Denominator:** All patients who died (retrospectively identified) **Exclusion: -** **Performance standard: -**	Nominator: number of patients who indicated that the caregivers regularly assessed how they were feeling Denominator: total number of patients for whom this indicator was measured (Pa) Nominator: number of family carers who indicated that the caregivers regularly talked to them about what it meant to them to care for their ill next of kin Denominator: total number of family carers who cared for their ill next of kin (Fc)
292 NEW Quality Markers, 2009 QM for primary care: They (GP practices) have mechanisms in place to assess and document the needs of those approaching the end of life (e.g. use of the Gold Standards Framework or equivalent), and to discuss, record and, (where appropriate) communicate the wishes and preferences of those approaching the end of life (advance care planning). Outcome Proportion of individuals whose preferred place for care has been recorded **Numerator**: - **Denominator**: - **Exclusion**: - **Performance standard**: -	**Netherlands** Percentage of patients who died in the location of their preference
293 NEW Quality Markers, 2009	**Netherlands** Percentage of patients who died in the location of their preference

QM for district/community nursing services. They have mechanisms in place to assess and document the needs of those approaching the end of life (e.g. use of the Gold Standards Framework or equivalent), and to discuss, record and, (where appropriate) communicate the wishes and preferences of those approaching the end of life (advance care planning). Outcome Proportion of individuals whose preferred place for care has been recorded **Numerator**: - **Denominator**: - **Exclusion**: - **Performance standard**: -	
305 Lorenz, 2007 Care-preference documentation IF a VE is admitted to the ICU and survives 48 hours, THEN within 48 hours of ICU admission, the medical record should document that the patient's preferences for care have been considered or an attempt was made to identify them, BECAUSE patient's values and preferences should guide life-sustaining care. Process **Numerator**: - **Denominator**: - **Exclusion**: - **Performance standard**: -	**United States** Patients Admitted to ICU who Have Care Preferences Documented Percentage of vulnerable adults admitted to ICU who survive at least 48 hours who have their care preferences documented within 48 hours OR documentation as to why this was not done.
311 NEW Miyashita, 2008 Decision making and preference of care: Patient's preference of care or advance directives.	**Belgium** Nominator: number of patients who indicated that the caregivers most of the times or always respected their personal wishes and that they could most of the time or always plan their day and decide about the care provided Denominator: total number of patients for whom this indicator was measured

Outcome **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization **Denominator:** All patients who died (retrospectively identified) **Exclusion: -** **Performance standard: -**	(Pa) Nominator: number of patients about whom a conversation about their care preferences took place between the caregivers and family carers in the first week after admission or start of palliative care Denominator: total number of patients for whom this indicator was measured (Ca) Nominator: number of patients with whom the physician discussed the care objectives Denominator: total number of patients for whom this indicator was measured (Ph) Nominator: number of patients for whom the prognosis, psychosocial symptoms, functional status, symptom burden and documentation about care wishes were entered in the file within 48 hours after admission or starting palliative care Denominator: total number of patients for whom this indicator was measured (Ca) **Netherlands** Extent to which patients in the last month before their death were in the location of their preference Percentage of patients who died in the location of their preference Presence of documentation concerning the desired care and treatment at the end of life Extent to which relatives indicate that the patient was asked about her/his opinions with regard to end-of-life decisions **Sweden** Proportion with a documented discussion between physician and patient about the transition to EOL care **United States**

	Hospice and Palliative Care – Treatment Preferences Percentage of patients with chart documentation of preferences for life sustaining treatments.
312 NEW Sato, 2008 Decision making and preference of care: Discussion with patient about goals of care. Process **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization **Denominator:** All patients who died (retrospectively identified) **Exclusion: -** **Performance standard: -**	**Belgium** Nominator: number of patients who indicated that the caregivers most of the times or always respected their personal wishes and that they could most of the time or always plan their day and decide about the care provided Denominator: total number of patients for whom this indicator was measured (Pa) Nominator: number of patients about whom a conversation about their care preferences took place between the caregivers and family carers in the first week after admission or start of palliative care Denominator: total number of patients for whom this indicator was measured (Ca) Nominator: number of patients with whom the physician discussed the care objectives Denominator: total number of patients for whom this indicator was measured (Ph) Nominator: number of patients for whom the prognosis, psychosocial symptoms, functional status, symptom burden and documentation about care wishes were entered in the file within 48 hours after admission or starting palliative care Denominator: total number of patients for whom this indicator was measured (Ca) **Netherlands** Extent to which patients in the last month before their death were in the location of their preference Percentage of patients who died in the location of their preference Presence of documentation concerning the desired care and treatment at the end of life

	Extent to which relatives indicate that the patient was asked about her/his opinions with regard to end-of-life decisions **Sweden** Proportion with a documented discussion between physician and patient about the transition to EOL care **United States** Hospice and Palliative Care – Treatment Preferences Percentage of patients with chart documentation of preferences for life sustaining treatments.
316 NEW Schenck, 2010 Ethical and legal aspects of care: Percent of patients with chart documentation of preferences for life sustaining treatments. Outcome **Numerator:** Number of patients with documentation = "Y" **Denominator:** Number of Patients **Exclusion: -** **Performance standard: -**	**United States** Hospice and Palliative Care – Treatment Preferences Percentage of patients with chart documentation of preferences for life sustaining treatments.
322 NEW Lorenz, 2009 Information and care planning IF a patient with advanced cancer is admitted to the ICU and survives 48 hours, THEN within 48 hours of ICU admission, the medical record should document the patient's preferences for care or attempt to identify them. Process **Numerator**: - **Denominator**: -	**United States** Patients Admitted to ICU who Have Care Preferences Documented Percentage of vulnerable adults admitted to ICU who survive at least 48 hours who have their care preferences documented within 48 hours OR documentation as to why this was not done.

Exclusion: - **Performance standard**: -	
324 $^{\text{NEW}}$ Claessen, 2011 Generic aspects: Presence of documentation concerning the desired care and treatment at the end of life The patient's wishes with regard to care and treatment at the end of life must be documented. Process **Numerator**: The number of patients for whom the desired care and treatment at the end of life is documented **Denominator**: Total number of patient files consulted **Exclusion**: - **Performance standard**: -	**Netherlands** Presence of documentation concerning the desired care and treatment at the end of life
325 $^{\text{NEW}}$ ELCQuA, 2011 Individuals have an agreed care plan. Process **Numerator:** Number of deceased patients with care plan in place **Denominator:** Total deaths for same time period **Exclusion:** - **Performance standard:** Care plans in place for all patients approaching the end of life	**Belgium** Nominator: number of patients about whom multidisciplinary consultations took place at least once a week about their care objectives Denominator: total number of patients for whom the palliative care service was involved for at least 1 week (Ca) Nominator: number of patients about whom a conversation about their care preferences took place between the caregivers and family carers in the first week after admission or start of palliative care Denominator: total number of patients for whom this indicator was measured (Ca) Nominator: number of patients with whom the physician discussed the care objectives Denominator: total number of patients for whom this indicator was measured (Ph) Nominator: number of patients whose caregivers were given the care objectives and resuscitation status during or after admission or starting palliative care Denominator: total number of patients for whom this indicator was measured (Ca)

	Nominator: number of patients for whom the prognosis, psychosocial symptoms, functional status, symptom burden and documentation about care wishes were entered in the file within 48 hours after admission or starting palliative care Denominator: total number of patients for whom this indicator was measured (Ca) **Netherlands** Presence of documentation concerning the desired care and treatment at the end of life **Sweden** Proportion with a documented discussion between physician and patient about the transition to EOL care **United States** Hospice and Palliative Care – Treatment Preferences Percentage of patients with chart documentation of preferences for life sustaining treatments

Eight domains are listed within the guidelines and these are: 1) Structure and processes of care; 2) Physical aspects of care; 3) Psychological and psychiatric aspects of care; 4) Social aspects of care; 5) Spiritual, religious and existential aspects of care; 6) Cultural aspects of care; 7) Care of the patient at the end of life; 8) Ethical and legal aspects of care

Note: the De Roo et al (2013) SR completed a search of all publications up to October 2011. Therefore, additional publications may have occurred since this time. However, our search strategy did not pick up any more recent SRs for use and therefore we mapped to the latest SR found.

Summary information:

Domain (as allocated by the SR)	Matches where similar indicators used	Exact matches with available national indicators	Countries using exact matches
Domain 1.1: Structure of care (33 indicators)	3	3	United States (2) Australia (1)
Domain 1.2: Process of care (62 indicators)	19	1	United States (1)
Domain 2: Physical aspects of care (112 indicators)	18	14	United States (9) The Netherlands (4) Australia (1)
Domain 3: Psychological and psychiatric aspects of care (33 indicators)	8	4	United States (2) The Netherlands (2)
Domain 4: Social aspects of care (15 indicators)	4	0	N/A
Domain 5: Spiritual, religious and existential aspects of care (6 indicators)	1	3	United States (1) The Netherlands (2)
Domain 6: Cultural aspects of care (1 indicator)	0	0	N/A
Domain 7: Care for the imminently dying patient (26 indicators)	10	5	United States (4) The Netherlands (1)
Domain 8: Ethical and legal aspects of care (45 indicators)	10	2	United States (1) The Netherlands (1)
326 indicators*	73 (22% of total indicators listed)	32 (10% of total indicators listed) Also this is 32/128 indicators available – 17.5%	

*Note – where 1 measure was counted across multiple domains it was only counted once in this study looking at ‘matching’. Therefore, the left-hand column adds up to 333 but actually refers to 326 distinct indicators

References

1. De Roo ML, Leemans K, Claessen SJ, et al. Quality indicators for palliative care: update of a systematic review. *Journal of Pain and Symptom Management* 2013; 46: 556-572.

2. National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care, Third Edition*. Pittsburgh, United States of America 2013.

