UTS UNIVERSITY OF TECHNOLOGY SYDNEY

Optimising care transitions from hospital to home for carers of people with palliative care needs.

by Celia Marston

Thesis submitted in fulfilment of the requirements for the degree of

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under the supervision of
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Certificate of original authorship

I, Celia Marston, declare that this thesis, is submitted in fulfilment of the requirements for the award of Doctor of Philosophy degree, 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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Abstract

Background

Transitioning from hospital to home can be distressing for people with palliative care needs and their carers. Carers provide most of the care at home and are crucial to its success. They often report unmet needs and poor support during this transition, leading to care breakdown and poor outcomes for both carer and patient. The best way to support carers during discharge is unclear, but the Carer Support Needs Assessment Tool – Intervention (CSNAT-I) has shown promise in community palliative care and may suit hospital settings.

Aims

The primary aim of this research was to *characterise the core elements of a carer-focused intervention model that would facilitate successful hospital-to-home transitions for carers and people with palliative care needs*.

The secondary aims addressed by three individual studies were to:

- Describe the characteristics and reporting quality of interventions, their core elements and mechanisms used in studies to improve the transition from hospital to home for carers of patients with advanced illness *(Systematic Review)*.
- Examine their alignment with selected domains of Care Transitions Framework, (66) specifically intervention characteristics, implementation measures and outcomes (*Systematic Review)*.
- Explore the implementation of an existing carer-focused intervention (CSNAT-I), administered by occupational therapists, into routine practice to support carers of people with advanced cancer at hospital discharge (*Mixed Methods Study)*
- Determine the feasibility of delivering the CARENET intervention to carers of advanced cancer patients in an acute oncology setting, and the feasibility of the study design (*Phase II Feasibility study)*

Methods

The doctoral program described in this thesis included one systematic review, one mixed methods study (consisting of two qualitative and one quantitative study of the implementation of the CSNAT-I), and a Phase II feasibility study (CARENET). Methods were informed by the Medical Research Council framework for complex interventions, and findings were mapped against the Care Transition Framework.

Results

The systematic literature review confirmed that carers of people with advanced cancer are routinely overlooked in the design, delivery and evaluation of interventions aimed at improving hospital-to-home transitions. This finding justified the subsequent studies to evaluate the implementation of the CSNAT-I into routine care and a controlled trial setting.

Clinicians (occupational therapists) and carers accepted the CSNAT-I, a dyadic intervention that is clinician-led, integrated into routine discharge planning, delivered across hospital and home, and targets the practical aspects of caring. They highly valued the CSNAT-I's identification, actioning and follow-up of carer needs. However, operationalising a carer-focused intervention was difficult and not congruent with the acute setting. Clinicians modified CSNAT-I components to improve contextual fit, but the protocolised version (CARENET) did not account for all carers requiring support and the personalised discharge plans involved. Evaluation of CSNAT-I intervention and implementation showed that the intervention treats carers as inherently linked to patient care, rather than individuals with needs beyond their preparatory caring role.

Conclusion

All carers require support at hospital discharge. To ensure equal access to support for all carers, intervention models need to be flexible and their development must be driven by a diverse representation of carers. In the short term, there is a need for co-design research that engages multiple carer groups before interventions proceed to testing and implementation.

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List of abbreviations

AKPS	Australian Karnofsky Performance Status
CARENET	**CAR**ing for car**E**rs of people with adva**N**c**E**d cancer at hospi**T**al discharge
CI	Confidence Interval
COPD	Chronic Obstructive Pulmonary Disease
COREQ	Consolidated criteria for reporting qualitative research
CSNAT	Carer Support Needs Assessment Tool
CSNAT-I	Carer Support Needs Assessment Tool – Intervention
CTF	Care Transition Framework
CTI	Care Transition Intervention
ED	Emergency Department
GH	Generalist Hospital
IQR	Interquartile Range
MADI	Model for Adaptation, Design and Impact
MRC	Medical Research Council
OT	Occupational Therapy
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta Analyses
RCT	Randomised Controlled Trial
SCH	Specialist Cancer Hospital
TDF	Theoretical Domains Framework
TFA	Theoretical Framework of Acceptability
UK	United Kingdom
US	United States
WHO	World Health Organization

Chapter 1. Introduction and rationale for doctoral program

Chapter 1 provides an introduction and rationale for the doctoral program. It includes a review of the literature on the current context and significance of care transitions for people with palliative care at individual, societal and policy levels, and identifies current gaps in research and practice that underpin the rationale for the doctoral program. Research aims, questions and objectives are stated and linked to chapters and publication outputs. The methodological and theoretical frameworks applied to the doctoral program are defined and their relevance explained.

1.1 Background

1.1.1 Transitions of care – definition and characteristics

Throughout the course of an illness, a person will frequently move through multiple different types of care delivery at multiple different sites including in their own home. Moving between these types and sites of care may be termed transitions. The World Health Organization (WHO) defines care transitions as “the various points where a patient moves to, or returns from, a particular physical location or makes contact with a health care professional for the purposes of receiving health care”. (1) The WHO states that transitions of care are a core part of healthcare, and are influenced by clinical and non-clinical factors such as the patients’ medical and functional status, healthcare resources; and the extent of informal family and carer supports in the community.(1)

Discharge from hospital is one transition point in a person’s care experience, (2) and was the primary focus of this doctoral work. “Hospital”, for the purposes of this research, refers to acute inpatient settings. Discharge planning is “the development of a personalised plan that assesses a patient's health and social care needs prior to them leaving hospital, to support the timely transition between hospital and home and improve the organisation of post-discharge service”. (3) In this thesis, a patient is a person living with palliative diagnosis or receiving care.

1.1.2 Australian health care context and transitions of care

The Australian healthcare system has been described as “a multi-faceted web of public and private providers, settings, participants and supporting mechanisms”. (4) Federal, state and territory governments are collectively responsible for the funding, operating and governance of the health system, (4) while the private sector operates private hospitals and health services. Services are delivered by a range of health professional across settings in both metropolitan and remote areas. These include medical specialists, nurses, allied health professionals such as occupational therapists (OTs), dentists, and support staff. The public health system is underpinned by a universal health insurance scheme – Medicare – which ensures all Australians have access to free (or heavily subsidised) hospital services and selected medicines. The private health system is funded by people who pay for health insurance or out-of-pocket costs, and offers a wide range of services that are not available in the public system or can be accessed more quickly.

Australia has 672 public hospitals, and in 2021–22 they cared for two thirds (59%) of people being hospitalised, with one third in the private system.(5) People are admitted for medical, surgical, mental health, childbirth, rehabilitation and other specialist care. The average length of stay in public hospitals in 2021–22 was 5.9 days.

This complex mix of public and private service providers occurring across a range of settings is likely to affect the safety and quality of transitions from hospital to home, particularly for vulnerable populations. (6) Governing bodies such as the Australian Commission for Safety and Quality in Health Care recommend health services integrate comprehensive care plans to support these transitions in the form of individualised discharge plans, shared decision-making and efficient clinical handover. (7) An Australian government consultation report found healthcare professionals and consumers viewed existing discharge planning models as inadequate and unsupportive, and proposed the health system improve definition of roles and accountability for communication at discharge and access to health information across settings. (5)

1.1.3 Transitions for people with palliative care needs and their carers

Characteristics and prevalence

Transition from hospital to home is a multifaceted and complex process that requires clinicians and health services to work together to meet the increasingly complex needs of patients and families. (1) Patients receiving palliative care exemplify this complexity because they move between health care settings, and require greater support than other patient populations because of their frailty and multiple care needs(8)

Complexities can manifest in several ways. Firstly, there are challenges in managing patients' symptoms, including pain and medication needs, outside the hospital setting. These can lead to unplanned admissions in response to palliative care emergencies. Emergencies can include intercurrent medical issues related or non-related to life limiting illness (e.g cardiac issues, infection, bowel obstruction), uncontrolled symptom issues and situations which are perceived by the patient/carer as emergencies (e.g predicted clinical deterioration, psychosocial distress, lack of access to community services).

Secondly, effective communication and care coordination are required across multiple healthcare providers and family carers. Thirdly, there is a high demand for emotional and psychological support for both patients and carers as they cope with increased stress and uncertainty while adapting to home-based care. Finally, the significant burden placed on carers in providing ongoing support at home can result in substantial emotional and physical strain.

One of the largest groups of people receiving palliative care are those with advanced cancer. Specifically, in Australia, patients who died from cancer were at least five times more likely to receive consultations with palliative care specialists compared to those dying from organ failure or frailty (21%, 3.7% and 2% respectively).(9) Furthermore, cancer diagnosis accounts for 40% of the palliative care-related hospitalisations in Australia.(10) Discharge from hospital to home settings for people with advanced cancer is a period of heightened stress. This is because care moves from a monitored,

structured hospital setting, overseen by health professionals, to a setting where patients and their carers are largely left to self-monitor and self-care. This transition can often lead to uncontrolled symptoms, and excessive burden on carers who are often unaware of what to expect in taking on the caring role for a person with advanced cancer. (3)

Many people with advanced cancer experience increasingly frequent transitions between hospital and home as they near end of life. (11, 12) The patterns and prevalences of these transitions varies according to health services and patient populations. A large cohort study of four European countries (Belgium, Italy, Netherlands and Spain) found that the transfer from home to hospital was the most common type of transition in the last month of life for cancer patients. (13) Similarly, an Australian study of hospital and emergency department (ED) use in the last year of life found cancer patients' use of EDs increased markedly in the last month compared to non-cancer patients. (12) In a Canadian study, (11) a cancer diagnosis was associated with multiple transitions for patients admitted to a palliative care program; in the last month of life, pain and symptom control were strongly associated with multiple transitions for this cohort.

Some authors have highlighted that symptom burden, disease progression and carers reaching capacity can lead to increased hospitalisation rates. (11, 14, 15) It is important to note that many cancer patients undergo a rapid and sudden decline in function in the last 60 days of life.(16) This is likely to mean significant and sudden increases in care needs for families and carers; and the likelihood of more transitions between hospital and home. (12) However, understanding the associations between the number of transitions and factors such as functional status and levels of carer support requires further research.

Experiences and outcomes of care transitions

The prevalences of adverse outcomes stemming from poorly managed transitions for this patient cohort are not well documented and limited largely to readmission and mortality rates. (17) However, rich qualitative data describes increased anxiety,

uncertainty and high levels of unmet need for both patients and their families. (18-20) A narrative review (21) of 14 qualitative studies from Europe, Australia and the United States (US) found patients' and carers' experiences at this transition point can be both positive and negative. Both patients and carers tried to maintain normality as they adapt to and redefine the "new normal". Patients found maintaining participation in daily activities and managing their symptoms helped navigate these transitions, whilst carers experienced redefinitions of self in the caring role whilst still trying to maintain a balance between their new and old life situations. Another narrative review found that transition experiences were also influenced by the patient–carer dyad's knowledge of prognosis, emotions during discharge, support after discharge, communication and care coordination amongst care providers, and carer overload. (20)

1.1.4 Intervention models that improve care transitions between hospital and home

A range of strategies can be applied to improve transitions of care. According to the WHO, these include:

- sharing and standardisation of tools across settings (e.g., using electronic medical records);
- a systems approach (e.g. discharge planning, medication reconciliation, timely handover, patients/carer education);
- early assessment of those at risk, with complex transition needs; and
- enhanced communication and relationships. (1)

Several systematic reviews have examined the impact of various CTIs that adopted a range of the WHO's proposed strategies and provide some insights into effective models. Most of the reviews targeted the older (3, 22, 23) and chronic disease population (and their carers), specifically patients with heart failure (24-26) and chronic obstructive pulmonary disease (COPD). (27) Most of the interventions examined adopted systems-based approaches incorporating processes to improve communication and continuity of care across hospital and home settings. These included enhanced discharge planning plus follow up programs, (3, 23-25, 27) virtual wards at home, (26) and clinician-led models using navigators (22) and nurse specialists. (28) Only one review focused on carers, presenting the carers as the core

part of the discharge intervention, rather than the recipient. (23)(23) The efficacy of these intervention models were primarily measured against service outcomes, mostly readmission rates and costs, (3, 23-26) followed by patient-related outcomes such as disease burden, quality of life, satisfaction. (24, 28) Carer-specific outcomes were largely absent. Most reviews found that these interventions were effective in reducing readmissions, (3, 23-26) but did not support their efficacy with respect to other outcomes.

