

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

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Thesis submitted in fulfilment of the requirements for
the degree of

Doctor of Philosophy 92984 Nursing

under the supervision of:

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January 2021

Certificate of original authorship

I, Claudia Vir dun, 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.

This research is supported by the Australian Government Research Training Program.

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Date: January 4, 2021

Acknowledgements

This PhD has certainly been a journey, with amazing learnings along the way as well as a number of challenges to navigate. First and foremost, this would not have been possible without the support of my family. Adrian, you have been by my side from enrolment to submission and provided constant support, encouragement and a belief that I would do it. Tulli, you were a constant presence in the study which I loved, and Sophia, you joined us in 2016 and have been the perfect distraction and support ever since. So, a huge thank you to all of you: we have done it! Also, to Mum who has provided extensive babysitting support and to Dad and all my brothers who have provided words of encouragement over the years – thank you. I hope the outcomes from this work can do us all proud.

To my supervision team: thank you so much for your incredible support and generosity throughout this entire Project. Jane, as my principal supervisor you have provided endless advice, mentorship and critique. You always encouraged me to be a more rigorous researcher and have been a very caring support throughout life's ups and downs. Tim, on several occasions you 'read' me very astutely and provided very wise words to help me through. In addition, your attention to detail and incredible knowledge have been critical. Karl, your input was so valued, reshaping my thinking in such significant ways at several key points over recent years, leading to important changes. Finally, to Trish: your feedback and positivity about this work has been so important, providing confidence and a belief in where we were heading. I feel incredibly lucky to have been guided, mentored and supported by such a talented and world-leading team – thank you to all of you.

Thank you also to my colleagues and friends from UTS who have supported me in so many ways. Through the sharing of the ups and downs of a PhD, your friendships have been invaluable – you 'get it' and know who you are: thank you. Also, a huge thank you to my colleagues within palliative care who have provided a sounding board as well as assisted screening, recruitment and development of recommendations. Your input and support have been incredible – thank you. Also, to my friends who have listened to me talk about this work for years and encouraged me to stick with it, or provided a great excuse for a time out – you are all just fabulous, thank you.

Finally, I want to acknowledge the patients and families I have worked with clinically as well as those who contributed to this research. Each of you has taught me so much, fueling my ongoing passion to optimise inpatient palliative care for all: I truly believe this is possible and will continue to work hard to enable this.

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

Virdun, C., Lockett, T., 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.

Virdun, C., Lockett, 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.

Virdun, C., Lockett, 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.

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Conference presentations

Accepted for oral presentation – peer reviewed

1. **Virdun, C.**, Phillips, J., Lockett, 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., Lockett, 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., Lockett, 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., Lockett, 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., Lockett, 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., Lockett, 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., Lockett, 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., Lockett, 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., Lockett, 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.**, Lockett, 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.**, Lockett, 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.**, Lockett, 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*
13. **Virdun, C.**, Lockett, T., & Phillips, J. (2017) Hospital end-of-life care: Using consumer identified areas of importance to improve practice. *International Conference on Cancer Nursing - July 9-12, California*
14. **Virdun, C.**, Lockett, 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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17. **Virdun, C.**, Lockett, 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*

Accepted for poster presentation – peer reviewed

1. **Virdun, C.**, Phillips, J., Lockett, 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., Lockett, 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., Lockett, 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., Lockett, 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., Lockett, 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., Lockett, 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., Lockett, 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., Lockett, 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.**, Lockett, 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., Lockett, 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., Lockett, 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., Lockett, 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.**, Lockett, 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.**, Lockett, 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., Lockett, 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.**, Lockett, 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.**, Lockett, 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., & Lockett, 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*

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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.
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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.
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Clinical Quality Register	System that contains “data about patients with a particular kind of condition, often including outcomes” ² (page 8)
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Clinician	<i>“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.”</i> ³ (page 69)
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Co-design	The OPAL Project used the following definition for co-design: <i>“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.”</i> ⁴ (p.4) Importantly, the OPAL Project added to this definition by also including carers alongside patients and staff within the co-design process.
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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: <ul style="list-style-type: none">• 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.
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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.
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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.
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Experience	An outline or description of an event or occurrence with which the person has had direct contact. ¹
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Family and carers	<i>“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.”</i> 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	<i>‘A measurable component of the standard, with explicit criteria for inclusion, exclusion, time frame and setting’</i> 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	<i>‘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.’</i> 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. <i>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’).</i> ⁵ (p.7)

Person-centred care	<i>"a standard of care that ensures the patient/client is at the centre of care delivery."</i> 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	<i>"Quality indicators are explicitly defined and measurable items referring to the outcomes, processes, or structure of care."</i> 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	<i>"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."</i> 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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