Appendix 17: Actions following a review of data from the co-creation workshop held (Study 4)

Aim: To generate a series of actions to strengthen the delivery of palliative care in the Australian acute care setting

Action	Key areas that need attention to progress this work
Evidence-informed practice and national benchmarking	Development of data items and key definitions to enable improvement work in inpatient palliative care to be underpinned by evidence. Predesigned pack to assist in experience and outcome measurement (overall focus – 10-15 questions + options to do a 'deeper dive' into each domain: Respectful and compassionate care; Effective communication and shared decision making; Effective teamwork; Enabling family involvement; Maintaining role, meaning and identity; Excellence in physical care; Impeccable assessment and care planning; Effective symptom management; Technical competence; Patient safety; Supported access to senior clinicians; Structural factors – patient focused (Eg.bed area, window access, shared rooms); Structural factors – family focused (comfort, privacy and access to food / drinks); Cleanliness to support infection control) – implementation guided by a facilitated project initially focused on redesign and support for senior clinical leadership at the ward level (via the NUM role) Predesigned pack to consider staff experience / morale and happiness at work Policy supported key definitions – palliative care, specialist palliative care, end-of-life care; Define what is specialist palliative care across NSW and related referral criteria; Define the minimal acceptable standards of care for end of life care – what are the 'vital signs' for ongoing measurement Embedded coding for identification of patients noted to be 'palliative' so retrieval of data is more possible from current sources National minimum data set for palliative care Facilitated access to complaints data Facilitated access to feedback from CEC dataset – what is possible? Reporting back in relation to data for NFR orders noted pre-death. Add to this data entry in relation to whether a family conference has been held. Facilitated access to reports for patient experience surveys conducted, linked to an identifier for a person being likely to have palliative care needs Develop a process for reporting on and reviewing expected deaths in hospital within the Morbidity and Mortality meetings (M&M meeting) as well as a mechanism for feeding this information back to the relevant nursing unit manager
Funding reforms	Challenge current funding drivers and resource allocation for people with palliative care needs, across hospitals and related care services. Link funding to noting a person as 'palliative' and remove barriers of access to support their care to live as well as possible (E.g. – rehabilitation services are currently not available to someone noted as 'palliative') Ensure consistency across each LHD in relation to palliative care resourcing and implementation of such resources Actively fund palliative care beds within acute care and resource in line with the Palliative Care Australia guidance

Securing executive level support	Explicit support from the hospital executive to underscore the importance of this work and resource it accordingly is fundamentally important. In order to secure this, develop a 'tool' to outline the importance of this work to hospital executives and highlight the key practice points required to enable optimal care. This tool needs to engage with and foster executive level champions and ensure executives are talking about the quality of care for people with palliative care needs and those imminently dying in hospital. This tool also needs to highlight the importance of valuing, resourcing and supporting staff to excel in this work and to understand the fact palliative care requirements are prevalent and care of people with palliative care needs, within the hospital setting, is everyone's business and a priority. Valuing, resourcing and supporting staff needs to explicitly include: • Explicit review and provision of staffing levels to enable optimal care for people with palliative care needs (and their families / carers), inclusive of adequate nursing, medical and allied health staffing to meet noted care needs • Executive support for supervision/de-briefing/reflective practices to support clinicians undertaking this work • Resourcing to support NUMs with education and opportunities to lead collaborative improvement work across the sector • Executive support for driving change/improvement and assisting navigation of any noted barriers • Developing a mechanism to reward excellence in care, based on the key practice points noted to enable optimal care for people with palliative care needs and their families / carers – both to acknowledge the hard work of the clinicians involved and to enable sharing of excellent practice Develop a process for palliative care to be 'at the table' at hospital executive levels and not to be at the whim of a changing senior executive role. Use data to support this including the use of economic arguments as appropriate
Mandatory clinical and ancillary education	Develop a focused education pack (with an explicit focus on communication skills) for clinicians in relation to optimal hospital based palliative care, with annual refreshers – optimal palliative care is everyone's business Develop a focused education pack for ancillary staff in relation to optimal hospital based palliative care – this needs to be considered explicitly for specific groups (E.g. – catering staff and diet aides; interpreter services; cleaners etc.), with annual refreshers Co-design, with consumer representatives, an educational tool which will touch all levels of hospital staff through orientation and other appropriate forums, which focuses on the need for kindness, gentleness, acknowledgment of personhood and human interaction which is vital to the wellbeing of both patients and carers / families requiring palliative care within the hospital setting
Fostering greater community awareness	Resource, develop and implement a state-wide campaign to promote palliative care in the hospital setting (co-design this with consumers). Echo the messages of the first 1000 days are vital to also state, the days/last year or so at the end of life are vital – we need to optimise care and support to enable the best experience possible. Make end of life care within hospitals part of daily language in healthcare – value good palliative care experiences. Manage this via a campaign to promote palliative care in the hospital setting, at a political level to State and Federal government health ministers; National medical, nursing, allied health organisations; Journalistic sources and academic platforms – basic message is people are dying in hospitals and we should be doing it better Resource co-design work with patients and families to optimise existing spaces for care

Policy reviews of care of the dying	Review the policy for care of a body after death – do they need to be identified via tags and placed into a body bag on the ward itself (in view of family) or could this be done after removal from the ward area? What is the time a body can remain insitu on the ward; Support for post death rituals
Better integration of advance care planning	Review and ensure adequate systems and processes for advance care planning information to inform care provision. This involves Identifying and accessing advance care planning documentation to inform current care provision, inclusive of documented discussions, nominated decision maker authorities and any available advance care directives Include an option for noting advance care planning documentation available and DNR/NFR status into the EMR system Inclusion of a screening question on admission in relation to the availability of an advance care plan
Strengthen nursing leadership	Equip and support nurses to lead in optimal provision of inpatient palliative care. It was suggested this would involve a radical redesign of the NUM role through co-design work with NUMs, key hospital leaders and quality personnel with respect to key areas noted below: b. Model through leadership and collaboration, a ward culture that enables the key points from respectful and compassionate care to be met – for all (inclusive of clinicians and ancillary staff): i. Move from valuing completion of tasks to valuing compassion, kindness as well as proficiency and clinical expertise ii. Lead the support of the multidisciplinary team in this work (medical, nursing, allied health and ancillary) c. Develop a system for regular review and identification of a patient case load that is assessed for palliative care needs (use of SPICT + Karnofsky). Where a patient is screened as likely to have a limited prognosis (approx. 12 mths or less) prioritise their care and care environment – ensure an action plan for care follows informed by evidence, current tools and programs available d. Lead and mentor a team (medical, nursing, allied health and ancillary) able to meet the key points noted for effective communication and shared decision making: i. Coordinate to ensure all patients with palliative care needs have a plan of care they and their families are aware of – be a point of 'linkage' across patients, families, teams and departments ii. Institute a process to routinely use the Patient Dignity Question (PDQ) – What do I need to know about you as a person to give you the best care possible? (Dr Harvey Chochinov) iii. Ensure a process for identifying and noting/documenting who the key people are within the family iv. Consider carefully the current hierarchies in place in relation to information provision to ensure clinicians are supported in the work they do v. Ensure the availability of information for medical team visits onto the wards – open this to be as patient and family centred as possible (i.e., not only noting availability at 6am etc.) – a notice board with teams and times readily available vi. Ensure a process for family meetings is available and accessible, that links with evidence-based templates to guide and document discussions (patient centred) and ensures use of interpreters if required. Also be mindful of space/ environment to run these and the potential need for technology to support attendance of multiple clinicians and/or family members.

  vii. Embed care for all clinicians and ancillary staff with respect to support, mentorship, self-care, supervision and access to extended support if needed

e. Lead and role model collaboration across team members, across multiple disciplines and departments including:
  i. Enable Nursing Unit Managers or a delegated senior nurse to attend medical ward rounds for succession planning, mentorship and to ensure centralised information of complex care planning for patients and families
  ii. Articulate clear handover processes supported by a key checklist for consideration – unique care needs / discharge plans / community requirements / ambulance palliative care plan / equipment needs / linkage to primary care team – try to consistent staffing as much as possible
  iii. Take leadership in person-centred care particularly in relation to bed management and patient flow – patients should not be moved when close to dying
  iv. Development of a structure / process for patients and families to know who is in charge of a ward at any given time (NUM / team leader / after-hours manager) for support and access to key information as required
  v. Ensuring effective integration with specialist palliative care services

f. To lead and mentor the clinical team to ensure expert practice is assured in line with practice points noted, including:
  i. Ensure each clinician is working to the top of their scope of practice and ensure they are all involved with the 'right work' – redesign where this is not the case
  ii. Establish clear parameters in relation to technical competence to enable rapid escalation to those most skilled in each key task (E.g. – IV cannulation, after 1 attempt – escalate)
  iii. Ensure a clear strategy is articulated and implemented to support clinician supervision/de-briefing/reflective practice for support and ongoing professional development

g. Consider and embed a process for assessing and supporting family / carer involvement in line with noted practice points – E.g. – Consider use of the PC-NAT; Ensure availability of a tool for families / carers to provide information about support available within each hospital for parking, Wi-Fi, catering and access to the hospital after hours

h. Develop a key process for supporting patients who are imminently dying and their families – proactively showing kindness, support, care and checking for any additional needs
  i. Ensure key supports are available for the patient who is imminently dying (and their family) – comfort trolley (music, fans etc), provision of bedding and meals for families
  ii. Embed a system to alert clinicians and staff to the fact a particular patient has palliative care needs and a poor prognosis (?tree / other symbol on outside of room)
  iii. Enable resourcing for provision of meals for carers of a person who is imminently dying (projected prognosis of days)
  iv. Ensure a clear process is in place to enable respectful and supportive care of a person after they have died on the ward – verification, certification, removal of body
  v. Develop a process for post death contact with a key person from the family – to 'check in' and provide key information about ongoing supports available

  vi. Consider how to best support the maintenance of role, identity and meaning for patients with palliative care needs, within the clinical environment - increase allied health supports, ensure access to technology, what is possible in relation to animal visits, access to outdoors, access to cannabis

  vii. Optimise the ward environment as best as is possible, in line with the key points noted

  viii. Lead and mentor clinicians to understand and value palliative care, working to assist every patient with palliative care needs to live as well as they can, within the context of

	their illness ix. Focus and development of the work within Standard 5 from the Commission's accreditation standards
Develop communities of practice	Develop networks of excellence, in relation to inpatient palliative care, to support ongoing focus and improvements at State/ Territory and National levels, supported by current lead organisations. In order to achieve this, develop and implement key supports at local (LHD), regional and national levels, to engage clinicians working in palliative care (in collaboration with leading clinicians in specialist palliative care) to maintain a focus on driving improvements, learning from experiences and sharing excellence– E.g. special interest groups across LHDs, education provision, linkage to and support for postgraduate study, develop and support new positions (E.g., NPs), champions underscored by a culture of strong nursing leadership. Reward and recognise great work. This work could be facilitated via a pillar within the NSW Ministry of Health (ACI, CEC) Resource statewide mapping of excellence and variation to enable identification of gaps and key areas for focused improvement

Appendix 18: Joint display tables for Research Question 2: Is there a suite of indicators to assist measurement of inpatient palliative care quality?

2a: What national quality indicators are available to support measurement of quality palliative care and do these align with the domains of care that matter most to inpatients with palliative care needs and their families?