Naylor and colleagues (24) identified and defined the core components of care transition interventions (CTIs) that resulted in positive outcomes for older, high-risk patients and carers moving from hospital to home in the US. Core components were defined as: "a critical element of traditional medical care, community-based services, and non-traditional services provided by the healthcare team that patients and cares should receive to promote positive health outcomes throughout periods of acute illnesses extending from hospital to home." A multi-stakeholder workgroup consisting of clinicians, patients and carers, established eight core components and recommended that they should be used together to optimise transitions. The eight core components are:

- patient engagement;
- carer engagement;
- complexity management;
- patient education;
- carer education;
- patient and carer wellbeing;
- care continuity (i.e., communication and care that reaches across hospital and home delivered to both patient and carer); and
- accountability at clinician, team and organisational levels. (24)

The optimal CTI model for advanced cancer has not yet been established or evaluated. However, qualitative studies provide insights into what this patient population and their carers would like to receive. They characterise discharge from hospital to home as lacking adequate communication and coordinated care between health care providers,

and offering poor support for patients and for carers to manage the complex demands of caring for someone at home. (17, 18, 20) They advocate for more education prior to discharge, open and inclusive discussions regarding goals of care and the venue of care, and increased home-based formal support to improve care transitions. (20)

It has been suggested that specialist palliative care can facilitate the hospital-to-home transition. However, a systematic review (8) was unable to determine the impact of specialist palliative care due to the heterogeneity of study designs, outcomes, findings and poor methodological quality. The palliative care interventions of the eight studies included in this review were embedded in multidisciplinary and transition care models, and the outcomes reported were length of stay, discharge support and hospital readmissions. Two out of eight of these included studies for people with advanced cancer.(29, 30) Both studies found a reduction in 30-day hospital readmission rates for and inpatient health service use. The authors of this review called for higher-quality studies and standardised outcome measures.

1.1.5 Role and importance of carers in care transition intervention models

In this thesis, a carer is defined as:

> a person who looks after someone who has a disability, mental illness, drug or alcohol dependency, chronic condition, dementia, terminal or serious illness, or who is frail or needs care due to ageing. They do this not as their paid job, but as a family member or friend. (31)

Carers of people with advanced cancer play a critical role in the transition from hospital to home. Firstly, they provide most of the care when a person returns home from hospital, often at an emotional, physical and financial cost to themselves. (32, 33) Secondly, their capacity to provide care s a major influence on a person's ability to achieve care at home and avoid readmission to hospital. (17, 34) Thirdly, carers have a set of unique needs that, according to a recent systematic review, are different from those of the patient and remain largely unmet. (33, 35) Wang and colleagues (33) noted that the need cited by carers as most frequently unmet is for information, including illness and treatment information and carer-related information. In contrast, most

patients reported their need for emotional support, help with fatigue and more information about side effects and benefits of treatment. (33)

The experience of caring changes throughout a person's illness. For example, during a hospital admission, carers also experience a shift in their role from "conductor" or coordinator of care to "second fiddle", meaning that clinical staff and the organisation are driving processes and decision-making. (36) The literature includes little evidence about the experience of carers when they are integrated into the discharge process. However, integrating carers into the discharge process can enhance the continuity of care as well as reduce health service use and cost. (37) For example, including carer support in discharge planning for older people with chronic conditions has been shown to significantly reduce readmission rates. (23) However, there is little detail on how this directly benefits the carer, and even less evidence of the efficacy of carer-focused discharge interventions in the advanced cancer setting.

1.1.6 National and international policy context for cancer carers

There is growing recognition of the important role and needs of carers during hospital discharge at international and national policy levels. However, there is little evidence of how this is operationalised into everyday practice. In the US and the United Kingdom (UK), legislation has mandated the inclusion of carers in discharge planning processes. In the US, the Caregiver Advise, Record, Enable (CARE) Act has been enacted across 40 states since 2016, and requires that hospitals must record the name of the carer in the medical record (if there is a recognised carer), inform the carer that the patient will be discharged, and provide education to the carer on caring related responsibilities that will need to occur at home. (38) The UK's Care Act stipulates that all carers should have access to assessment and support that is on par with the person receiving care in the hospital. The implementation of these acts has been problematic due to systemic barriers and has fallen short of meeting the unique needs of carers of people with advanced cancer. (39, 40)

There is no legislation mandating support for carers in Australia. Similarly, carer support is not included in the National Safety and Quality Health Standards – an

accreditation framework used to assess the quality and safety of health care provision and protect the public from harm.(7) Carers are considered in some of the processes aimed at reducing patient harm, such as ensuring care plans and critical patient information is communicated to them. However, there are no standards dedicated explicitly to carer engagement to optimise quality and safety. Similarly, there is acknowledgement of the role and contribution of carers in the community in national and state policy, (41, 42) but details on how to operationalise these policies to support carers in the discharge context are absent. For example, integration of the Victorian Carer Strategy (41) into the Victorian Cancer Plan (43)has been proposed, with the aim of optimising wellbeing and support for cancer carers and the people for whom they care. However, the only concrete plan to date is a single action across four years of increasing support for rural carers only. Without policy direction on how to implement better care for cancer carers, recommended health services and researchers' capacity to change how they support carers, may be difficult to achieve. Finally, the Australian Commission for Safety and Quality in Health Care assesses health services against national standards aimed at ensuring safe and effective care is delivered to patients.(7) However, this commission does not consider carers needs.

1.1.7 Role of occupational therapists in hospital discharge.

Occupational therapy (OT) is defined as a person-centred health profession concerned with promoting health and wellbeing through occupation. OT aims to help people to participate in activities of everyday life. This is achieved by therapists working with people and communities to build skills, adapt tasks and environments to improve their participation and wellbeing. (44, 45)

Occupational therapists are university-qualified allied health professionals who must meet national registration standards to practise. Internationally, qualifications vary by country but typically require a bachelor's or master's degree in occupational therapy and recognition by a professional regulatory body. In Australia, Occupational therapists must have completed an accredited undergraduate degree (Bachelor of Occupational Therapy) or a Master's degree.; and be registered with the Australian Health Practitioner

Regulation Agency (AHPRA). Common work settings for occupational therapists in Australia include public and private hospitals, community health centres, aged care, disability, education, mental health, workplace rehabilitation, rural health and research. (44)

Occupational therapists play a key role in facilitating safe and effective hospital discharge for the generalist population.(46) As integral members of the multi-disciplinary team, occupational therapists provide assessment of a patient's functional performance, and determine the impact changes in function will have on returning home as safely and independently as possible. OT intervention aims to optimise people's functional abilities and modify the home environment to accommodate for these limitations. They do this by means of rehabilitation, education, provision of assistive equipment, and establishing formal support services for patient and carers.(46) Discharge planning has been reported as a core OT skill and most common interventions provided to people with cancer and palliative care needs. (47) A primary focus in this area is enabling carers to provide care at home through practical training, additional supports and education to reduce risk of carer burden or injury. (48) Moreover, patients and carers with palliative care needs value the interventions implemented by occupational therapists, specifically the practical help required to adapt to care at home. (19) The impact of hospital-based occupational therapy interventions can also be effective in reducing readmissions in different medical and surgical populations (49); and more recently the cancer population. (50) A recent meta-analysis (49) found that there was moderate quality evidence for 4 out of 7 (n=16718 participants) included studies that OT interventions targeting the transition from hospital to home were effective in reducing 1 month readmissions to hospital compared to standard care. Similarly, a retrospective analysis of US-based specialist cancer hospital data over five years found the receipt of OT services significantly decreased the odds risk for 30 day readmission and had a protective association. (50) This evidence indicates that OT may be a critical resource for ensuring a safe and effective hospital discharge; and may be well positioned to support carers and deliver care transition interventions. However, the role of occupational therapists in delivering

care transition interventions for people with advanced cancer and their carers remains underreported.

The author of this thesis (CM) has worked as an occupational therapist in cancer and palliative care for over 15 years. A core part of her practice has been supporting patients and carers to return home for end of life care. Preparing for discharge home requires CM to view both the patient and carer as clients requiring care. Unfortunately, evidence based support models to guide practice with carers are largely absent in the real world clinical setting. This motivated CM to complete a qualitative research study as part of a Masters degree in 2012. This qualitative research study explored palliative care patient and carers' experiences with occupational therapy when preparing for discharge home. Holding the position as lead occupational therapist in a specialist cancer hospital led CM to (1) the development of local clinical procedures to support patient and carers in discharge planning; and importantly (2) a collaboration with senior researchers, Gail Ewing and Gunn Grande. Gail and Gunn developed a carer support intervention that improved carer outcomes in the community palliative care setting. This raised the question: Could this intervention be implemented in an acute setting? Answering this question was one of the main reasons for pursuing a PhD.

1.1.8 The Carer Support Needs Assessment Tool – Intervention (CSNAT-I)

An emerging body of work aims to find a way to meet the needs of carers of people with advanced cancer. One such project focuses on the development of a needs assessment tool integrated with intervention. A paper-based tool – the Carer Support Needs Assessment Tool (CSNAT) – was developed in the UK for carers of people with palliative care needs living in the community. The CSNAT was a standalone needs assessment tool that covered 14 areas of support identified by carers, (51) and was validated using 255 carers for advanced cancer patients receiving home-based care in the UK. (51)This tool evolved into the CSNAT Intervention (CSNAT-I) – a five-stage person-centred intervention model in which carers lead the assessment and actioning (intervention) of their support needs related to their role as a carer and their own health and wellbeing. (52) The CSNAT-I works by "creating space for separate needs of carers, providing an opportunity for carers to express support needs and responding to carers'

self-defined priorities. (53) It can be delivered in multiple contexts and meet the individual preferences of carers.

Community-based trials of the CSNAT-I have shown positive outcomes for carers but also some methodological and implementation challenges. An Australian step-wedge cluster non-randomised trial of the CSNAT-I was conducted across three community-based palliative care services between 2012 and 2014. (54) The tool was introduced at each site at different time points, with the pre-intervention period as a control period. The CSNAT-I was delivered to 233 carers of people with cancer and non-cancer diagnosis at two visits from nurses (2–3 weeks apart). It resulted in a significant mean reduction in carer strain, but not in carer distress or patient functional performance. There was 45% attrition due to patient deaths, and imbalanced groups (233 carers in the intervention group compared to 89 in the control group) because of slow recruitment at the start of the trial. The high attrition meant the trial was underpowered whilst the group imbalance may have resulted in not all eligible carers being approached and thus limiting the final interpretation of findings.