Quantitative data **(Study 3)** ***National quality indicators for palliative care***	**Meta-inference outcomes** **(Studies 1a, 1b and 2)** ***Domains of importance for optimal care***	**Quantitative data** **(Study 3) –** ***Available national quality indicators to measure palliative care provision mapped to each domain***	**Data convergence**	**Meta-inference**
• 128 national quality indicators available from across 5 countries ○ Netherlands (n=43) ○ Belgium (n=31) ○ USA (n=25) ○ Australia (n=20)	Respectful and compassionate care	*Belgian indicators:* • Nominator: number of patients who indicated that the caregivers most of the times or always respected their personal wishes and that they could most of the time or always plan their day and decide about the care provided / Denominator: total number of patients for whom this indicator was measured	Confirmed – part coverage	The available indicators (n=128) mostly report on areas noted to be important to inpatients with palliative care needs and/or their families (consumers), with 113 (88%) measuring some noted aspect of importance. However, most domains are not measured in entirety and some not at all
		The Netherlands indicators:		

○ Sweden (n=9) *Indicator types* • Structural - 0 • Process - 49 (38%) • Outcome - 79 (62%) *Areas of measurement* • 48 (38%) - physical care • 41 (32%) - social care • 35 (27%) - processes of care delivery • 21 (16%) - psychological care • 21 (16%) - spiritual / religious care		• Extent to which patients are satisfied with the counselling aspects of "politeness" and "being taken seriously" • Extent to which patients experience respect for their privacy		(patient safety; supported access to senior clinicians; structural factors – patient focused; and cleanliness to support infection control). The domain for effective symptom management has available indicators in line with consumer noted areas of importance. Given these indicators have been tested in clinical practice, it would be sensible to continue to refine and optimise these for ongoing clinical application and focus specifically on patient and family (where proxy required) reported outcomes within this domain. Indicators within the domain for impeccable assessment and care planning almost address all noted areas of importance with gaps of measurement in relation to the assessing of social needs and specific measuring of whether a clinician appears knowledgeable
		United States indicators: • CAHPS® Hospice Survey (family experience with care) – Treating Family Member with Respect (numerator / denominator description provided above)		
	Effective communication and shared decision making	*Belgian indicators:* • Nominator: number of patients who received the right amount of information about their diagnosis / Denominator: total number of patients for whom this indicator was measured • Nominator: number of patients who received the right amount of information about the course of the disease / Denominator: total number of patients for whom this indicator was measured • Nominator: number of patients who received the right amount of information on palliative care options / Denominator: total number of patients for whom this indicator was measured • Nominator: number of patients who indicated that they most of the time or always received clear and comprehensible and never or sometimes contradictory	Confirmed – part coverage	

• 17 (13%) - quality of care through the dying process • 9 (7%) - cultural care • 9 (7%) - ethical and legal aspects of care • 36 key measurement domains • 13 occasions where a country is measuring something in isolation • 23 occasions where 2 or more countries are measuring similar concepts but with different measures • All five countries with national indicators for		information / Denominator: total number of patients for whom this indicator was measured • Nominator: number of family carers who received the right amount of information about the patient's condition and treatments / Denominator: total number of family carers for whom this indicator was measured • Nominator: number of family carers who received the right amount of information about the patient's approaching death / Denominator: total number of family carers for whom this indicator was measured • Nominator: number of patients about whom a conversation about their care preferences took place between the caregivers and family carers in the first week after admission or start of palliative care / Denominator: total number of patients for whom this indicator was measured • Nominator: number of patients with whom the physician discussed the care objectives / Denominator: total number of patients for whom this indicator was measured • Nominator: number of patients who were in touch with their family physician on a weekly basis in the last 3 months before death (personally or by telephone) / Denominator: total number of patients for whom this indicator was measured • Nominator: number of patients (or representatives) who were asked how they felt about end of life decisions and		about a person's specific health needs within the context of their broader health concerns to avoid care focused on one component of care only. It is worth noting that some of the domains with no available indicators could be measured within the hospital system via a different mechanism. That is local approaches to measuring technical competence, patient safety and hospital cleanliness could provide good data in line with consumer noted areas of importance. There are two domains with limited indicator availability and these are those of enabling family involvement and maintaining role, meaning and identity. Both domains have clearly articulated areas of importance and would be ideal for co-design of indicators that

measuring the quality of palliative care have indicators relating to general symptom management and pain. No other key area is measured by all five countries. *Care providers for whom the indicators can be used to assist in measurement work:* • 2 national indicators sets available for specialist palliative care providers (Belgium and Australia) • 1 national indicator set for		euthanasia / Denominator: total number of patients for whom this indicator was measured • Nominator: number of patients for whom the prognosis, psychosocial symptoms, functional status, symptom burden and documentation about care wishes were entered in the file within 48 hours after admission or starting palliative care / Denominator: total number of patients for whom this indicator was measured		are meaningful for patients and families.
		The Netherlands indicators: • Extent to which relatives indicate that the patient received support with preparations for saying goodbye • Extent to which patients know who the contact person is for the care • Extent to which patients receive information about the expected course of the illness • Extent to which patients receive information about the advantages and disadvantages of various types of treatments • Extent to which patients indicate that they receive understandable explanations • Presence of documentation concerning the desired care and treatment at the end of life • Extent to which relatives indicate that the patient was asked about her/his opinions with regard to end-of-life decisions		

primary care providers only (Sweden) • 2 national indicator sets available for all care providers (Netherlands and USA) • This study's outcomes combined with indicators listed from a 2013 systematic review – total of 390 indicators		• Extent to which direct relatives received information that was understandable and unambiguous at the time of the patient's death • Extent to which direct relatives received information about the advantages and disadvantages of various types of treatment		
		Swedish indicators: • Proportion with a documented discussion between physician and patient about the transition to EOL care		
		United States Indicators: • Patients Admitted to ICU who Have Care Preferences Documented - Percentage of vulnerable adults admitted to ICU who survive at least 48 hours who have their care preferences documented within 48 hours OR documentation as to why this was not done. • Hospice and Palliative Care – Treatment Preferences - Percentage of patients with chart documentation of preferences for life sustaining treatments. • CAHPS® Hospice Survey (family experience with care) – Hospice Team Communication • Family Evaluation of Hospice Care (tool with 54 questions for bereaved caregivers to complete) • The Bereaved Family Survey (BFS) - 19 items		
	Effective teamwork	*Belgian indicators:*		

		• Nominator: number of patients about whom multidisciplinary consultations took place at least once a week about their care objectives / Denominator: total number of patients for whom the palliative care service was involved for at least 1 week • Nominator: number of patients whose palliative care started at least 2 weeks before death / Denominator: total number of patients for whom this indicator was measured	Confirmed – part coverage	
		The Netherlands indicators: • Extent to which patients indicate that they have access to a counsellor for spiritual problems • Extent to which relatives indicate that the patient had access to a counsellor for spiritual problems • Extent to which patients indicate that they receive contradictory information • Extent to which patients experience expertise and continuity • Extent to which direct relatives perceived the expertise of caregivers and the continuity of care		
		United States Indicators: • Proportion of patients who died from cancer not admitted to hospice • Proportion of patients who died from cancer admitted to hospice for less than 3 days		

		• Family Evaluation of Hospice Care (tool with 54 questions for bereaved caregivers to complete)		
	Enabling family involvement	*Australian indicators:* • At least 90% of patients with absent or mild family / carer problems at the beginning of their phase of palliative care have absent or mild family / carer problems at the end of the phase. • At least 60% of patients with moderate or severe family / carer problems at the beginning of their phase of palliative care have absent or mild family / carer problems at the end of the phase • Case-mix adjusted Family / carer as rated by the clinician using the problem severity	Confirmed – part coverage	
		Belgian indicators: • Nominator: number of family carers who indicated that the caregivers regularly talked to them about what it meant to them to care for their ill next of kin / Denominator: total number of family carers who cared for their ill next of kin • Nominator: number of family carers who indicated that the caregivers regularly asked how they were feeling / Denominator: total number of family carers for whom this indicator was measured • Nominator: number of family carers who were given as much assistance as necessary with the care process /		

		Denominator: total number of family carers who needed assistance with the care process • Nominator: number of family carers who felt they had adequate support after the patient's death (inclusive evaluation meeting) and were informed of the possibilities of after-care / Denominator: total number of family carers for whom this indicator was measured • Nominator: number of patients whose caregivers were given the care objectives and resuscitation status during or after admission or starting palliative care / Denominator: total number of patients for whom this indicator was measured		
		The Netherlands indicators: • Extent to which the direct relatives felt that they were treated well in all respects by the caregivers • Extent to which, according to the direct relatives, their autonomy was respected • Extent to which direct relatives felt supported by the caregivers immediately after the patient’s death • Extent to which direct relatives were informed about the possibilities of aftercare • Extent to which a final conversation or discussion was held to evaluate the care and the treatment		
	Maintaining role, meaning and identity	*The Netherlands indicators:*	Confirmed – part coverage	

		• Extent to which patients experience respect for their autonomy • Extent to which patients indicate that caregivers respect their life stance • Extent to which patients indicate that they feel that life is worthwhile		
	Excellence in physical care	*The Netherlands indicators:* • Extent to which patients receive help with physical care	Confirmed – part coverage	
		Swedish indicators: • Proportion with pressure ulcers at death (Norton grade 2-4)		
		United States Indicators • The Bereaved Family Survey (BFS) - 19 items		
	Impeccable assessment and care planning	*Australian indicators:* • Case-mix adjusted Psychological / spiritual as rated by the clinician using the problem severity	Confirmed – part coverage	
		Belgian indicators: • Nominator: number of patients who were subjected to a general symptom assessment on a validated scale / Denominator: total number of patients for whom this indicator was measured		

		• Nominator: number of patients who were subjected to a pain assessment, with or without pain scale / Denominator: total number of patients for whom this indicator was measured • Nominator: number of patients who indicated that the caregivers regularly assessed how they were feeling / Denominator: total number of patients for whom this indicator was measured • Nominator: number of patients with a score of 5 or more on a scale of 0 to 10 for quality of life / Denominator: total number of patients for whom this indicator was measured • Nominator: number of patients who scored 5 or more on a scale of 0 – 10 for the quality of death according to family carers / Denominator: total number of patients for whom this indicator was measured • Nominator: number of patients who scored 5 or more on a scale of 0 – 10 for the quality of death according to physicians / Denominator: total number of patients for whom this indicator was measured		
		The Netherlands indicators: • Percentage of patients with anxiety • Percentage of patients who feel depressed • Extent to which patients receive support when they feel anxious or feel depressed		

		• Extent to which patients receive attention from their caregivers • Percentage of relatives who indicate that the patient died peacefully • Extent to which relatives indicate that there was attention and respect for the psychosocial and spiritual well-being of the patient • Percentage of patients who receive medical aid soon enough		
		Swedish indicators: • Proportion with systematic pain assessment • Proportion with systematic symptom assessment • Proportion with documented assessment of oral health		
		United States Indicators: • Patients with Advanced Cancer Screened for Pain at Outpatient Visits - Percentage of adult patients with advanced cancer who have an assessment of pain with a standardized quantitative tool at each outpatient visit • Hospice and Palliative Care -- Pain Screening - Percentage of hospice or palliative care patients who were screened for pain during the hospice admission evaluation / palliative care initial encounter • Hospice and Palliative Care -- Pain Assessment - Percentage of hospice or palliative care patients who		

		screened positive for pain and who received a clinical assessment of pain within 24 hours of screening • Hospice and Palliative Care -- Dyspnea Treatment - Percentage of patients who screened positive for dyspnea who received treatment within 24 hours of screening • Hospice and Palliative Care -- Dyspnea Screening - Percentage of hospice or palliative care patients who were screened for dyspnea during the hospice admission evaluation / palliative care initial encounter • Beliefs and Values - Percentage of hospice patients with documentation in the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/caregiver did not want to discuss • CAHPS® Hospice Survey (family experience with care) – Getting Emotional and Religious Support (numerator / denominator description provided above) • Family Evaluation of Hospice Care (tool with 54 questions for bereaved caregivers to complete) • The Bereaved Family Survey (BFS) - 19 items		
	Effective symptom management	*Australian indicators:* • 90% of patients are in the unstable phase for 3 days or less.	Confirmed	

		• At least 90% of patients with absent or mild PCPSS pain at the beginning of their phase of palliative care have absent or mild PCPSS pain at the end of the phase • At least 60% of patients with moderate or severe PCPSS pain at the beginning of their phase of palliative care have absent or mild PCPSS pain at the end of the phase • At least 90% of patients with absent or mild SAS pain at the beginning of their phase of palliative care have absent or mild SAS pain at the end of the phase • At least 60% of patients with moderate or severe SAS pain at the beginning of their phase of palliative care have absent or mild SAS pain at the end of the phase • At least 90% of patients with absent or mild fatigue at the beginning of their phase of palliative care have absent or mild fatigue at the end of the phase • At least 60% of patients with moderate or severe fatigue at the beginning of their phase of palliative care have absent or mild fatigue at the end of the phase • At least 90% of patients with absent or mild breathing problems at the beginning of their phase of palliative care have absent or mild breathing problems at the end of the phase. • At least 60% of patients with moderate or severe breathing problems at the beginning of their phase of		

		palliative care have absent or mild breathing problems at the end of the phase. • Case-mix adjusted Pain as rated by the clinician using the problem severity • Case-mix adjusted Other symptoms as rated by the clinician using the problem severity • Case-mix adjusted Pain as rated by the patient using the Symptom Assessment Scale • Case-mix adjusted Nausea as rated by the patient using the Symptom Assessment Scale • Case-mix adjusted Breathing problems as rated by the patient using the Symptom Assessment Scale • Case-mix adjusted Bowel problems as rated by the patient using the Symptom Assessment Scale		
		Belgian indicators: • Nominator: number of patients whose symptom burden was mostly or completely under control in the final week of life / Denominator: total number of patients for whom a palliative care service was involved for at least 3 days • Nominator: number of patients who, after treatment, experienced significant improvement in pain / Denominator: total number of patients treated for pain • Nominator: number of patients whose shortness of breath was relieved within 48 hours after admission or		

		starting palliative care / Denominator: total number of patients with shortness of breath		
		The Netherlands indicators: • Percentage of patients with moderate to severe pain • Percentage of patients with fatigue • Percentage of patients with shortness of breath • Percentage of patients with constipation • Extent to which patients receive support for their physical symptoms (pain, fatigue, shortness of breath, and constipation)		
		Swedish indicators: • Proportion with individualized prn parenteral anxiolytic medication • Proportion with individualized prn parenteral opioid medication		
		United States indicators: • Comfortable Dying: Pain Brought to a Comfortable Level Within 48 Hours of Initial Assessment* - Numerator Statement: Patients whose pain was brought to a comfortable level (as defined by patient) within 48 hours of initial assessment / Denominator Statement: Patients who replied "yes" when asked if they were uncomfortable because of pain at the initial assessment		

		• Patients Treated with an Opioid who are Given a Bowel Regimen • Percentage of vulnerable adults treated with an opioid that are offered/prescribed a bowel regimen or documentation of why this was not needed • CAHPS® Hospice Survey (family experience with care) – Getting Timely Care • CAHPS® Hospice Survey (family experience with care) – Getting Help for Symptoms • Family Evaluation of Hospice Care (tool with 54 questions for bereaved caregivers to complete) • The Bereaved Family Survey (BFS) - 19 items		
	Technical competence	*United States indicators:* • Hospitalized Patients Who Die an Expected Death with an ICD that Has Been Deactivated - Percentage of hospitalized patients who die an expected death from cancer or other terminal illness and who have an implantable cardioverter-defibrillator (ICD) in place at the time of death that was deactivated prior to death or there is documentation why it was not deactivated	Confirmed – part coverage	
	Patient safety		Nil available	
	Supported access to senior clinicians		Nil available	

	Structural factors – patient focused		Nil available	
	Structural factors – family focused	*The Netherlands indicators:* • Extent to which direct relatives considered that the patient had the opportunity to be alone • Extent to which the direct relatives had the opportunity to be alone with their relative	Confirmed – part coverage	
	Cleanliness to support infection control		Nil available	

Summary of data in relation to number of indicators available to measure domains of importance for optimal inpatient palliative care

	Australia	**Belgium**	**Netherlands**	**Sweden**	**United States**	**Overall**	**Coverage of areas of importance**
Respectful and compassionate care		1	2		1	**4**	Part
Effective communication and shared decision making		11	9	1	5	**26**	Part
Effective teamwork		2	5		3	**10**	Part
Enabling family involvement	3	5	5			**13**	Part

Maintaining role, meaning and identity			3			**3**	Part
Excellence in physical care			1	1	1	**3**	Part
Impeccable assessment and care planning	1	6	7	3	9	**26**	Part
Effective symptom management	15	3	5	2	7	**32**	Full
Technical competence					1	**1**	Part
Patient safety						**0**	No
Supported access to senior clinicians						**0**	No
Structural factors – patient focused						**0**	No
Structural factors – family focused			2			**2**	Part
Cleanliness to support infection control						**0**	No

2b: Where a country has national palliative care indicators available, have they been successfully implemented?

Quantitative data **(Study 3)**	**Qualitative data** **(Study 3)**	**Data convergence**	**Meta-inference**
Published quantitative data outlining the impact of measurement is available for Australia and Sweden: *Australia* Data from 30 specialist palliative care services were analysed[39] representing 65,463 phases of care including 19,747 patients, 46 % being female and 85 % with cancer. Improvements seen in: Pain - $p<0.001$ Other symptoms - $p<0.001$ Family/carer - $p<0.001$ Psychological/spiritual- $p<0.001$ *Sweden*	Key points from a synthesis of participant interviews outlines four key enablers for development and implementation of national palliative care quality indicators identified, namely: 1. National project / program work (Australia, Belgium and The Netherlands); 2. Use of mandatory accreditation frameworks (England, France, Australia and Singapore); 3. Availability of a national palliative care data registry (Sweden); and 4. Incentivising quality indicator use (US). Three main barriers were also identified by experts that prevent quality measurement of palliative care, including:	Enhanced understanding	The provision of data infrastructure for clinical services, including legal and regulatory support, is a key enabler to successful implementation of the routine collection of palliative care patient outcome data. Where this has occurred (Australia and Sweden), improvements in patient outcomes are noted over time. While, accreditation processes are useful, few are informed by discrete patient outcome measures. The impacts of mandating and/or incentivising data collection and reporting is unclear and requires further investigation.

Data from the Swedish Register of Palliative Care (SRPC) were analysed to understand improvements over time with the following results[20]: Participants: 30 283 patients including 54% women, 46% men and 60% with a cancer diagnosis. • Reduction in prevalence of the following symptoms in the last week of life: ○ Shortness of breath – p<0.001 ○ Confusion – p<0.001 ○ Nausea – p<0.05 ○ Death rattle – p<0.01 ○ Pain – p<0.001 ○ Anxiety – p<0.001 • Increase in 'no distressing symptoms' – p<0.001 • Increase in availability of 'as needed' prescriptions for: ○ Pain medication - p<0.001 ○ Death rattle medication - p<0.001 ○ Nausea medication - p<0.001 ○ Anxiety medication - p<0.001 • Information from doctor to patient - Not significant • Information from doctor to next of kin - Not significant • No one present at the moment of death- Not significant • Improvement in 'Place of death corresponded to preference' - p<0.001 • Improvement in 'Next of kin offered follow-up appointment' - p<0.001 • Results in relation to pressure ulcers showed: ○ Pressure ulcer grade 1- p=0.016 ○ Pressure ulcer grade 2 - NS ○ Pressure ulcer grade 3 - NS ○ Pressure ulcer grade 4 - NS ○ No pressure ulcer - p=0.006 ○ Do not know if patient had pressure ulcer - NS	1. Lack of a national data collection system focused on quality of palliative care (England); 2. Legal and regulatory constraints in relation to data access (England); and 3. Policy frameworks that focus on availability, access and activity, rather than a more holistic understanding of quality palliative care (England and France).		

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Appendix 19: Joint display tables for Research Question 3

Research question 3: What are the key drivers for enabling improvement in palliative care provision within Australian hospitals?

Meta-inference outcomes **(Studies 1a, 1b and 2) – practice points to inform care provision within each domain of importance**	**Qualitative data from co-design study (Study 4) – actions to enable change in line with areas of importance**	**National quality indicators available (Study 3)**	**Data convergence**	**Meta-inference**
Category – Person-centred care **Domain – Respectful and compassionate care**				
Practice points (n=11) *What did patients and families describe as enabling the quality of care received in hospital to feel respectful and compassionate?* 1. Clinicians who provide care in a compassionate, empathetic, personalised, kind, friendly, supportive and willing way, who are professional and appear happy to be at work 2. Clinicians who are honest, trustworthy, knowledgeable, able to anticipate needs and	Action- Strengthen nursing leadership: Equip and support nursing unit managers (NUMs) to model through leadership and collaboration, a ward culture that enables the key points from respectful and compassionate care to be met – for all (inclusive of clinicians and ancillary staff) with a focus on: i. Moving from valuing completion of tasks to valuing compassion,	4 indicators (Belgium, n=1; Netherlands, n=2; United States, n=1) Part coverage of practice points confirmed.	Enhanced	The key drivers to enable respectful and compassionate care, based on what patients and families have noted for optimal care provision, include: ***1. A positive policy environment*** (macro) valuing inpatient palliative care is required to enable optimal care; **2. *Leadership*** – macro (policy), meso (hospital) and micro (ward) levels: Hospital executive are needed to provide leadership in valuing inpatient palliative care, resourcing accordingly and supporting unit level managers as they work to enable optimal care,

confident, efficient, attentive, responsive and mindful in their care delivery 3. Clinicians who connected to their particular situation and circumstances, were unhurried, non-judgmental and acknowledged them as a unique human being 4. Preservation of dignity described in relation to physical care, consideration of quality of life, and through the tone of communication used (particularly noting the need for use of names and not terms such as 'darling', and not talking down to the patient or family member) 5. Use of humour throughout an admission to assist a patient to cope and have a laugh 6. Feeling welcomed and deserving of a hospital admission, and where they may have experienced multiple admissions, to be acknowledged by clinicians and ancillary staff, assisting a feeling of homeliness 7. Kind and empathetic kitchen staff and diet aides who return to talk with patients about dietary choices if they are not available on	kindness as well as proficiency and clinical expertise; ii. Leading the support of the multidisciplinary team in this work (medical, nursing, allied health and ancillary). *[Addresses practice points 1-11]* Action - Strengthen nursing leadership: Develop a key process for supporting patients who are imminently dying and their families – proactively showing kindness, support, care and checking for any additional needs. *[Addresses practice point 10]* Action: Mandatory clinical and ancillary education Co-design, with consumer representatives, an educational tool which will touch all levels of hospital staff through orientation and other appropriate forums, which focuses on the need for kindness,			in line with the practice points noted by patients and carers. Nursing Unit Managers need to transform ward cultures to prioritise respectful and compassionate care provision in addition to competent clinical task completion. The co-design and implementation of an educational tool for all healthcare staff (clinical and ancillary) focusing on the need for kindness, gentleness, acknowledgment of personhood and human interaction is recommended as a tool to assist each ward/unit area as they make improvements within this domain of care; ***3. Measurement*** (macro, meso and micro): Measurement of patient and family experience of care provision, in line with the noted practice points for respectful and compassionate care, is required to inform a ward area and hospital about current experience and key areas for improvement. Provision of policy supported indicators (noting four currently exist), based on noted practice points, for ward areas will enhance implementation as well as the ability to develop collaborative improvement opportunities over time.