Similarly, in the UK, step-wedged design trial was conducted testing the outcomes of delivering the CSNAT-I at various time points across community-based episodes of care in six community-based services to 348 carers.(55)Carer outcomes were measured 4–5 months after bereavement. With a 25% completion rate of carer-related outcomes and low adherence, the small but significant reduction in prolonged grief and higher satisfaction with venue of death was assessed to be more likely due to the raising of awareness of carers needs rather than the CSNAT-I itself. In 2020 a trial in Denmark recruited a larger sample of community-based carers (182 carers in intervention group and 255 in the control group) and found that the CSNAT-I had a positive effect on carer distress, home care responsibility and communication with healthcare professionals at two-week follow-up. (56)

Recent developmental work demonstrates that the CSNAT-I shows promise as an intervention to assist carers in the hospital discharge planning process. (57) Compared to the other care transition models described in the systematic reviews mentioned

earlier, the sole purpose of the CSNAT-I is to benefit the carer. It creates opportunity and agency for the carer to identify, prioritise and action their needs. Interviewed carers and clinicians described the CSNAT-I as expanding the discharge planning focus to include carers, preventing unrealistic expectations of what care at home would entail and the likelihood of breakdown of care at home after discharge. (57) Carers also recommended that this tool be applied as early as possible during hospital admission and reviewed upon the initial transition home. (57) To date, no published trials have tested the delivery of the CSNAT-I across hospital and home settings for carers of people with palliative care needs. However, in Western Australia, an outreach service for carers of older people recently discharged from a short stay hospital ward was found to improve carers' (N=62) preparedness and reduce carer strain.(58) An adapted version of the CSNAT-I was delivered as part of the bundle of care delivered after discharge by a dedicated nurse.

Implementation of the CSNAT-I into practice

Alongside trials, there is a growing body of research examining the implementation of the CSNAT-I into routine care. Research has reported mostly on individual experiences and response to using the CSNAT-I and factors that have helped or hindered the implementation process. Clinicians' experiences with adopting the CSNAT-I into their practice have been both positive and negative. Several qualitative studies across Australia, the UK and Denmark in acute aged care and palliative care community settings described the carers and clinicians' positive experiences with the CSNAT-I. (59-61) In summary, the CSNAT-I offered a systematic approach to improving carer support, legitimising the carers' needs and enhancing rapport, relationships, and communication with carers.

Some clinicians experienced difficulties with positioning carers alongside patients in their care and allowing carers to lead the CSNAT-I process. (52, 57, 62)For example, in a controlled trial of the impact of the CSNAT-I in a stroke rehabilitation setting, (62) clinicians struggled to understand how the carer-led process should work and did not complete all the elements of the CSNAT-I as intended. Similarly, interviewed nurses working in home hospice settings in the UK viewed the CSNAT-I as something they

could initiate and add on to pre-existing clinician-led processes that continued to centre around the patient. (52)

CSNAT-I implementation were explored at a larger scale with 36 palliative care services in the UK.(63) Findings highlighted the importance of robust implementation strategy, adequate organisational support, and “clinical champions” positioned within the clinical teams with enough authority and reach to influence practice change. This body of work led to the development of an evidence-based Training and Implementation Toolkit (64) that organisations and researchers can use to support CSNAT-I implementation and outcomes and eliminate behavioural and contextual barriers throughout the practice change process.

To date, most implementation studies have been based in home hospice and community care settings, with little evidence to draw upon regarding how the CSNAT-I can work successfully in an acute hospital discharge setting. However, a qualitative study explored clinicians’ experiences of implementing the CSNAT-I in a UK hospital to help with discharge for carers of people with palliative care needs. The CSNAT-I was received by a small number of carers (n=12) and implementation was found to be challenging. Although the structure and focus on carers needs facilitated initial acceptance by the clinicians, their organisational focus on performance metrics meant they viewed the CSNAT-I as an outcome measure rather than an intervention. There was also uncertainty around who was best placed to complete the CSNAT-I and difficulty in connecting with carers prior to discharge. (65)

The research to date highlights that implementation of the CSNAT-I is context-dependent, and that individual behaviours and features unique to the setting (e.g., cultural and organisational factors) will influence practice change and implementation outcomes. Hence, to apply the CSNAT-I to an Australian acute cancer setting, developmental and piloting work is needed.

1.2 Aim, research questions and objectives

This doctoral research program aimed *to characterise the core elements of a carer-focused intervention model that can be delivered to carers for people with palliative care needs to facilitate successful care transitions from hospital to home*. The program of work was viewed through the lens of the Care Transitions Framework and followed the Medical Research Council (MRC) framework for design and evaluation of complex interventions. (66) The program consisted of three related projects.

Project 1

A systematic review and narrative synthesis to identify the characteristics of CTIs for carers with palliative care needs and determine the reporting quality of the intervention studies.

Project 2

A convergent mixed methods study of the implementation of a proposed carer-focused intervention for carers of people with advanced cancer and the components and underlying mechanisms that are most critical and likely to bring about change.

This project consisted of three studies: (2a) a qualitative study of patient and carer experiences, (2b) a longitudinal qualitative study of clinician experiences, and (2c) a quantitative study of intervention contents and delivery. As part of a mixed methods design, the findings of these studies were merged in overall analysis and interpretation.

Project 3

A phase 2 trial of the feasibility of the proposed intervention (informed by Project 2) and the study conduct and design.

1.2.1 Aim

To characterise the core elements of a carer-focused intervention model that would facilitate successful hospital-to-home transitions for carers and people with palliative care needs.

1.2.2 Research questions

1. What are the characteristics and mechanisms of carer-focused intervention models that target carers of people with palliative care needs to improve outcomes related to transitioning from hospital to home?
2. What are the key factors that influence implementation of a carer-focused intervention into usual practice in an oncology setting to assist with hospital discharge?

1.2.3 Objectives

1. To identify the evidence gap related to optimal CTIs and components delivered to carers of people with palliative care needs by:
    a. Characterising the intervention and outcomes used in CTI studies
    b. Examining the reporting quality of the CTIs using a standardised reporting tool and constructs of the Care Transition Framework (CTF) (Project 1).
2. To understand the experiences and views of people with advanced cancer and their carers about the integration of a carer-focused intervention to assist with hospital discharge from an oncology setting (Project 2).
3. To understand OTs' experiences with and views on acceptability of delivering a carer-focused intervention in routine practice before, during and after implementation (Project 2).
4. To describe the behavioural and contextual factors that influence clinician experience and acceptance of the carer-focused intervention over time (Project 2).
5. To examine how a carer-focused intervention is delivered and received in a real-life clinical environment (Project 2).
6. To determine the feasibility of a carer-focused intervention delivered and received in a controlled clinical trial environment (Project 3).
7. To describe the critical elements of a carer-focused intervention model and successful implementation into acute oncology practice (Projects 1, 2 and 3).

1.3 Frameworks and overview of research plan

This section describes the methodological and conceptual frameworks that applied to the doctoral program and how they were applied to specific projects. Figure 1 illustrates how this occurred and how the elements related to each other.

1.3.1 Methodological framework

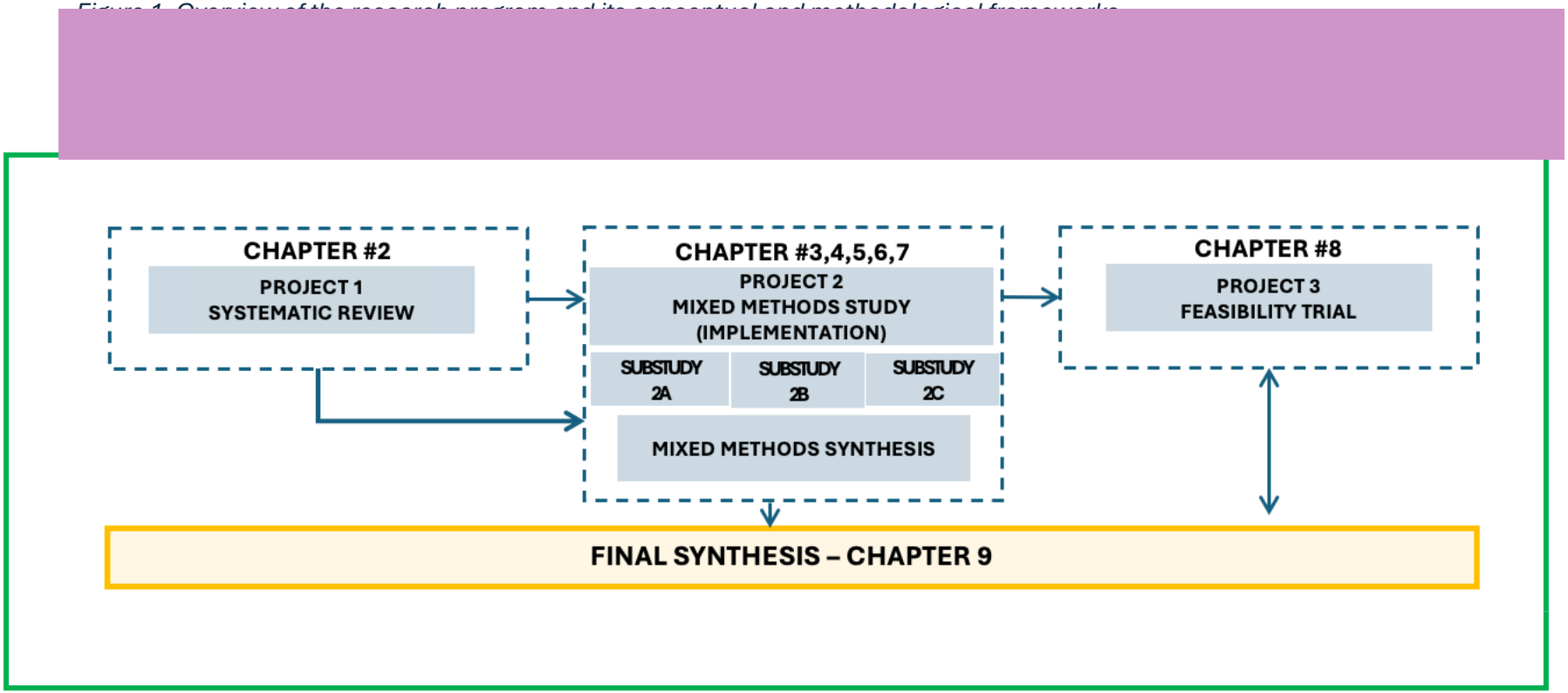
The MRC framework provides a systematic best practice approach for researchers undertaking development and evaluation of complex interventions. CTIs meet the MRC's definition of complex interventions in the following ways:

- multiple interactions occur between the components of the intervention;
- delivery and receipt of the interventions relies on behavioural responses and changes; and
- interventions are tailored to the individual. (66)

The MRC framework consists of four stages.

1. **Development**. The *identification of relevant evidence and theory* to understand what is already known about the effectiveness of the proposed intervention and why and how an intervention works. A systematic review of relevant literature is recommended if existing evidence and theory is insufficient to inform intervention development. *Modelling processes and outcomes* can improve understanding of the components of the intervention and the underlying mechanisms that may influence outcomes and how they interact with each other. This often involves a series of smaller observational and qualitative studies to determine whether a full-scale evaluation is warranted. (66)

Figure 1. Overview of the research program and its conceptual and methodological framework



2. **Feasibility and piloting stage**. Testing the study for acceptability, estimation of recruitment and retention rates, and determining the sample size in preparation for a larger-scale randomised controlled trial (RCT). Piloting the intervention also allows examination and resolution of uncertainties identified in earlier development work. A mixed methods approach is required to understand the barriers to participation and likely response rates in preparation for the larger multi-site study.
3. **Evaluation**. Large-scale randomised or non-randomised controlled studies to measure intervention effectiveness. A process evaluation is required to understand how well the intervention was delivered and the factors that helped or hindered it. Economic evaluation should be included to provide valuable data for health service and policy decision-makers.
4. **Implementation stage**. Disseminating findings to facilitate intervention adoption and implementation into routine practice or policy. Additional research may be needed to understand the factors influencing behaviour change and successful implementation into other settings. Long-term monitoring of the intervention effects in this stage is recommended to identify unexpected consequences or problems occurring in the usual practice context.