their first visit (asleep, at a procedure, in the bathroom etc) 8. Provision of good food at the right temperature, in line with preferences, that aides in wellbeing and a sense of comfort (E.g. a hot cup of tea or coffee in the morning) as well as timely assistance with accessing food items on the tray when unable to manage independently 9. Gentleness and kindness from ancillary staff, particularly noting the impact of cleaners, catering staff and those working in hospital cafes 10. Checking in with family members when their loved one is dying (prognosis of days only), even when there are no clinical tasks to be completed, to show kindness, support and care and to understand if they have any concerns at this time 11. Talking with patients when unconscious and after death, in relation to their care provision	gentleness, acknowledgment of personhood and human interaction which is vital to the wellbeing of both patients and carers / families requiring palliative care within the hospital setting. *[Addresses practice points 1, 3, 7 and 9]* Action: Evidence-informed practice and national benchmarking Development of data items and key definitions to enable improvement work in hospital based palliative care to be underpinned by evidence and guidance for key areas of improvement - Predesigned pack to assist in experience and outcome measurement (overall focus – 10-15 questions + options to do a 'deeper dive') into each domain: Respectful and compassionate care. Implementation guided by a facilitated project initially focused on redesign and support for senior			

	clinical leadership at the ward level (via the NUM role) *[Addresses practice points 1-11]*			

Meta-inference outcomes **(Studies 1a, 1b and 2) – practice points to inform care provision within each domain of importance**	**Qualitative data from co-design study (Study 4) – actions to enable change in line with areas of importance**	**National quality indicators available (Study 3)**	**Data convergence**	**Mixed methods inference**
Category – Person-centred care **Domain – Effective communication and shared decision making**				
Practice points (n=16) *What do patients and family members state is important to enable effective communication and shared decision making?* 1. Communication that is honest, clear, uses layman's language, demonstrates understanding of the current situation and is delivered in a compassionate, connected and mindful way (including sitting at eye level, near to the person and managing hearing impairments effectively) 2. Communication that enables a shared understanding and feels unpressured by time	Action: Strengthen nursing leadership Equip and support nursing unit managers (NUMs) to lead and mentor a team (medical, nursing, allied health and ancillary) able to meet the key points noted for effective communication and shared decision making with specific attention to: i. Developing a process to ensure all patients with palliative care needs have a plan of care they and their families are aware of *[Addresses practice points 2, 3, 4, 6, 7, 8, 10, 11, 15 and 16]*	26 indicators (Belgium, n=11; Netherlands, n=9; Sweden=1; United States, n=5) Part coverage of practice points confirmed.	Enhanced	The key drivers to enable effective communication and shared decision making, based on what patients and families have noted for optimal care provision, include: **1. *A positive policy environment*** (macro) valuing inpatient palliative care is required to enable optimal care; **2. *Leadership*** – macro (policy), meso (hospital) and micro (ward) levels: Macro and meso level leadership focused on adequate resourcing for both care provision and requisite skills training is recommended. Ensuring electronic medical records enhance effective communication and shared decision making is also critical with efficiency of both input and retrieval of key

3. Communication that works with a patient's/ family's own knowledge and expertise about their condition 4. Listening to the patient and family member and using this information to guide clinical assessments and care planning, especially in relation to symptoms, being mindful of the fact patients and family members might want to meet separately with clinicians at times 5. Communication that maintains positivity and hope within the context of their illness 6. Communication that focuses on the bigger picture in relation to their care, not just the immediate day to day issues 7. Accurate documentation of communications held with patients, families and across teams and departments 8. For difficult conversations to be led by a senior clinician and held directly with patients, as appropriate 9. Acknowledgment and support for the requirements within cross cultural communication to prevent misunderstanding	ii. Ensure a point of 'linkage' is noted across patients, families, teams and departments *[Addresses practice point 11]* iii. Institute a process to routinely use a validated tool to understand what the patient is needing in order to receive the best care possible (Eg. the Patient Dignity Question (PDQ) – *What do I need to know about you as a person to take the best care of you that I can?*[1] *[Addresses practice points 1-4, 6-8, 15 and 16]* iv. Ensure a process for identifying and noting/documenting who the key people are within the family *[Addresses practice points 7 and 16]* v. Consider carefully the current hierarchies in place in relation to information provision to ensure clinicians are supported in the work they do			information required. Micro leadership via Nursing Unit Managers to lead and mentor improvements informed by targeted feedback about patient and family experience (measurement) is also recommended. The introduction of key processes such as the routine use of a Patient Dignity Question followed by evaluating the impact of such a change will be an important facet of this work; ***3. Measurement*** (macro, meso and micro): Measurement of patient and family experience of communication and shared decision making, in line with the noted practice points for this domain is required to inform a ward area and hospital about current experience and key areas for improvement. Provision of policy supported indicators (noting 26 currently exist) based on noted practice points, for ward areas will enhance implementation as well as the ability to develop collaborative improvement opportunities over time; ***4. Skills development*** (meso and micro): Skills development is recommended for all staff (clinical and ancillary) supported by the

and negativity across patient, family and clinician groups *What information do patients and family members want to enable effective communication and shared decision making?* 10. Regular updates throughout an admission about the patient's current condition and plan of care 11. Consistent messages across teams and departments with a lead clinician to pull complex information together and a key contact who can address any noted concerns 12. What is likely to happen with the patient's physical condition over time, to enable planning 13. When the patient is close to death, clinicians being explicit about the fact the patient may die within the next few days/a week to enable important conversations and preparations as much as possible	*[Addresses practice points 1, 3, 5, 6-16]* Action: Mandatory clinical and ancillary education Mandatory face to face education for all clinicians and ancillary staff in relation to palliative care underpinned by skills in effective communication: i. Develop a focused education pack for clinicians in relation to optimal hospital based palliative care, with annual refreshers ii. Develop a focused education pack for ancillary staff in relation to optimal hospital based palliative care – this needs to be considered explicitly for specific groups (Eg – catering staff and diet aides; interpreter services; cleaners etc), with annual refreshers *[Addresses practice points 1-7, 9-16]*			development and implementation of mandated education modules modelled on the mandated approach for resuscitation skills embedded across hospital settings. Meso support to resource the implementation is required to enable each ward/unit to engage with such an opportunity for all clinicians and ancillary staff. Engagement with these opportunities by all individual staff members (micro) to improve their skills is vital for improvements to be seen in practice.

14. When the patient is close to death, clinicians checking with family members about whether they are wanting explicit information about the physical changes that occur as a patient nears death (e.g., breathing and circulatory changes) *What do patients and family members want in relation to shared decision making?* 15. To be engaged in care planning and supported in making decisions in line with personal needs to be able to live as well as possible 16. To support patient choices as discussed with family members informally or more formally through advance care planning processes, advance care directives, and nomination of preferred decision makers	Action: Better integration of advance care planning Review and ensure adequate systems and processes for advance care planning information to inform care provision with specific attention to: i. Identifying and ensuring accessibility of advance care planning documentation to inform current care provision, inclusive of documented discussions, nominated decision maker authorities and any available advance care directives ii. Including an option for noting advance care planning documentation available and DNR/NFR status into the EMR system iii. Inclusion of a screening question on admission in relation to the availability of an advance care plan *[Addresses practice point 16]*			

	Action: Evidence-informed practice and national benchmarking Development of data items and key definitions to enable improvement work in hospital based palliative care to be underpinned by evidence and guidance for key areas of improvement - Predesigned pack to assist in experience and outcome measurement (overall focus – 10-15 questions + options to do a 'deeper dive') into each domain: Effective communication and shared decision making. Implementation guided by a facilitated project initially focused on redesign and support for senior clinical leadership at the ward level (via the NUM role) *[Addresses practice points 1-16]*			

Meta-inference outcomes (Studies 1a, 1b and 2) – practice points to inform care provision within each domain of importance	Qualitative data from co-design study (Study 4) – actions to enable change in line with areas of importance	National quality indicators available (Study 3)	Data convergence	Mixed methods inference
Category – Person-centred care **Domain – Effective teamwork**				
Practice points (n=5) *What do patients and family members state is important in relation to effective teamwork?* 1. To see clinicians working together in relation to the patient's care, both within the ward environment and across different teams and/or departments and also with primary care providers or lead clinicians from other hospitals 2. To ensure complex care needs are accurately handed over in depth between shifts to enable good care and prevent continual repeating of needs by patients, and where possible to roster the same	Action: Strengthen nursing leadership Equip and support nursing unit managers (NUMs) to lead and role model collaboration across team members, across multiple disciplines and departments including: i. Enabling NUMs or a delegated senior nurse to attend medical ward rounds for succession planning, mentorship and to ensure centralised information of complex care planning for patients and families *[Addresses practice points 1,2 and 4]* ii. Ensuring clear handover processes are in place supported by a key checklist that addresses the requirements of people with palliative care needs (Eg. unique	10 indicators (Belgium, n=2; Netherlands, n=5; United States, n=3) Part coverage of practice points confirmed.	Enhanced	The key drivers to enable effective teamwork, based on what patients and families have noted for optimal care provision, include: ***1. Leadership*** – macro (policy), meso (hospital) and micro (ward) levels: Macro and meso level leadership focused on requisite infrastructure and policy to support integrated working across teams, wards, departments and indeed other settings of care delivery (primary care, aged care and other hospitals) is vital. In addition, a large focus of work to enable improvements in this domain focuses on the Nursing Unit Manager role (micro) to lead and mentor improvements. This would include

nurse to a patient to support continuity in care 3. To enable access to multidisciplinary expertise to help patients be as well as they can be, with specific noting of the need for increased access to physiotherapy support, and a key clinician to support people with dementia 4. Efficient discharge planning and management with specific noting of timely provision of paperwork, accurate medication management with this information also provided for the GP, physical supports such as a wheelchair and/or wardsperson to assist with getting to the car and integration with primary care supports as required 5. Effective integration with specialist palliative care services in relation to when they are consulted, how their service is described to families (to enable understanding of their expertise and role) and how their advice is integrated into care planning	care needs / discharge plans / community requirements / ambulance palliative care plan / equipment needs / linkage to primary care team) *[Addresses practice points 2 and 4]* iii. Where possible, allocating consistent staffing for this patient cohort *[Addresses practice point 2]* iv. Taking leadership in person-centred care particularly in relation to bed management and patient flow – patients should not be moved when close to dying *[Addresses practice points 1and 2]* v. Developing a process for patients and families to know who is in charge of a ward at any given time (NUM / team leader / after hours manager) for support and access to key information as required *[Addresses practice points 1and 2]* vi. Ensuring effective integration with specialist palliative care services *[Addresses practice point 5]*			redesign of the NUM role to enhance their ability to function as a senior clinical leader, visible to clinicians and consumers alike. This redesigned role would be able to ensure senior nursing representation for all care planning discussions both to enable integration and advocacy for people with palliative care needs. This role would necessarily need to ensure accurate handover processes, multi-disciplinary inputs and be supported in their advocacy for person-centred care. In addition, clear processes for referral to and working with specialist palliative care services are needed. Medical (micro) and executive support (meso) to enable success in this role redesign is critical; ***2. Measurement*** (macro, meso and micro): Measurement of effective teamwork, in line with the noted practice points for this domain is required to inform a ward area and hospital about current experience and key areas for improvement. Measurement ought to be two-fold – focused both on consumer

	Action: Evidence-informed practice and national benchmarking Development of data items and key definitions to enable improvement work in hospital based palliative care to be underpinned by evidence and guidance for key areas of improvement - Predesigned pack to assist in experience and outcome measurement (overall focus – 10-15 questions + options to do a 'deeper dive') into each domain: Effective teamwork. Implementation guided by a facilitated project initially focused on redesign and support for senior clinical leadership at the ward level (via the NUM role) *[Addresses practice points 1-5]*			experience as well as clinician experience in relation to working across teams / departments and specialties. Provision of policy supported indicators (noting 10 currently exist) based on noted practice points, for ward areas will enhance implementation as well as the ability to develop collaborative improvement opportunities over time.

Meta-inference outcomes (Studies 1a, 1b and 2) – practice points to inform care provision within each domain of importance	Qualitative data from co-design study (Study 4) – actions to enable change in line with areas of importance	National quality indicators available (Study 3)	Data convergence	Mixed methods inference
Category – Person-centred care **Domain – Enabling family involvement**				
Practice points (n=9) *What do patients and family members state is important in relation to family involvement whilst they are in the hospital?* 1. Family inclusion to advocate for optimal care and help patients understand complex information provision given they are so unwell and their cognition can be affected by illness or various medications 2. Family inclusion to provide comfort, emotional healing and ongoing sharing as part of a long-term partnership 3. Supportive hospital processes to enable family members to fully participate including:	Action: Strengthen nursing leadership Equip and support nursing unit managers (NUMs) to lead a ward that is inclusive of family participation with specific noting of: i. Ensuring the open availability of information for when medical team visits are likely to occur *[Addresses practice point 3]* ii. Ensuring a process for family meetings is available and accessible, underpinned by evidence-based templates to guide and document discussions (person-centred), using interpreters as required and being mindful of the appropriate environment	13 indicators (Australia, n=3; Belgium, n=5; Netherlands, n=5) Part coverage of practice points confirmed.	Enhanced	The key drivers to enabling family involvement, based on what patients and families have noted for optimal care provision, include: ***1. A positive policy environment*** (macro) valuing families as partners in care. Specifically, a focus on the policy for care of a person immediately after death to ensure respectful care that also aligns with minimising family / carer distress is important; ***2. Innovation –*** understanding how to partner with families in line with unique family needs within a complex health system will require co-design and innovative thinking. For example, implementing a process for identifying

• understanding the timing of medical ward rounds (to prevent having to sit all day waiting) • supporting them to be part of the team, respecting their knowledge of their loved one's care needs (enhancing patient safety) and inviting them to participate in care if they are wanting to • enabling access for visits at any time • comfort when staying overnight (to enable rest) and consideration of the carer's wellbeing 4. A clear process for communicating with a senior member of the medical team, in charge of the care plan 5. Opportunity for a family conference to guide care planning at complex points of care 6. Explicit information and guidance, on admission about: • how to best manage parking costs • availability of Wifi • supported accommodation options for those who are from rural locations	to run these assisted by technology to support attendance of multiple clinicians and/or family members if required. *[Addresses practice point 5]* iii. Embedding a process for assessing and supporting family / carer involvement in line with noted practice points *[Addresses practice points 1-4]* iv. Ensuring availability of information for families / carers about support available within each hospital for parking, Wifi, catering and after-hours access *[Addresses practice point 6]* v. Embedding a system to alert clinicians and staff to the fact a particular patient has palliative care needs and a poor prognosis (Eg. symbol on outside of room) when they are imminentely dying *[Addresses practice point 7]*			carer need is a great first step, but understanding how to meet those needs efficiently and effectively will be complex. Likewise, enabling clear information about medical availability seems simple in some ways but is impacted upon by several variables (internal and external to each ward) and therefore, innovation and openness to change will be vital for real improvements to be seen. Embracing technology will be important as will a commitment to changing entrenched practices. ***3. Measurement*** (macro, meso and micro): Measurement of level of family involvement within a ward that is enabled, in line with the noted practice points for this domain is required to inform a ward area and hospital about current experience and key areas for improvement. Measurement ought to be focused on consumer experience and interpreted alongside clinician experience with changes made (for example, medical staff noting their

• access to carer's payments • access to subsidies for clinical equipment required for transition home (E.g. Incontinence pads) What do families need at the time of and immediately after their loved one's death? 7. Supportive care and processes at the time of a patient's death (respectful care of the body; not feeling rushed; timely and accurate death certification completion) 8. Supportive information provision (verbal and written) about processes of care (death certification, removal of body) 9. A follow up contact (call or email), conducted in a compassionate and kind manner, by a clinician connected to their loved one's care to check in with the family and provide information about options for counselling or other supports (with routine bereavement letters from a separate service noted to be less supportive and feeling somewhat tokenistic)	vi. Ensuring a clear process is in place to enable respectful and supportive care of a person after they have died on the ward with a focus on verification, certification and removal of body *[Addresses practice points 7 and 8]* vii. Development of a process for post death contact with a key person from the family – to 'check in' and provide key information about ongoing supports available *[Addresses practice point 9]* Action: Policy reviews of care of the dying Review hospital policies in relation to care of a person at the time of death with a specific review of whether people who have died need to be identified via tags and placed into a body bag on the ward itself (in view of family members) or could this be done after removal from the ward area? Length of time a body can remain insitu			visiting times – does this impact their work patterns in any negative ways). Provision of policy supported indicators (noting 13 currently exist) based on noted practice points, for ward areas will enhance implementation as well as the ability to develop collaborative improvement opportunities over time.

	on the ward and support for post death rituals. *[Addresses practice points 7 and 8]*			

Meta-inference outcomes (Studies 1a, 1b and 2) – practice points to inform care provision within each domain of importance	Qualitative data from co-design study (Study 4) – actions to enable change in line with areas of importance	National quality indicators available (Study 3)	Data convergence	Mixed methods inference
Category – Person-centred care **Domain – Maintaining role, meaning and identity**				
Practice points (n=3) *What do patients state they are wanting to support their sense of role, meaning and identity?* 1. To be supported and encouraged to maintain independence and live as well as possible, within the context of life limiting illness, minimizing feelings of being powerless and burdensome 2. To isolate their illness from life and engage in meaningful activity on a day to day basis to assist in wellbeing, even	Action: Strengthen nursing leadership Equip and support nursing unit managers (NUMs) to lead a ward that considers how to best support the maintenance of role, identity and meaning for patients with palliative care needs, within the ward environment with a specific focus on: i. increasing allied health supports *[Addresses practice points 1 and 2]*	3 indicators (Netherlands, n=3) Part coverage of practice points confirmed.	Enhanced	The key drivers to enable patients to maintain their role, meaning and identity based on what patients noted for optimal care provision, include: ***1. A positive policy environment*** (macro) – a shift in policy support away from seeing hospital care as for acute exacerbation management to valuing both that as well as focusing on helping people to be as strong and as well as they can be, despite their illness, is important. This includes removing funding barriers to

whilst in hospital, suggesting the following would assist in this: Access to reading materials (papers/magazines) or puzzles/games, access to information about what is available across the hospital and encouragement for patients to get out of bed and engage in an activity 3. To feel a sense of control and avoid becoming institutionalised noting the importance of access to technology to support social connections, beauty treatments for those who require it (waxing and hair for example) and the need to maintain a focus on work where able	ii. ensuring access to technology, reading materials, games, a process in relation to possible animal visits, access to outdoors, access to cannabis etc *[Addresses practice point 2]* iii. prioritising the need to assist every patient with palliative care needs to live as well as they can, within the context of their illness *[Addresses practice points 1-3]* iv. understanding patient experience in relation to this aspect of their care *[Addresses practice points 1-3]* Action: Strengthen nursing leadership Resource co-design work with patients and families to optimise existing environments for care			accessing multidisciplinary input, rehabilitation and valuing the opportunity each day to assist patients in their wellbeing; ***2. Innovation*** (meso and micro) – hospitals and wards will need to carefully think about current environments and care practices and how these can be modified to enable this domain. Co-design with consumer representatives will be critical to enable work to meet identified needs as will ensuring multi-disciplinary input into solution development; ***3. Leadership*** – valuing this domain and prioritising work to enable this will be important within an environment so focused on episodic care. Leadership at ward level working collaboratively with other wards grappling with similar challenges will be useful. ***4. Measurement*** – Understanding patient experience in relation to this domain is critical to inform teams as they implement changes. Although three indicators exist in relation to this domain, none truly measure the full extent of this

	[Addresses practice points 1-3]			domain and so co-design of a new indicator is recommended.

Meta-inference outcomes (Studies 1a, 1b and 2) – practice points to inform care provision within each domain of importance	Qualitative data from co-design study (Study 4) – actions to enable change in line with areas of importance	National quality indicators available (Study 3)	Data convergence	Mixed methods inference
Category – Expert care **Domain – Excellence in physical care**				
Practice points (n= 2) *What do patients and family members look for in relation to physical care?* 1. Excellence in physical care 2. Attention to the patient's nutrition to maintain weight throughout an admission and assist in management of chronic conditions (Eg. Diabetes) and overall recovery/wellbeing	Action: Evidence-informed practice and national benchmarking Development of data items and key definitions to enable ward level understanding of quality of care provision in line with noted practice points *[Addresses practice points 1 and 2]*	3 indicators (Netherlands, n=1; Sweden, n=1; United States, n=1) Part coverage of practice points confirmed.	Enhanced	The key driver to enable excellence in physical care based on what patients and families noted for optimal care provision, include: ***1. Measurement -*** Whilst the domains within the category of person-centred care require focus on multiple innovative project designs (most often led by NUMs and often co-designed with palliative care consumer representatives) and complex change management processes, this domain was described as being more responsive to direct measurement of patient outcomes to assess outcomes of physical

				care provision and thereby inform improvement efforts.