Progression from one stage to another may not be linear, allowing for an iterative and adaptive process to occur. For example, researchers can re-examine theoretical aspects if they prove to be unacceptable in practice. (66)

1.3.2 Overview of research plan and alignment to the MRC framework

This doctoral program and the embedded projects and studies were aligned with the MRC framework. Figure 1 shows how the projects occurred in the development stage, followed by the feasibility and piloting stage. An overview of these projects and their alignment with the MRC framework is given below.

Project 1: Systematic review

The systematic review provided a description of CTIs to date and their theoretical underpinnings and revealed how well these were reported in accordance with the Template for Intervention Description and Replication (TiDiER) (67) reporting guidelines and constructs from the Care Transition Framework (CTF). (68) Findings from the review informed Project 2 by providing insight into the degree of evidence and theory supporting CTIs.

Project 2: A mixed methods study

A theoretical understanding of carer-focused interventions was built upon an exploration of how an existing carer-focused intervention (the CSNAT-I) can be delivered and implemented in a real-world hospital discharge context. *Project 2* was a convergent mixed methods study using a pragmatic approach. Specifically, it explored individual experience and response (patient, carer, clinician) to the intervention, identified factors that influenced implementation, and described key components and underlying mechanisms of the intervention that are most critical and likely to bring about a change. Project 2 included three sub studies: (1) Sub study 2a - a qualitative study of patient-carers' experience with using the CSNAT-I; (2) Sub study 2b - a longitudinal study of clinicians' experience of and response to using the intervention over time, and (3) Sub study 2c – a quantitative study of intervention content, receipt and delivery. The findings of this project informed the development of the proposed intervention model that was tested in Project 3.

Project 3: Phase 2 Trial

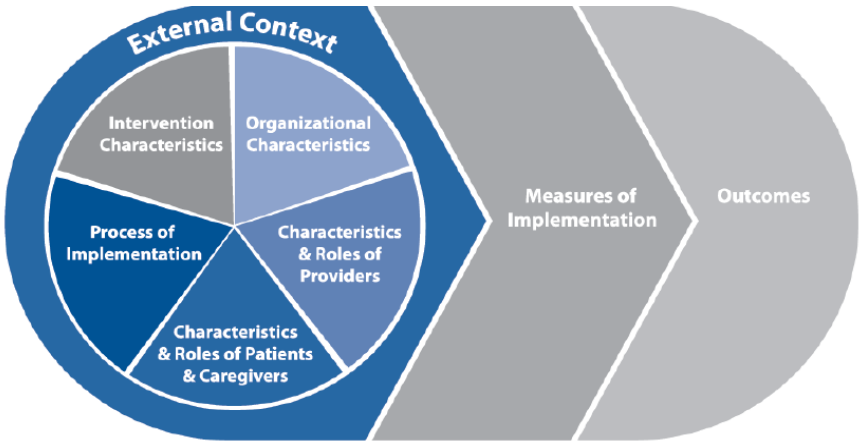
The proposed intervention model (**CAR**ing for car**E**rs of people with adva**N**c**E**d cancer at hospi**T**al discharge – CARENET) was tested in a controlled feasibility trial. The purpose of the trial was to determine what aspects of the proposed intervention and study parameters are likely to work to achieve desired outcomes and whether to proceed to the next stage of larger-scale trials.

1.3.3 Conceptual framework

The Care Transition Framework (CTF) underpinned the development stages of this program of work.(68) The CTF was adapted from the Consolidated Framework for Implementation Research (CFIR); (69) both frameworks aim to assist in the design and evaluation of complex systems intervention implementation. They both provide a comprehensive set of domains and constructs related to intervention characteristics and list internal and external factors that are likely to influence implementation and outcomes (Figure 2). The CTF provides additional constructs that are unique to CTIs and the contexts in which they occur and offers an in-depth guide to the conditions needed for successful implementation and replication. For example, CTI design and success relies on meeting the needs of patients and carers, not just health care organisations, so patients' and carers' needs exist in the CTF as two distinct domains alongside intervention characteristics, process of implementation and characteristics and roles of providers.

The domains and constructs of the CTF and their relationships with each other are illustrated in Figure 2. The five domains in the circle on the left represent the intervention, organisations, individuals and processes. These are surrounded and influenced by the external context domain. An arrow points to the measures of implementation that influence the outcomes resulting from implementation. Definitions of these domains and their constructs are presented in Appendix 1.

Figure 2. Framework for implementation research on care transitions (62)



CTF authors recognise that there a vast number of domains and constructs. Researchers can select domains and constructs that are best suited to their intervention, setting and overall research goals. The CTF also has a step-by-step guide to assist researchers in selecting the most relevant domains and constructs (Figure 3).

The CTF was selected for this doctoral program because it offered constructs that:

- could be applied through aspects of empirical work and then support synthesis of findings;
- enable researchers to identify common and missing elements that could inform intervention development, implementation and testing in future trials;
- acknowledges the inclusion of patients and carers in CTIs that traditionally sit in system and service levels; and
- was built on a well-recognised and robust implementation framework. (69)

The CTF also allowed the researcher to align their work with new domains and constructs as data revealed new insights/information. Studies aligned with different domains depending on the nature of the research questions and findings. Table 1 summarises the program, including research aims and questions, the embedded studies, their alignment with the CTF domains, and the chapters containing the corresponding reports. This table shows that at the completion of the studies, and the convergence of results; the later chapters covered more domains; reaching the overall goal of characterising a CTI model for carers.

Figure 3. How to use the Care Transition Framework (68)

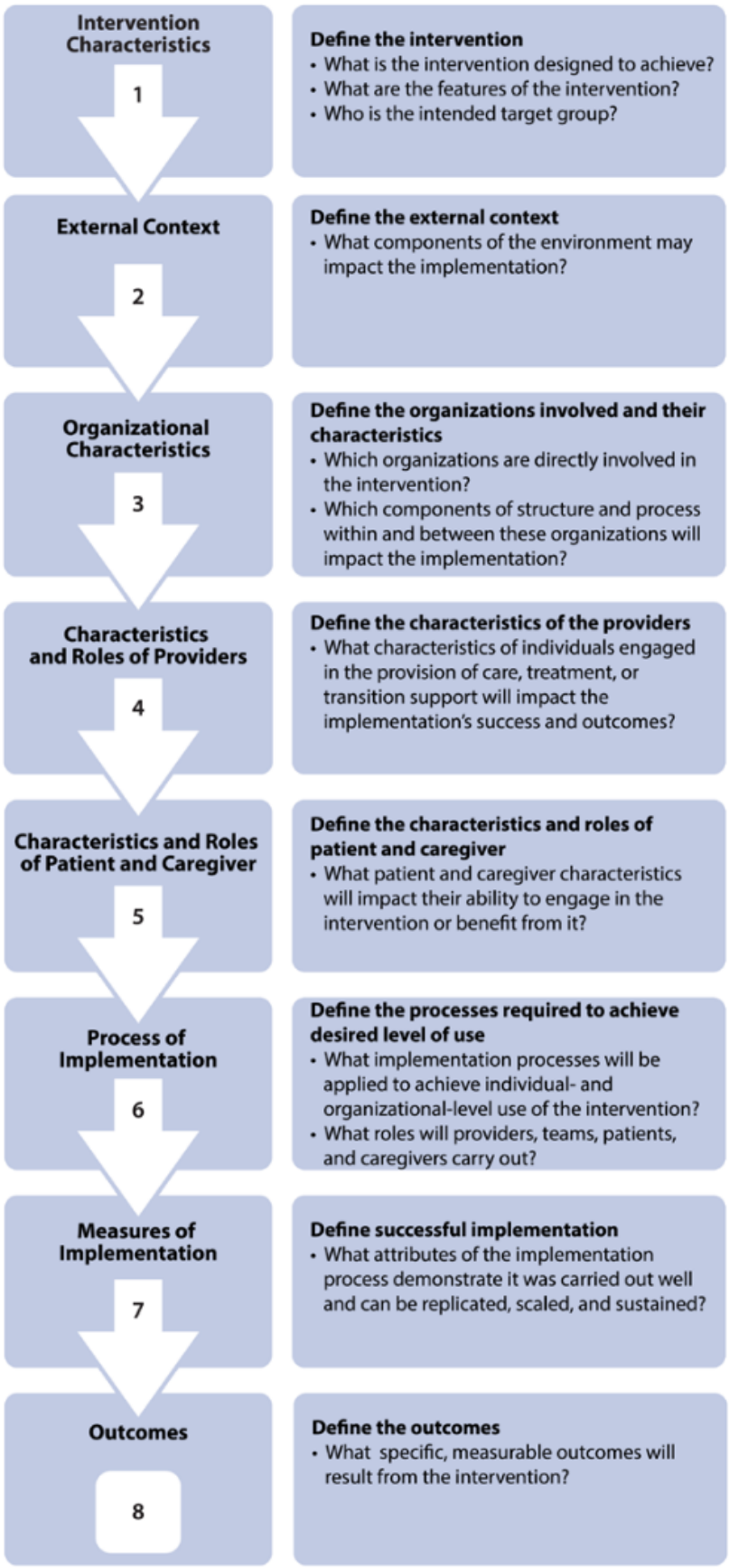


Table 1. Relationship between the Care Transition Framework domains and doctoral research projects

	Care Transition Framework Domains							
	Intervention Characteristics	**External Context**	**Organisational characteristics**	**Characteristics and roles of providers**	**Characteristics and roles of patients and carers**	**Process of implementation**	**Measures of implementation**	**Outcomes**
Project 1: Systematic Review:								
Chapter 2 *What are **the characteristics and reporting quality of intervention studie**s aimed at improving hospital-to-home transitions for people with advanced illness?*	**X**			**X**	**X**		**X**	**X**
Project 2: Mixed Methods								
2a Qualitative (Patient) *Chapter 4*								
*What are the **experiences and acceptance levels of people with advanced cancer and their carers** of receiving the CSNAT-I in usual hospital discharge contexts?*	*X*				*X*			
2b: Qualitative (Clinician) *Chapter 5*								
*What are **OTs' experiences** with implementation of the CSNAT-I into usual practice before, during and after implementation?*	*X*		*X*	*X*		*X*		

2c: Quantitative (Patient, Carer, Clinician, Service) *Chapter 6*								
If the CSNAT-I is introduced to OTs and carers as part of usual practice, what are the contents of the therapeutic encounter?	*X*			*X*	*X*	*X*		
Synthesis and interpretation of 2a, 2b and 2c findings *Chapter 7*								
What are the key elements of a carer-focused intervention model and the requirements for successful implementation into hospital discharge context?	*X*		*X*	*X*	*X*	*X*	*X*	
Project 3: Feasibility Trial *Chapter 8*								
How well is a proposed intervention (CARENET) and study parameters likely to work to achieve desired outcomes and proceed to large-scale trials?	*X*		*X*	*X*	*X*		*X*	*X*