Meta-inference outcomes (Studies 1a, 1b and 2) – practice points to inform care provision within each domain of importance	Qualitative data from co-design study (Study 4) – actions to enable change in line with areas of importance	National quality indicators available (Study 3)	Data convergence	Mixed methods inference
Category – Expert care **Domain – Impeccable assessment and care planning**				
Practice points (n= 3) *What do patients and family members look for in relation to assessment and care planning?* 1. That the clinician is knowledgeable about their specific health care needs within the context of their broader health issues, enabling them to accurately assess the current situation and related care requirements to achieve a good clinical outcome (not being focused purely on one component of care or one organ system only) 2. That the clinical team pays attention to a person's holistic health care needs, inclusive	Action: Strengthen nursing leadership Equip and support nursing unit managers (NUMs) to lead and mentor the clinical team to ensure expert practice is assured in line with practice points noted, including to: i. develop a system for regular review and identification of patients that are assessed to have palliative care needs using validated tools to assess prognosis. Where a patient is screened as likely to have a limited prognosis (approx. 12 mths or less) prioritise their care and care environment in accordance with practice points noted to be important *[Addresses practice points 1-3]*	26 indicators (Australia, n=1; Belgium, n=6; Netherlands, n=7; Sweden, n=3; United States, n=9) Part coverage of practice points confirmed.	Enhanced	The key drivers to enable excellence in impeccable assessment and care planning based on what patients and families noted for optimal care provision, include: ***1. Leadership -*** Impeccable assessment and care planning for patients assessed to have a poor prognosis rely firstly on these people being identified within the hospital environment. A regular system to inform this understanding will enable this, led by the NUM at each ward level (micro). Once identified, appropriate care planning underpinned by validated tools and

of their physical, social, emotional and spiritual wellbeing 3. Identification of when a patient is in their last days of life and ensuring their comfort	ii. ensure a care plan is available for each patient assessed as having a poor prognosis informed by evidence, validated tools and local, state and national programs available to assist in quality palliative care provision. This care plan needs to be underpinned by a holistic approach to assessment and care *[Addresses practice points 1 and 2]* iii. ensure each clinician is working to the top of their scope of practice and ensure they are all involved with the 'right work' and redesign where this is not the case *[Addresses practice point 1]* iv. develop an evidence based process for proactive care for people in the last days of life to enhance responsiveness to noted distress that can be anticipated *[Addresses practice point 3]*			evidence that inform holistic assessment and planning follow. Such tools need to consider patients with a poor prognosis and also patients who are imminently dying. All levels of engagement (macro/meso/micro) will support this work in identifying tools and processes to support clinicians in achieving this within a busy clinical environment; ***2. Measurement*** - Discrete patient outcome measures will need to be in place to monitor how well care delivery is being provided in line with noted practice points, and inform ongoing improvement efforts.

Meta-inference outcomes **(Studies 1a, 1b and 2) – practice points to inform care provision within each domain of importance**	**Qualitative data from co-design study (Study 4) – actions to enable change in line with areas of importance**	**National quality indicators available (Study 3)**	**Data convergence**	**Mixed methods inference**
Category – Expert care **Domain – Effective symptom management**				
Practice points (n= 2) *What do patients and family members look for in relation to symptom management?* 1. Regular assessment and rapid management (pharmacological and non-pharmacological) of any symptoms causing discomfort or distress, especially in relation to pain and breathlessness 2. Responsive attention to any forms of distress identified for a patient who is imminently dying, with medication orders available for nursing staff to act immediately (not have to wait for medical review)	Action: Evidence-informed practice and national benchmarking Implementation of outcome measures to inform ward level understanding of how effective their symptom management is *[Addresses practice points 1 and 2]*	32 indicators (Australia, n=15; Belgium, n=3; Netherlands, n=5; Sweden, n=2; United States, n=7) Full coverage of practice points confirmed.	Enhanced	The key driver to enable excellence in effective symptom management based on what patients and families noted for optimal care provision, include: ***1. Measurement -*** Several processes and approaches to care will inform the clinical team's ability to manage symptoms effectively. For example, developing a ward that truly enables person-centred care founded in respectful, compassionate and expert communication principles is likely to enhance assessment and management of symptoms. However, the most credible way to inform this domain is through

				outcome measures for patients and their family members (when a proxy is needed). Bereaved carers also ought to have an opportunity to respond to whether a clinical team provided optimal care for the dying person.

Meta-inference outcomes **(Studies 1a, 1b and 2) – practice points to inform care provision within each domain of importance**	**Qualitative data from co-design study (Study 4) – actions to enable change in line with areas of importance**	**National quality indicators available (Study 3)**	**Data convergence**	**Mixed methods inference**
Category – Expert care **Domain – Technical competence**				
Practice points (n= 2) *What do patients and family members look for in relation to technical competence?* 1. That their clinician is an expert in procedures such as cannulation (insertion and care) or management of a pleural effusion 2. Ability to discuss and appropriately deactivate an implanted cardiac device in a timely way	Action: Strengthen nursing leadership Equip and support nursing unit managers (NUMs) to establish clear parameters in relation to technical competence to enable rapid escalation to those most skilled in each key task (Eg – IV cannulation, after 1 attempt – escalate) *[Addresses practice point 1]* Action: Policy reviews of care of the dying Establish a policy to inform clinicians about appropriate deactivation of implanted cardiac devices *[Addresses practice point 2]*	1 indicator (United States, n=1) Part coverage of practice points confirmed.	Enhanced	The key drivers to enable excellence in technical competence based on what patients and families noted for optimal care provision, include: ***1. A positive policy environment -*** In relation to more specialist procedures, policy support at hospital, regional and/or national levels would be supportive and this would be the case when considering appropriate deactivation of implanted cardiac devices for an imminently dying patient. ***2. Skill development -*** the importance of technical competence for optimal hospital palliative care is undisputed. In relation to more general procedures such as IV cannulation, effusion drainages and ascitic taps, clear parameters in how to manage such work are required. Co-designing such parameters with clinicians and consumers is important so as to address consumer experience as

				well as the need for clinician mentorship and skill development. Such work needs to be completed at ward unit level so as to be realistic about staffing availability and related supports as this will change across units, across hospitals and across geographical locations; ***3. Measurement*** – understanding ward performance in relation to technical competence from a patient experience perspective is important to inform any areas of ongoing improvement needed.

Meta-inference outcomes (Studies 1a, 1b and 2) – practice points to inform care provision within each domain of importance	Qualitative data from co-design study (Study 4) – actions to enable change in line with areas of importance	National quality indicators available (Study 3)	Data convergence	Mixed methods inference
Category – Expert care **Domain – Patient safety**				
Practice points (n= 2) *What do patients and family members look for in relation to safety?* 1. To feel their care is safe and well managed without them needing to continually have oversight of the care (including risks of over-investigation and/or overtreatment), given the patient is so unwell 2. Accuracy in medication prescription and administration, with particular noting of translation of complex medication regimes in the home setting to the hospital setting (and vice	No specific recommendations from the co-design study specifically mapped to this domain.	No indicators available.	Unclear	It is interesting to note that the co-design study recommendations did not specifically articulate to the patient safety domain. This could be explained by the fact patient safety traverses so many of the domains already outlined. For example, effective teamwork enabling integrated care, emphasizing patient and family involvement and effective communication documenting care preferences all align with patient safety.[2] Aspects related to medication management may be felt to be

versa), accuracy in timing of administration and managing an error in the computer system once entered				covered by national accreditation systems where one standard is dedicated to medication safety. However, it is noteworthy that patients and families articulated the need for additional support in relation to medication safety and also feeling their care was well managed without their oversight and so improvement initiatives should ensure these areas are examined closely.
Meta-inference outcomes **(Studies 1a, 1b and 2) – practice points to inform care provision within each domain of importance**	**Qualitative data from co-design study (Study 4) – actions to enable change in line with areas of importance**	**National quality indicators available (Study 3)**	**Data convergence**	**Mixed methods inference**
Category – Expert care **Domain – Supported access to senior clinicians**				
Practice points (n= 1)	Action: Strengthen nursing leadership Equip and support nursing unit managers (NUMs) to develop	No indicators available.	Enhanced	The key drivers to enable supported access to senior clinicians based on what

What do patients and family members look for in relation to access to senior clinicians? 1. Access to senior medical and nursing clinicians with high levels of expertise (email / mobile phone numbers) enabling prompt attention to any noted concerns, answers to questions, time for support and planning, comfort in relation to ongoing support on discharge home and continuity of care	systems and processes within their ward that explicitly outline key contact points for patients with palliative care needs, and their families *[Addresses practice point 1]*			patients and families noted for optimal care provision, include: ***1. Leadership -*** Supported access to senior clinicians is critical to good palliative care provision and can be facilitated at each ward level (micro). Some patients will have known access to specialist nurses (renal nurse specialists, cancer care specialists, palliative care nurses), others won't and so each local area will need to plan and consider this. All patients screened to have a limited prognosis should have access enabled.

Meta-inference outcomes (Studies 1a, 1b and 2) – practice points to inform care provision within each domain of importance	Qualitative data from co-design study (Study 4) – actions to enable change in line with areas of importance	National quality indicators available (Study 3)	Data convergence	Mixed methods inference
Category – Optimal environment for care **Domain – Structural factors – patient focused (E.g. bed area, window access, shared rooms)**				
Practice points (n= 7) *What do patients and family members state is important in relation to the structural environment in the hospital?* 1. That the bed area is restful to enable sleep and recovery including the need for quiet, appropriate lighting and temperature 2. Access to a window to enable a connection to the day/night cycle, to feel connected to the world, to feel warmth from sunlight and to prevent feeling claustrophobic 3. Prevention of frequent bed changes as patients try to develop a sense of belonging within their space and feel disorientated when moved regularly (the loss of personal items when moved was also noted)	Action: Strengthen nursing leadership Equip and support nursing unit managers (NUMs) to optimise the ward environment as best as is possible, in line with the key points noted *[Addresses practice points 1-7]*	No indicators available.	Enhanced	The key drivers to optimise the structural environment for patient focused supports based on what patients and families noted for optimal care, include: ***1. A positive policy environment –*** Policy support at all levels (macro, meso and micro) to support and resource environmental factors in line with the principles of person-centred design[3] are important. ***2. Leadership*** – ward level leadership to identify how patient focused factors of support can be achieved is important and can be progressed under the leadership of a NUM. For example, processes in relation to managing bed changes, access to windows and

4. To consider comfort when waiting in the emergency department, through the provision of a bed to wait in (rather than a chair only), given they are so unwell 5. To consider practical supports such as emergency access to toiletries for unplanned admissions and more practical audio-visual controls for the TV (not to be handheld if possible) 6. Consideration of supports for people with breathlessness, including the provision of fans, cooling air and adequate ventilation in bathrooms specifically to assist with showering 7. To consider the implications of a shared room with positives noted in relation to the company and helpfulness of fellow patients but challenges noted in relation to being disturbed by noise, having to tolerate different smells/odours, feeling quite confronted by other people's illnesses, discomfort with mixed gender wards and lack of privacy for both care and important conversations				managing shared rooms can all be managed locally. ***3. Innovation*** – not all ward environments will be ideal, nor funding available to redesign them. Therefore, working innovatively to consider the areas of importance noted and how these could be met in innovative ways will be useful. Such thinking should be informed by broad thinking – clinicians but also consumers, designers and others who may be able to assist.

Meta-inference outcomes (Studies 1a, 1b and 2) – practice points to inform care provision within each domain of importance	Qualitative data from co-design study (Study 4) – actions to enable change in line with areas of importance	National quality indicators available (Study 3)	Data convergence	Mixed methods inference
Category – Optimal environment for care **Domain – Structural factors – family focused**				
Practice points (n= 4) *What do family members state is important in relation to the structural environment in the hospital?* 1. Access to seating and preferably a place to lie at night, alongside the patient's bed, as well as simple kitchen items (water, ice, microwave) 2. A dedicated space or room to enable private conversations to be held, a break from caring or for quality family time away from the bedspace (inclusive of the patient) 3. Access to affordable meals onsite (a suggestion of subsidised	Action: Strengthen nursing leadership Equip and support nursing unit managers (NUMs) to: i. optimise the ward environment as best as is possible, in line with the key points noted *[Addresses practice points 1-4]* ii. consider the environmental needs of families of people who are imminently dying including ensuring availability of items such as a comfort trolley, music, fans, provision of bedding and resourcing for provision of meals *[Addresses practice points 1-4]* iii. embed a system to alert clinicians and ancillary staff to the fact a particular patient has palliative care needs and a poor prognosis (other symbol on outside of room)	2 indicators (Netherlands, n=2) Part coverage of practice points confirmed.	Enhanced	The key drivers to optimise the structural environment for family focused supports based on what patients and families noted for optimal care, include: ***1. A positive policy environment –*** Policy support at all levels (macro, meso and micro) to support and resource environmental factors in line with the principles of person-centred design^3 are important. In addition, hospital level policy addressing provision of subsidised meals for families is important for consideration. ***2. Leadership*** – ward level leadership to identify how family focused factors of support can be achieved is important and can be progressed under the leadership of a NUM. For example, enabling a private room for someone imminently dying can be managed locally.

hospital cafeteria access for this population of people) 4. A private room for someone who is very close to dying to enable privacy for meaningful conversations and space for families to be present	*[Addresses practice point 4]*			***3. Innovation*** – not all ward environments will be ideal, nor funding available to redesign them. Therefore, working innovatively to consider the areas of importance noted and how these could be met in innovative ways will be useful. Such thinking should be informed by broad thinking – clinicians but also consumers, designers and others who may be able to assist. The need to co-design future clinical environments with palliative care consumer representatives to enable their needs to be listened to and met as much as is possible is important.

Meta-inference outcomes **(Studies 1a, 1b and 2) – practice points to inform care provision within each domain of importance**	**Qualitative data from co-design study (Study 4) – actions to enable change in line with areas of importance**	**National quality indicators available (Study 3)**	**Data convergence**	**Mixed methods inference**
Category – Optimal environment for care **Domain – Cleanliness to support infection control**				
Practice points (n= 1) *What do patients and family members state is important in relation to cleanliness in the hospital?* Cleanliness, specifically in relation to infection control and managing the unique requirements of those who are immunosuppressed in a timely and efficient way	Action: Strengthen nursing leadership Equip and support nursing unit managers (NUMs) to optimise the ward environment in relation to cleanliness in line with this noted practice point. *[Addresses practice point 1]*	No indicators available.		The key drivers to address this domain are two-fold: ***1. A positive policy environment*** – significant policy and accreditation supports in Australia already focus on cleanliness and what is required to enable this; ***2. Leadership -*** The role of the Nursing Unit Manager is critical in ensuring standards for cleanliness within the ward are upheld. Patients with palliative care needs require reassurance about the cleanliness of their environment, especially if they are also immunosuppressed. Ward level

				management of this is important as is meeting such requirements within national accreditation standards.

Recommendations that are overarching across multiple domains from the co-design study

Meta-inference outcomes **(Studies 1a, 1b and 2) – practice points to inform care provision within each domain of importance**	**Qualitative data from co-design study (Study 4) – actions to enable change in line with areas of importance**	**National quality indicators available (Study 3)**	**Data convergence**	**Mixed methods inference**
Data overarches multiple domains	Action: Securing executive level support Valuing this work as a key priority for the hospital will be an enabler for improvement work to progress. Explicit support from the hospital executive to underscore the importance of this work and resource it accordingly is important. A recommendation includes the development of a 'tool' to outline the importance of this work to hospital executives and highlight the key practice points required to enable	N/A	Enhanced	Recommendations to enable optimal inpatient palliative care strongly noted the importance of hospital executive level (meso) ***policy support and leadership.*** This needs to remove barriers and enhance enablers for clinicians, ancillary staff and consumer representatives to work together to innovate and lead care that addresses the key areas of

	optimal care. This tool needs to engage with and foster executive level champions and ensure executives are talking about the quality of care for people with palliative care needs and those imminently dying in hospital. This tool also needs to highlight the importance of valuing, resourcing and supporting staff to excel in this work and to understand the fact palliative care requirements are prevalent and care of people with palliative care needs, within the hospital setting, is everyone's business and a priority. Valuing, resourcing and supporting staff needs to explicitly include: 1. Explicit review and resourcing to enable optimal care for people with palliative care needs (and their families / carers), inclusive of adequate nursing, medical and allied health staffing guided by levels of resourcing articulated by Palliative Care Australia[4] 2. Executive support for supervision/de-briefing/reflective practices to support clinicians undertaking this work – this needs to be embedded in practice and available for all 3. Resourcing to support NUMs with education and opportunities to lead collaborative improvement work across the sector			importance for optimal care. Adequate resourcing, support mechanisms and a method to enable NUMs to lead and innovate across the sector is required.

	4. Executive support for driving change/improvement and assisting navigation of any noted barriers 5. Developing a mechanism to reward excellence in care, based on the key practice points noted to enable optimal care for people with palliative care needs and their families / carers – both to acknowledge the hard work of the clinicians involved and to enable sharing of excellent practice 6. Develop a process for palliative care to be 'at the table' at hospital executive levels and not to be at the whim of a changing senior executive role. Use data to support this including the use of economic arguments as appropriate.			
Data overarches multiple domains	Action: Develop communities of practice Fostering leadership and excellence through the development of hospital based palliative care networks of excellence will support ongoing focus and improvements at State/Territory and national levels, supported by lead organisations. In order to achieve this is is recommended to: 1. Develop and implement key supports at local (LHD), regional and national levels, to engage clinicians working in palliative care (in collaboration with leading clinicians in specialist palliative care) to	N/A	Enhanced	Investment in ***leadership*** and excellence through collaborative networks for sharing, rewarding and recognising great work is important in supporting sustained improvements across the system. Ensuring learnings across networks will facilitate collaboration, sharing of excellence, prevention of duplicated effort and recognition for clinicians working hard within a busy sector.

	maintain a focus on driving improvements, learning from experiences and sharing excellence– Eg. special interest groups across LHDs, education provision, linkage to and support for postgraduate study, develop and support new positions (Eg, NPs), champions underscored by a culture of strong nursing leadership 2. Reward and recognise great work facilitated via a pillar within State / Territory networks (Eg. NSW Ministry of Health - ACI, CEC) 3. Resource statewide mapping of excellence and variation to enable identification of gaps and key areas for focused improvement			
Data overarches multiple domains	Action: Funding reforms Challenge current funding drivers and resource allocation for people with palliative care needs, across hospitals and related care services. Link funding to noting a person as 'palliative' and remove barriers of access to support their care to live as well as possible (Eg. rehabilitation services are currently not available to someone noted as 'palliative'). Consistency of such funding and implementation of resources across regions, States/Territories is important	N/A	Enhanced	***A positive policy environment*** to enhance resource allocation to enable a person with palliative care needs to receive care in line with their unique needs is essential. Current funding drivers need reviewing to enable more person-centred care provision.

Data overarches multiple domains	Action: Fostering greater community awareness Increasing the health literacy of the general community about palliative care, what this means and how it can support people to live as well as possible is needed. In order to achieve this a recommendation was made to resource, develop and implement a state-wide campaign to promote palliative care in the hospital setting (co-design this with consumers). This campaign ought to echo the messages of the first 1000 days are vital to also state, the last 1000 days are vital – we need to optimise care and support to enable the best experience possible. Make end of life care within hospitals part of daily language in healthcare – value good palliative care experiences. Manage this via a campaign to promote palliative care in the hospital setting, at a political level to State and Federal government health ministers; National medical, nursing, allied health organisations; Journalistic sources and academic platforms – basic message is people are dying in hospitals and we should be doing it better	N/A	Enhanced	***A positive policy environment*** that values palliative care is imperative if optimal care is to be successfully provided. Raising community awareness and health literacy about the need for optimal hospital palliative care and emphasising the urgency of this, is important. Valuing this work as a priority and co-designing this campaign with palliative care consumer representatives is needed.
Data overarches multiple domains	Action: Evidence-informed practice and national benchmarking	N/A	Enhanced	Enabling optimal palliative care in the hospital setting, based on the key areas of importance articulated by patients with

	Effective measurement of palliative care quality is needed informed by: 1. Implementation of indicator use, where needed development of data items and key definitions to enable improvement work in hospital based palliative care to be underpinned by evidence and guidance for key areas of improvement Eg. Patient reported outcome measures, patient reported experience measures, a predesigned pack to consider staff experience / morale and happiness at work 2. Policy supported key definitions to enable consistent communication and measurement– palliative care, specialist palliative care, end-of-life care; Define what is specialist palliative care across regions and their related referral criteria; Define the minimal acceptable standards of care for end of life care – what are the 'vital signs' for ongoing measurement 3. Embedded coding for identification of patients noted to be 'palliative' so retrieval of data is more possible from current sources 4. National minimum data set for palliative care 5. Facilitated access to complaints data			palliative care needs and their families, can only be achieved if some form of ***measuring*** current outcomes and experience is achieved. At present, a comprehensive method to enable this is lacking. However, there is significant data available, some of which may answer components of the noted areas of importance. Development of a set of indicators and mapping to existing data for hospital use is an important piece of work to be achieved to support this work.

	6. Facilitated access to feedback from existing datasets – (Eg. Clinical Excellence Commission in NSW - what is possible? Reporting back in relation to data for NFR orders noted pre-death. ?Add to this data entry in relation to whether a family conference has been held.) 7. Facilitated access to reports for patient experience surveys conducted, linked to an identifier for a person being likely to have palliative care needs 8. Develop a process for reporting on and reviewing expected deaths in hospital within the Morbidity and Mortality meetings (M&M meeting) as well as a mechanism for feeding this information back to the relevant nursing unit manager 9. Focus on data within accreditation standards from the Australian Commission for Safety and Quality in Healthcare[5], noting Standard 5 is important but several other standards inform quality palliative care provision (Eg. communication, cleanliness, medication safety)			

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