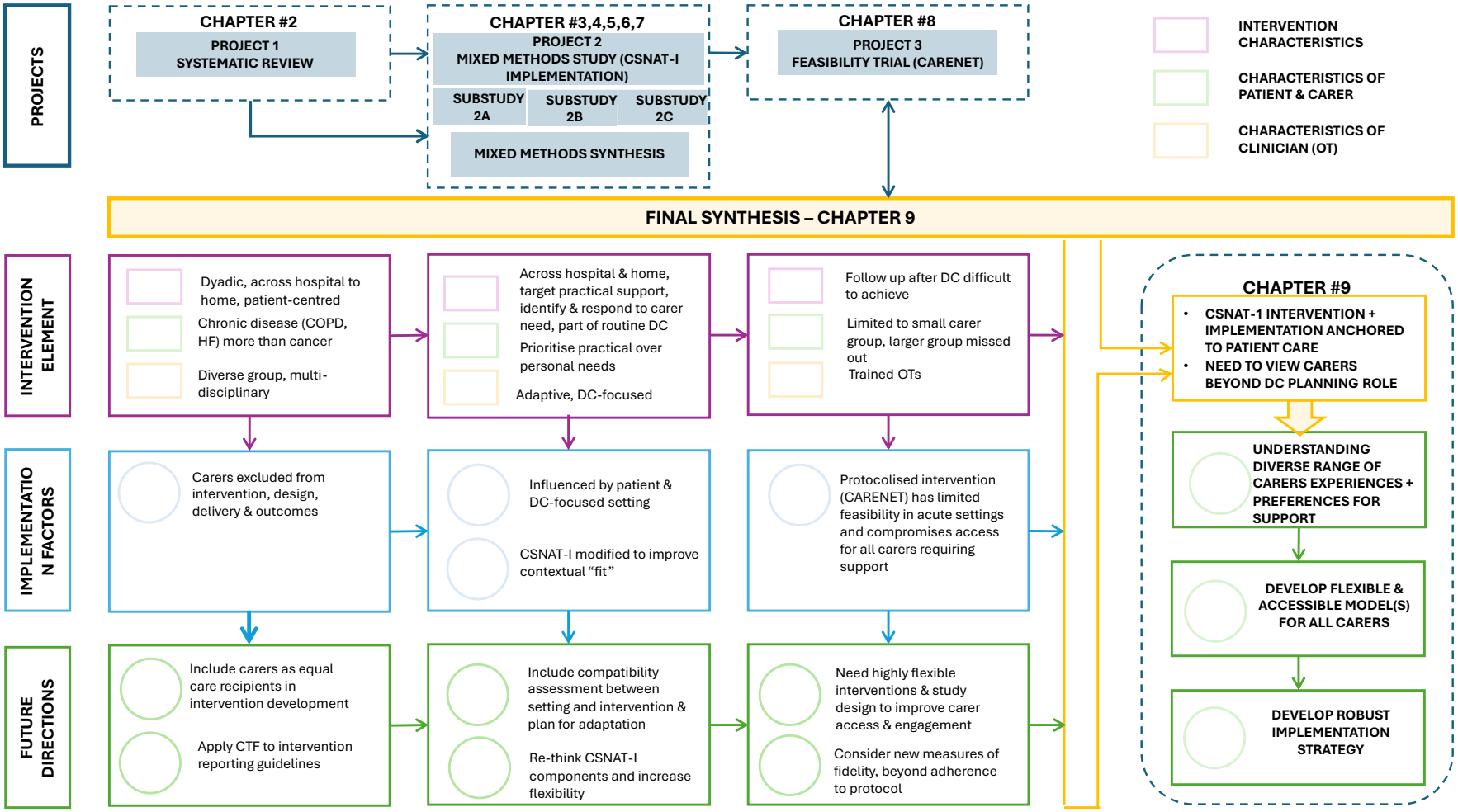
CSNAT-I = Carer Support Needs Assessment Tool – Intervention, OT = occupational therapist

1.4 Thesis outline

The doctoral work consisted of three projects. Project 1 was a systematic review of the literature conducted to determine the characteristics of previous interventions, Project 2 was a mixed methods sequential study with three components, and Project 3 was a feasibility trial. The design, methods and findings of these projects and the implications of this doctoral program are reported in thesis chapters 2 to 9.

The multiple components of this research and how they relate to each other is represented in Figure 4. This figure and its components are referred to in each chapter; it illustrates how findings were brought together to form the final discussion and conclusions in chapter 9 (see the orange and green squares in the 4th column).

Figure 4. Research Components and Their Relationships



Chapter 2 presents project 1, a systematic review of the methodological and reporting quality of studies delivering CTIs for people with advanced illness and their carers moving from hospital to home.

Chapter 3 reports on the study design, methodology and application of theoretical frameworks for Project 2.

Chapter 4 describes findings from study 2a – a qualitative study of people with advanced cancer and their carers' lived experience and acceptance of a carer-focused intervention delivered in an acute oncology setting to assist with hospital discharge.

Chapter 5 reports on findings from study 2b – a longitudinal qualitative study of occupational therapists' experiences with implementation of a carer-focused intervention and the factors that influenced practice change and acceptability.

Chapter 6 describes findings from study 2c – a quantitative study of the delivery of the carer-focused intervention and its reception by patients, carers, clinicians and services.

Chapter 7 presents the final synthesis of all three studies in Project 2 and the proposed intervention model and implementation approach (informed by the CTF).

Chapter 8 reports on the quantitative findings of Project 3 – a single-arm, open label phase 2 feasibility trial of the delivery and receipt of an intervention (CARENET) informed by Project 2 findings.

Chapter 9 is the final chapter, bringing together the empirical findings and interpretation of the studies included in the thesis, and reporting on how they addressed the research program's aim and research questions. Future research directions are also summarised in this chapter.

1.5 Significance of study and original contribution to knowledge

It is anticipated that the work undertaken in this doctoral program will contribute to palliative care practice and research in the following ways.

1. **Inform future feasibility trials and clinical translation**
   This doctoral work was designed to produce findings that can inform the design and conduct of future feasibility trials and successful implementation of a carer-focused intervention in everyday clinical practice. Project 2 and 3 were intended to reveal the factors influencing the implementation and feasibility of a novel CTI for consumers, clinicians and services.

2. **Support patient and carers in achieving end of life care at home**
   Most people with a palliative diagnosis want to spend most of their time at home; with many also wanting to die at home. Supporting a person to receive care in their place of choice has become a key objective of national frameworks and policies. It remains a complex issue that is influenced by multiple factors including a person's socio-economic status, functional status, access to home based palliative care and family/carer supports. This program of work was designed to develop an intervention model that will optimise transition from hospital to home and ultimately support patient and carers preferences.

3. **Transform how we care for carers across broader populations**
   Carers are traditionally seen as a resource to help patients return home, yet support for them to undertake this role is, at best, haphazard. Projects 2 and 3 position carers as the recipients of the intervention and facilitate them to lead this process during the initial transition between hospital and home. This will transform the way we support carers in cancer care. Findings from this doctoral program of research will improve our understanding and value of this carer-focused intervention from an individual, service and societal perspective that can assist in large-scale translation into practice and health service policy.

4. **Support development of standardised reporting guidelines for CTI**

The systematic review was the first to examine the reporting quality of CTF studies involving carers and apply the TiDIER and CTF framework. Its findings will readily inform the development of standardised reporting guidelines for CTIs and subsequentially improve the replicability of CTI studies and their translation into clinical practice.

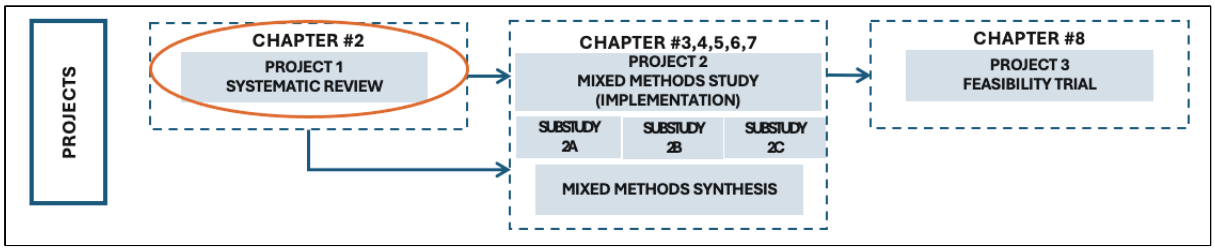
5. **Align with state and federal government strategic plans for cancer and carers**

The Victorian Cancer Plan 2020–2024 (43) positions carers as integral to the cancer care team. The Victorian government's primary objective is to implement the Victorian carer strategy (41) into cancer care to ensure supports are tailored to carers' individual needs. Similarly, the National Carer Strategy aims to ensure all carers are recognised, valued and supported to participate in their caring role. One of the priority outcome areas of this study is to build "evidence on carers to better understand who carers are, what are their experiences, what works for them and why". (42) This doctoral program, involving the design and early testing of an evidence-based intervention model that targets and prioritises carers' needs in an advanced cancer setting, will contribute to the evidence base that can inform operationalisation of national strategy and policy.

Chapter 2. Project 1: Systematic review

Chapter 1 introduced the topic of the quality of care for people with advanced illness moving from hospital to home, and for their carers; the unmet needs of carers in this context; current gaps in practice, research and policy in this area; and an overview of the research topic and design. This chapter describes a systematic literature review (Project 1) that aimed to describe the characteristics and reporting quality of the interventions used to improve the hospital-to-home transition for carers of patients with advanced illness and examine the alignment of reported interventions to the CTF. This project forms the first stage of this research program, as illustrated in Figure 5.

Figure 5. The first stage of this research program



The systematic review presented in this chapter was published in 2023 in the Journal of Palliative Medicine, a peer-reviewed scholarly journal with an impact factor of 2.8 (Appendix 2).

> **Marston C**, Morgan DD, Philip J, Agar M. Supporting carers as patients move between hospital and home: A systematic review of interventions to support these transitions in care. Journal of Palliative Medicine. 2023 Feb 1;26(2):270-98.

2.1 Background

As disease progresses, it is common for a person to move through multiple different types of care (acute care, palliative care, primary care) delivered at a range of sites including in their own home. The move between these types and sites of care are termed transitions.(1)) People receiving palliative care in the last year of their life have increasingly complex needs, and more frequent transitions; commonly between hospital and home. (11-14) Transitions can be burdensome and result in increased anxiety for patients,(18) uncertainty for families or carers(19, 20) and may be accompanied by increased mortality. (17)(The carers of people with palliative care needs play a critical role in the transition from hospital to home. Carers provide most of the care at a personal cost to themselves. (32, 33) Their capacity to care remains a key determinant of whether someone can be cared for at home and avoid readmission to hospital. (17, 34) They have a set of unique needs that remain largely unmet and unsupported. (33, 35) According to one review, the most commonly reported unmet needs related to factors associated with transition between hospital and home.(33)

Interventions that aim to improve these transitions can be defined as "a set of actions designed to ensure the coordination and continuity of health care, as patients transfer between different locations". (70, 71) These set of actions include communication, relationship and process strategies that are specific to the context they are occurring in. These interventions are inherently complex and the way they are reported in studies varies considerably. They have proven effective in reducing disease burden, hospital readmissions and healthcare costs in the older and chronic disease population.(23, 72, 73) The economic benefits of these interventions have also led to wide implementation into US health care service delivery and policy.(73)

Interventions that target carers of people with palliative care needs during hospital-to-home transition are not thoroughly understood in palliative care research and practice. Specialist palliative care which explicitly prioritises carers, has been identified as one model of care that may facilitate discharge home. However, a recent review(8)

examining the impact of inpatient specialist palliative care delivered before discharge excluded carers from their review.

The complex nature of hospital-to-home transition interventions, the absence of evidence detailing the optimal intervention and its components that target carers of people with advanced illness; justifies the need for this review. According to the Medical Research Council (MRC) framework for developing and evaluating complex interventions,(74) before an intervention can be tested and implemented, preliminary work is needed to identify and characterise the interventions, its core elements and mechanisms. No systematic reviews to date have evaluated the reporting quality of carer-focused interventions that aim to improve hospital-to-home transitions; leaving a gap in empirical data to inform intervention design, evaluation and translation.

2.2 Aims

This review aimed to:

1. Describe the characteristics and reporting quality of interventions, their core elements and mechanisms used in studies to improve the transition from hospital to home for carers of patients with advanced illness.
2. Examine their alignment with selected domains of Care Transitions Framework,(68) specifically intervention characteristics, implementation measures and outcomes.

2.2.1 Review questions

What are the characteristics and reporting quality of interventions and outcomes used in studies aimed at improving care transitions for carers for patients with advanced illness; and secondly, how well do they align with the Care Transition Framework?

2.3 Methods

A systematic review was conducted using a narrative approach to synthesise and reported according to the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) guidelines and was registered on the international prospective register of systematic reviews (PROSPERO) (ID: CRD42020192088).(75)

2.3.1 Eligibility criteria

All prospective studies evaluating interventions related to improving transition of care across hospital and home for carers of patients with palliative care needs. For the purpose of this review "palliative care needs" refers to people with advanced illness. A broader eligibility criterion was deemed necessary to capture all relevant studies because CTIs are multicomponent and interventions targeting carers can often be part of an "intervention bundle".

For the purposes of this review, transitions of care were defined as the movement of the patient and family between health care settings, specifically across hospital/inpatient and community/home-based settings. Transitions of care occurring between clinicians or streams of care in the one physical setting (e.g., from intensive care to palliative care) were excluded.

2.3.2 Inclusion criteria

1. Prospective studies (quantitative, qualitative or mixed-methods design)
2. Studies evaluating interventions related to improving transition from hospital to home.
3. Adult patients with chronic and/or advanced illness; can include carers.
4. Interventions that aim to improve the transitions of care across hospital/inpatient and home/community settings (home or residential care)
5. Interventions must include one or more of the key components recommended by World Health Organization (WHO): (1)
    a. Sharing and standardisation of tools across settings (e.g., tracking systems)
    b. Systems approach (e.g., discharge planning, medication reconciliation, timely patient follow-up, timely clinical handovers, patient and carer support and education)
    c. Early assessment of those at risk, with complex transition needs.
    d. Enhancing communication and relationships.

2.3.3 Exclusion criteria

1. Retrospective, case studies/series, commentary pieces.
2. Studies evaluating interventions that aim to improve transitions of care between clinician or streams of care in one physical setting only (e.g., from ICU to palliative care).
3. Adult patients with asthma, diabetes, curative cancer.

If systematic reviews were identified in the abstract/title screening stage as meeting the inclusion criteria 2, 3 and 4 they were submitted to the full text screening stage, so their included studies could be reviewed for inclusion/exclusion. The systematic review was not considered an included study.

The authors conducted the full text screening in two parts: (Figure 1) (1) Assessment against the above inclusion/exclusion criteria and (2) a second screen looking for evidence in the intervention description of carers having received part or all the intervention. This was because it was not always evident in the titles or abstracts whether carers had been targeted in the study.

2.3.4 Information sources

A comprehensive search of three databases (MEDLINE, EMCare and PsycINFO) was conducted. The search strategy (Box 1) was developed with assistance of the librarian and included: (1) subject headings, MeSH terms and keywords to search for palliative care, chronic and advanced illness and care transition terms (2) studies published from 2000 to current and (3) Adult population over 18 years. Must have citation of patient discharge or transition of care. Grey literature (including clinical practice guidelines) and unpublished studies were not included. Lateral searching was conducted for checking reference lists of 20 systematic reviews. The search was run in February 2020 and repeated in August 2021. Search strategy as per Box 1.

Box 1 – Search strategy

Database: Ovid MEDLINE(R) ALL <1946 to August 06, 2021>

Search Strategy:

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1 exp Palliative Care/ (53046)

2 exp Terminal Care/ (50519)

3 exp neoplasms/ (3295695)

4 exp Chronic Disease/ (260765)

5 (palliat* or terminal* or life limiting or chronic disease* or end stage or end of life or hospice or inoperable).mp. (970645)

6 (cancer* or carcinoma* or neoplas* or tumo?r* or malignan* or oncolog* or leuk?emia* or metasta* or adenoma* or adenocarcinoma* or adeno-carcinoma* or lymphoma* or melanoma* or sarcoma*).mp. (4363611)

7 (chronic adj4 (disease* or condition* or illness*)).mp. (552285)

8 (copd or cardiovascular disease* or cardiovascular disorder*).mp. (303406)

9 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 (5746094)

10 exp patient discharge/ or exp patient transfer/ or exp transitional care/ (36850)

11 (patient discharge or patient transfer or patient transition* or care transition* or transitional care or hospital discharge or hospital transition or discharge planning).mp. (62928)

12 10 or 11 (62928)

13 9 and 12 (9331)

14 palliative care transitions from acute care to community-based.m_titl. (2)

15 13 or 14 (9331)

16 1 or 2 or 5 (984269)

17 12 and 16 (3360)

18 exp Home Care Services/ or exp Community Health Services/ (299287)

19 (home care or community healthcare community health care or primary healthcare or primary health care or community based care or home healthcare or home health care or post hospital care).mp. (143897)

20 18 or 19 (391198)

21 13 and 20 (1096)

22 limit 21 to english language (963)

23 14 or 22 (963)

2.3.5 Study selection and data extraction

Following removal of duplicates, a screening process was independently undertaken by four researchers with medical and allied health backgrounds (CM, MA, JP and DM). Screening criteria were tested by each researcher with 20 studies exported onto excel from Endnote before commencing formal title/abstract screen within Covidence. Title and abstracts were double screened – one researcher (CM) screened all the studies whilst three other researchers (MA, JP, DM) double screened one third of studies each. Discrepancies regarding study selection were resolved by group consensus. Abstracts that met the eligibility criteria were reviewed as full-text articles by two researchers, by applying the same distribution method used for title/abstract screening. Conflicts were managed via verbal discussion and revision of eligibility criteria between two researchers. Conflicts were resolved through discussion with a third reviewer. During full text screening handpicked 89 studies from 20 systematic reviews that met the criteria via abstract/title screen. A full text screen was conducted on these 89 studies against criteria. An additional full text screen was conducted to identify studies describing interventions that targeted carers either exclusively or in conjunction with patients.

Data were extracted by two reviewers (MA and CM) using a Microsoft Excel 2010 spreadsheet. Data were extracted under the following headings: Author, year, title, study aim, population/setting, design, description of intervention and control intervention, outcome measures and results.

2.3.6 Quality assessment

Quality assessment was conducted for selected studies that had reported on intervention components designed for carers – either for carers exclusively or a combined model for both patients and carers. Two approaches (described below) were used to assess reporting quality and alignment with the care transitions framework and overall ratings applied.

The TIDieR checklist(67) was used to review the reporting quality of each study intervention by ensuring comprehensive description of all key components are

described for the purpose of replication and assessment by reviewers. The studies were assessed against all the 11 items on the checklist and received one of two ratings: reported or not reported for each item.

The Care Transitions Framework (CTF)(68)[v] was used to determine study alignment with the different constructs within the following domains: (i) Intervention characteristics, (ii) Measures of Implementation; and (3) Outcomes. The CTF is typically used to guide design and evaluation of CTIs. It was chosen for this review because it offers constructs that are particularly relevant to hospital-to-home transitions and identifies the range of contextual factors that can influence the success of implementation of these interventions. It also incorporates carer-specific constructs such as "carer needs and resources" and "carer-centred outcomes". The selection of these domains and relevant constructs were determined by an expert working group of medical, nursing and allied health clinicians and considered important to care transitions from hospital to home for advanced illness. Data extracted from the study content was linked to a relevant CTF construct and rated according to the reporting quality of this construct. Star rating was applied – two stars meant the construct was well described; one star = poorly described; and no star = not described. Each construct was rated according to criteria pre-determined by the primary researcher (CM) and outlined in Appendix 3. The first nine items of the TIDieR and the "intervention characteristics" domain of the CTF both cover the features and rationale for the intervention. This close alignment meant that the results were presented in the TIDieR format only to avoid duplication.

2.3.7 Synthesis of results

A narrative synthesis approach was used to provide a coherent understanding across the expected heterogeneity of studies describing complex and variable interventions.(76) Synthesis was structured around descriptive summaries of the common intervention and outcome components, the quality of the reporting of these and quality of alignment with the CTF domains. Included studies were reviewed iteratively exploring commonalities and differences and informed by the constructs of the CTF and TIDieR. Synthesis of efficacy was not planned because the focus was on understanding the nature of the intervention; and to include early intervention studies.

2.3.8 Risk of bias

The purpose of the review was to describe the components of the interventions, not their efficacy. As a result, risk of bias was not formally assessed.

2.4 Results

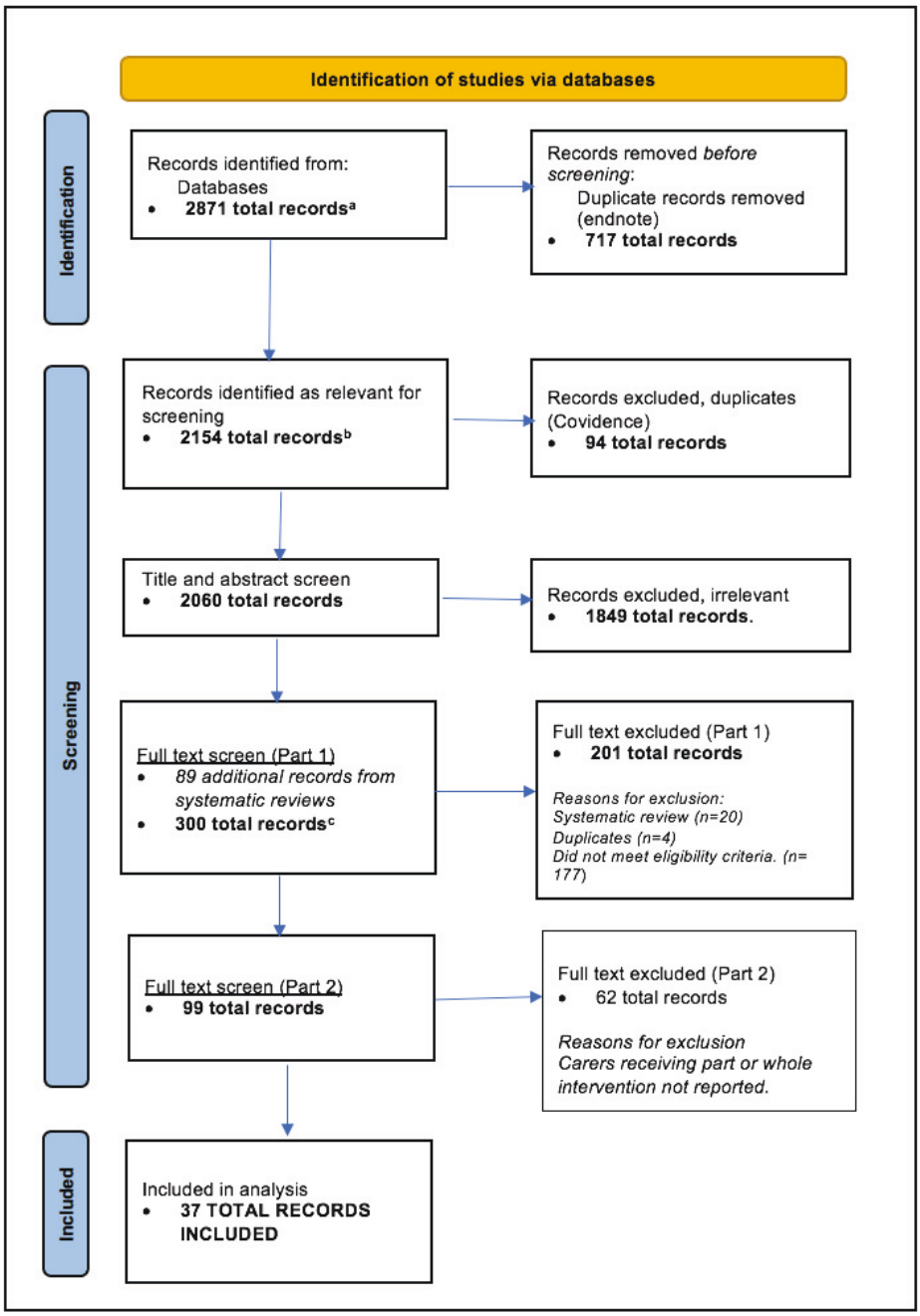
2.4.1 Study selection

Of the 2871 records found on the data bases and an additional 89 papers handpicked from 20 systematic reviews (SR), 2154 were identified for screening. Ninety-nine met Part 1 full-text screening process, and 37 met the Part 2 full-text screening process (i.e., evidence in the intervention description that carers received part or all the intervention). The PRISMA flow diagram (Figure 6) outlines the results of the first and second search.

2.4.2 Study characteristics

Table 2 outlines characteristics of the included studies. Twenty-eight of included studies were randomised controlled trials, (38, 58, 77-101) followed by experimental (n= 6) (102-108) and observational (n= 3). (109-111) Studies were conducted in United States (n=16) (38, 77, 78, 86, 91, 92, 96, 97, 100, 101, 104, 105, 107, 109-111), Europe (n=9), (79, 81-85, 87, 99, 102) United Kingdom (n=2),(93, 98) Australia (n=5),(58, 78, 90, 94, 95) Asia (n=4)(88, 103, 105, 106) and Iran (n=1).(108) Populations studied were patients with different diagnoses. Primarily non-malignant advanced illness: specifically, older population with chronic disease burden (n= 18),(58, 72, 77, 85, 90, 91, 93-96, 100, 101, 104-107, 109, 111) , heart failure (n=8), (80, 82, 83, 92, 97, 98, 103, 108) COPD (n= 8),(79, 81, 84, 86-89, 102) followed by advanced cancer (n =3).(78, 99, 110) Study participants were predominantly patients (n =28), (38, 72, 80-95, 97, 98, 100-102, 104-108, 111) patient-career dyads (n=6)(58, 77-79, 99, 103) and carers (n =3).(96, 109, 110) Studies were mostly published after 2010 (n =21), half of these within the last 5 years (n=10), and the remainder between 2001 and 2010 (n=16).

Figure 6. PRISMA flow diagram of included and excluded studies



[a]Includes original (n=2514) and update (n=357) searches; [b]includes 20 systematic reviews; [c]includes 89 studies from 20 systematic reviews

Carers were included in the aim, intervention and outcome descriptions of eight studies(58, 78, 79, 96, 103, 109, 110) and in the aim and intervention for three studies. (38, 77, 86) Four studies identified carers in the interventions and outcomes (81, 89, 94, 99) while 22 studies only mentioned carers in the intervention section.(80, 82-85, 87, 88, 90-93, 95, 97, 98, 100-102) In the latter group of studies, carers were briefly

described in the intervention section as recipients of different elements of the intervention like phone-based education on symptom management.

Table 2. Summary of included studies

Author and Country	Study Design	Aim(s)	Participants	Outcome and Measures	Findings	Carer elements
Piette et al 2020,[77] United States	Randomised Controlled trial, multi-site	Evaluate care-partner (CP) intervention to improve post discharge outcomes; specifically improve 30 day readmission rates and ED use	Patient-Carer Dyad: Inpatients with medical diagnosis (>50% COPD and HF). N=283; Intervention (n=123) and Control (n=140)	30 day readmission rates and combined readmission/ED visits Differences in rates of outpatient follow up; characteristics of inpatient and outpatient episodes of care via medical records. Completion/success of call attempts	No improvement in readmission rates overall - 11.4% intervention patients and 17.9% controls readmitted within 30 days (HR:0.59; 95% CU:0.31-1.11; p=0.102). Pulmonary intervention patients had most clinical alerts (p=0.004) and reduced 30 day risk of readmission (HR: 0.31; 95%CI:0.11-0.87; p=0.026) compared to controls	Aim, intervention
Shaw et al 2016,[78] Australia	Randomised Controlled trial, multi-site	(1) Test effectiveness of a phone-based caregiver intervention on improving QOL 3 months post discharge (2)	Upper GI Cancer, Metastatic liver disease, Stage 4 colorectal cancer adult inpatients. Intervention Group:	Patient and carer-related measures related to QOL and psychosocial outcomes; service data and interviews to	At 3 months caregiver QOL scores and other reported outcomes were similar in both groups,. Intervention group experienced	Aim, intervention and outcome

		Determine effectiveness on reducing carers unmet need, burden and distress; and indirectly reduce patient distress, unmet needs, hospital presentations and QOL	Patient (n=64); Caregiver (n=64); Control Group: Patient (n=64); Caregiver (n=64)	determine views on acceptability	increased sense of social support (p=0.049) and less worry about finances (p=0.014). Patients in intervention group had less ED presentations and unplanned readmissions at 3 months. High fidelity throughout intervention period and high acceptance from caregivers	
Toye et al 2016, [58] Australia	Randomised controlled trial	To evaluate impact of Further Enabling Care at Home on caregivers outcomes, then patients and the health care system when delivered after discharge	Older medical inpatients. Patient-carer dyads. Intervention Group (n=62); Control (n=79)	Primary: Preparedness for Caregiving Scale from Family Care Inventory. Secondary: (1) Caregiver-rated Symptom Assessment Scale, (2) Barthel ADL Index, (3) Family Appraisal of Caregiving Questionnaire; (4) Caregiver wellbeing rating (SF-12v2 Health Survey). All across 3	Intervention group significantly improved preparedness to care from Time 1 to Time 3 (effect size =0.52, p=0,006) and Time 1 to Time 3 (effect size = 0.43; p= 0.019). Small significant differences in carer strain and other outcomes	Aim, intervention and outcome

				time points. Resilience Scale demographic details of caregivers obtained at Time 1.		
Coleman et al 2006,[72] United States	Randomised controlled trial	To test whether a care transitions intervention (for older people and their caregivers) can reduced rates of hospitalisations	Inpatients. Intervention: (n=379) and Control (n=371). advanced age, advanced disease, high hospitalisation and ED use	Primary: Rate of non-elective rehospitalisation at 30, 90 and 180 days after discharge. Secondary: Rate of rehospitalisation for the same condition. 180 days	Intervention patients had lower rehospitalization rates at 30 days (8.3 vs 11.9, P=.048) and at 90 days (16.7 vs 22.5, P=.04) than control and (2) lower rehospitalization rates for the same condition at 90 days (5.3 vs 9.8, P=.04) and at 180 days (8.6 vs 13.9, P=.046) than controls. Intervention patients has lower mean costs at 180d days than controls (P=.049)	Aim, intervention
Utens et al 2014,[79] Netherlands	Sub study of RCT (non-blinded)	To evaluate impact of hospital at home on informal caregiver strain, satisfaction	Inpatients with COPD exacerbation and their caregivers. Control: Patients (N=69),	Caregiver Questionnaire at Day 7 post treatment and 90 day follow up.	No significant difference in care strain between intervention (T + 4	Aim, intervention and outcome

		and preferences for venue of care compared to usual hospital care	Caregivers (N=62); Intervention: Patients (N=70); Carers (N=62)	Measures included caregiver strain (CSI), satisfaction with patient care and intervention, and preference for venue of care	days: MD 0.47 95%CI -0.96 to 1.91, p=0.514 and T + 90 days MD 0.36 95%CI - 1.85 to 1.35, p=0.634); most carers preferred hospital at home programs and strongly associated with patient preference for hospital at home. Overall satisfaction with program	
Naylor et al 2004,[80] United States	Randomised controlled trial, multi-site	To test effectiveness of transitional care intervention delivered by advanced practice nurses (APNs) to elders hospitalized with heart failure (HF)	Population: inpatients >65yo from home, admitted with heart failure. N= 641 eligible. Sample: Intervention n= 118 and Control n = 121	Time to first rehospitalization or death, number of rehospitalizations, quality of life, functional status, costs, and patient satisfaction	Intervention increase time between discharge and readmission or death (P=0.026, CI=1.13-2.40), reduced total number of readmissions, reduced costs. Short term improvements in physical QOL (P<-.0.05) and patient satisfaction (P<0.001)	Intervention

Aimonino et al 2008,[81] Italy	Randomised controlled trial	To evaluate the impact of physician-led hospital at home model for older people with COPD on hospital readmission rates and mortality	Acute inpatients>75yo, COPD exacerbation. Intervention n=52, Control n=52	Primary: hospital readmission and mortality rates at 6 months. Secondary measures of function (Katz ADL, Lawton IADL), depression (GDS), nutrition, cognition (MMSE), Quality of Life (Nottingham Health Profile), carer stress (Relative Stress Scale) and satisfaction questionnaire. Costs of acute episodes of care compared. and nutritional status; depression; caregiver stress, and quality of life were at 6 months after discharge	Physician-led hospital at home is associated with reduced risk of readmission for COPD patients at 6 moths, lower costs and better QOL. Intervention group had lower readmission rate than control (42% vs 87%, P=0.001). No difference in mortality. Intervention group has significantly better improvement in depression and QOL scores than control. No differences in function, cognition or carer burden outcomes. High satisfaction across both groups. Cost per patient per day lower for intervention group ($101.4 +-6.1.3 vs	Intervention, outcome

					$157.7 +-96.4, P=.002).	
Angermann et al 2012,[82] Bavaria	Randomised controlled trial, multi-site	To evaluate mode of action and effects of a nurse coordinated disease management program (DMP) (HeartNetCare-HF)	Patients discharged from hospital after cardiac decompensation. Intervention n=352, Usual Care n=363	End point time to death or rehospitalisation (and primary outcomes); secondary: HF symptoms and QOL (SF-36)	Primary endpoint was neutral; Intervention group improved re NYHA class (P=0.05), physical functioning (P=0.03) and physical health (P=0.03). High compliance. Non-cardiac problems should also be considered in future models	Intervention
Atienza et al 2004,[83] Spain	Randomised controlled trial, multi-site	To assess effectiveness of discharge and outpatient program in patients admitted for HF	Patients discharged with CHF. Sample: Intervention: n=164 Control: n=174	Primary: Event-free survival at 1 year. Secondary: Rate of and time to all- cause and HF readmissions; QOL (Minnesota Living with HF) after 1 year and cost of management	Intervention group had significantly less events (readmission or death), per year (P<0.001); longer time to first event; and lower readmission rates compared to control. QOL improved and cost of care reduced in intervention group	Intervention

Casas et al 2006,[84] Spain and Belgium	Randomised controlled trial, multi-site	To evaluate impact of integrated care intervention can prevent readmission for COPD patients	Patients admitted with COPD exacerbation. Intervention: n=65, Control n= 90	Healthcare utilisation (readmission and hospitalisation rates, mortality) at 1,3 ,6 , 9 and 12 months via phone interviews	Intervention group had lower hospitalisation rate (1.52.6 versus 2.1¡3.1) than control and higher percentage without readmissions (49% versus 31%). No significant differences in mortality. Standardised integrated care can prevent hospitalisations	Intervention
Hendrix et al 2011,[109] United States	Feasibility /pilot study	Examine feasibility of caregiver training program and impact on carer self-efficacy and preparedness for discharge	Caregivers of older hospitalised veterans. N=50	(1) Service and process data (2) Self-efficacy (Lorig's self-efficacy scale) and preparedness (Family caregiving inventory) taken at 4 time points pre and post discharge; (3) Phone interviews at week 1 or 4 after discharge	Feasible intervention, viewed positively by carers, and may improve self-efficacy and preparedness	Aim, intervention. outcome
LeGrain et al 2011,[85] France	Randomised controlled trial, multi-site	To determine if a new multimodal	Patients >70years old admitted to acute	Primary: Emergency hospitalization or ED	Intervention group: At 3 months, significantly less readmissions to	Intervention

		comprehensive discharge-planning intervention would reduce emergency rehospitalizations or emergency department (ED) visits for older inpatients	geriatric unit (AGU). Intervention: n=317; control: n=348	visit 3 and 6 months after discharge. Secondary: Cost analysis of secondary health care per participant	hospital or ED (P=.03) and higher survival rate (P=.03) compared to control. Lower secondary health care cost for intervention at 6 months	
Hendrix et al 2006,[110] United States	Pilot study	To determine feasibility of caregiver training before discharge at bedside of older cancer patients	Informal caregivers of older patients with cancer (plus comorbidities) n=7 (female, mean age of 56 years), >50% African American	Caregiver experience and views of intervention via interview data. Acceptance and completion rates of training	High completion rate of training. Individual experiential training on symptom management and home care is a feasible model and received well by caregivers	Aim, intervention, outcome
Abad-Corpa et al 2013,[102] Spain	Quasi-experimental	To evaluate the effectiveness of discharge planning intervention for patients with chronic obstructive pulmonary disease (COPD)	Patients with COPD admitted to hospital. Intervention: n=56, control: n=87	Readmission rate, patient satisfaction (LOPSS12), quality of life (St. George's Respiratory Questionnaire) and level of knowledge about COPD	Discharge planning improves QOL of COPD patients at 12 and 24 weeks after discharge and knowledge of disease. Ineffective in reducing readmissions	Intervention

Aboumatar et al 2019,[86] United States	Randomised controlled trial	To evaluate outcomes of hospital-initiated transition program for COPD patients and their family caregivers	Patients with COPD admitted to hospital. Intervention: n=120, control: n=120	Primary: Readmission and ED visit and patient HRQOL at 6 months after discharge. Secondary: Mortality rates, intervention implementation and adverse events	Significant higher readmissions and ED visits in intervention (1.40 (95%CI,1.01-1.79) versus control (difference 0.68[95%CI, 0.22-1.15], P=.004). No significant improvement in QOL for both groups	Aim, intervention
Chiang et al 2012,[103] Taiwan	Quasi-experimental	Evaluate the effectiveness of nurse-led telehealth care on the outcomes of family caregivers of heart failure (HF) patients	HF patient-primary family caregiver dyad. Intervention: n= 30 Control n=30	(1) Caregiver burden Inventory (CBI), (2) Master of Stress Scale (MMS) and (3) Feetham Family Functioning Survey (FFFS): Two time points - pre-discharge and at 1 month follow up clinic visit	Total score of caregiver burden, stress mastery and family function significantly improved for Intervention Group. Telehealth plus discharge planning can benefit caregiver outcomes within 30 days post discharge	Aim, outcome , intervention
Coleman et al 2004,[104] United States	Quasi-experimental	To test if a care transitions intervention for older patients and	Older adults admitted to hospital. Intervention: n=158, Control: n=1235	Hospitalisations at 30, 60 and 90 days post discharge. Patient experience using Care Transition Measure	Intervention group less likely to readmit at 30, 90 and 180 days compared to control. They have more	Aim, intervention, outcome

		caregivers can reduce readmission rates		between 24 and 28 days post discharge	confidence in their disease management during transition	
Lainscak et al 2013,[87] Slovenia	Randomised controlled trial	To test whether coordination of discharge from hospital reduces hospitalizations in patients with chronic obstructive pulmonary disease (COPD)	Inpatients admitted with COPD, Intervention: n= 118, Control: n=135	Primary: Readmission rates Secondary: time to readmission, all-cause mortality, all-cause readmission, days alive out of hospital and HRQOL. At 7 or 10 days, 30, 90 and 180 days	Discharge coordinator intervention reduced both COPD hospitalizations (P=0.002) and all-cause hospitalizations (P=0.33)	Intervention
Li et al 2014, [88] China	Randomised Controlled Trial	To observe the effects of transitional care on the quality of life of chronic obstructive pulmonary disease (COPD) patients	Inpatients with diagnosis of COPD. Intervention= 57 , control n=57	St George's Respiratory Questionnaire (SGRQ), GHQ-12 and BMI. At pre discharge and 3 month home visit	Patients had significant improvements in quality of life including symptoms, activity, and mental status. No changes noted in BMI	Intervention.
Jenq et al 2016,[105] United States	Quasi-experimental	To evaluate whether overall Medicare FFS readmissions were reduced through an intervention applied to high-risk discharge patients	Population: Hospital patients >64 years screened as high risk. Sample: Pre-intervention period: Intervention: n=12345, control: n=11775;	30-day unplanned same-hospital readmission rates in the baseline and intervention period.	Reduced readmissions by 9.3% among the full population targeted by the CMS despite being delivered only to high-risk patients. But it did	Intervention

			Intervention Period: Intervention: n= 18223, Control: n=20077		not achieve the goal reduction set by the CMS	
Kwok et al 2004,[89] China	Randomised Controlled Trial	To evaluate the effectiveness of an intensive community nurse (CN)-supported discharge program in preventing hospital readmissions of older patients with chronic lung disease (CLD)	Population: Older hospital patients with diagnosis of CLD. Intervention : n=77, Control: n=80	Primary: Readmissions within 6 months. Secondary: Readmissions within 4 weeks; number of bed days, ED visits, 6MWT, psychosocial scores (London Handicap scale, GHQ score and Multidimensional Health Locus of Control scales); and CCI. Latter measures taken at baseline and 6 months. Caregiver burden via interviews at baseline	There was no evidence that an intensive CN-supported discharge program can prevent hospital re-admissions in older patients with CLD, or significantly change secondary measures except for social handicap score	Intervention, outcome
Preen et al 2005,[90] Australia	Randomised Controlled trial	Evaluate impact of multi-disciplinary discharge care plan on hospital utilisation, quality of life and clinician satisfaction	Older (mean age 75 years) inpatients with a primary diagnosis of chronic cardiorespiratory	(1) Patients QOL (SF-3) before and 7 days after discharge. (2) Patient satisfaction survey 7 days post discharge, (3) GP survey and	For intervention group significant improvements in patient satisfaction, mental QOL. No difference in length of	Intervention

			disease. Intervention: n= 91. Control n=98	general practitioners surveyed pre-discharge and 7 days post-discharge (40 (4) Hospital length of stay	stay between groups. Significant improvement in speed and extent of GP communication	
Shu et al 2011,[106] Taiwan	Prospective experimental study	To investigate the impact of an integrated post-discharge transitional care (PDTC) program	Older inpatients admitted with general medical disease. Intervention: n=219 (Mean Age: 69 years). Control: n= 94 (Mean Age: 71 years)	Primary endpoint: Unplanned readmission or unexpected death within 30day of discharge. Secondary: ED or unplanned clinic visits	Integrated PDTC using disease-specific care, telephone monitoring, hotline counselling and a hospitalist-run clinic can reduce rates of post discharge readmission and death within 30 days of discharge (15%vs 25%, P=0.021)	Intervention
Watkins et al 2012,[111] United States	Descriptive, single group non-experimental study	To evaluate effectiveness of a social-worker navigator transitional care model for at risk older people being discharges from hospital	Older inpatients (65 years or older) N=292, mean age 80 years	Post discharge ED visits, hospital readmissions, quality of life via SF-36 and patient satisfaction (survey), service/activity data	Reduced readmission rates by 61% and subsequent cost savings. Significant improvement in QOL for mental and physical aspects ($p<0.004$). High patient/family satisfaction (99%) with program	Intervention

Zimmerman et al 2017,[107] **United States**	Experimental	Assess cost-effectiveness of four different doses of home-based CTI (HBCTI) compared to usual care at 2, 6 months after discharge	Inpatients with chronic disease. N=126. Group 1 – low cognition/low activation (LC/LA), Group 2 – low cognition/high activation (LC/HA) Group 3 – normal cognition/low activation (NC/LA), Group 4 – normal cognition/high activation (NC/HC) cognition and patient activation levels	Patient QOL (EQ-5D) between baseline, 2 and 6 months follow up , health service utilisation (readmissions rates, ED visits) at 2 and 6 months. Patient activation measure (PAM) and cognition (MOCA) baseline to 2 months	Intervention most cost effective for normal cognition/high activation patients; least cost effective for low cognition/low activation group	Intervention
Enguidanos et al 2012,[91] **United States**	Randomised controlled trial	To evaluate the impact of nurse practitioner intervention on care transitions for older hospitalised patients discharged home	At-risk older adults (>50 years) discharged home. Intervention Group n= 100, Control group n=99	(1) Patient self-efficacy survey , (2) Patient satisfaction with care (Home case satisfaction measure), (3) Service utilisation (ED visits, hospital admissions, length of stay)	Improved patient satisfaction (p=0.008) and self-efficacy (p=0.001) and less primary care visits (p=0.036); no change in hospital readmissions at 6 months	Intervention
Laramee al 2003,[92] **United States**	Randomised controlled trial	Test effect of Chronic Heart failure (CHF)	Patients admitted with primary or secondary	Primary: All cause readmission within	90-day readmission rates were equal in IG	Intervention

		Case Management (CM) on the 90-ay readmission rate in a more heterogeneous setting	CHF, LVD < 40%, or evidence of pulmonary oedema. Intervention Group: n= 141, Control Group: n=146	90day. Secondary: adherence to treatment plan, patient satisfaction CHF medication dosages, cost of medical care. Other: cause for readmission, length of stay, no. of CHF readmissions, no. hospital days and no. of days to first readmission	and CG (37%). Reduced inpatient median costs (14%) and readmission median costs (26%) for IG. Significantly better adherence to treatment plan for IG. Subgroup of patients showed significant decrease in readmissions (P=0.03)	
Nazareth et al 2001,[93] United Kingdom	Randomised controlled trial	To investigate the effectiveness of a pharmacy discharge plan in elderly hospitalised patients	Inpatients >75years and on 4 or more medications. Intervention Group: n=181, Control Group: n=181	Primary: Readmission within 6 months. Secondary: mortality, clinic attendance, GP visits (via GP questionnaire), hospital days, patients well-being (via questionnaire), satisfaction (via questionnaire) and medication adherence (via interview)	No difference found in readmissions and secondary outcomes across both groups. Co-ordinated hospital and community pharmacy discharge plan in older patients does not improve outcomes	Intervention

Lim et al 2003,[94] Australia	Randomised controlled trial	To evaluate the benefits of coordinating community services through the Post-Acute Care (PAC) program in older patients after discharge from hospital	Inpatients 65 years and over who met risk criteria and required community services after discharge. Intervention n= 311; Control n=287	Primary: Hospital readmissions within 6 months; Secondary: QOL (via AQoL), carer stress at baseline and one month after discharge, mortality, hospital and community service utilisation and health-related service costs 6 m after discharge	Significant improvements in QOL in 1 month; less hospital bed days in 6 months (IG: mean, 3.0 days; 95% CI, 2.1–3.9; CG: (5.2 days; 95% CI, 3.8–6.7)); and less hospitalisation, community resource and intervention costs in PAC (Intervention) group than control (mean difference, $1545; 95% CI, $11–$3078)	Intervention, outcome
Naunton et al 2003,[95] Australia	Randomised controlled trial	To evaluate pharmacist-conducted follow-up at home of high-risk elderly patients discharged from hospital	High risk medical inpatients (>60years and prescribed 4 or more medications). Intervention n= 57, Control: n=64	Primary: Readmissions within 30days, total days of readmission and out of hospital deaths. Secondary: DRPs, number and type of medications, compliance level, patient satisfaction questionnaire (at 90 days)	Improved compliance in intervention group after 90 days- ($p<0.0001$). Less readmissions in 90 days for intervention compared to control ($p=0.05$). Intervention well received by patients and GPs. GP implemented	Intervention

					pharmacist recommendations in 79% cases.	
Dellsega et al 2002,[96] United States	Randomised controlled trial	To investigate if an advance practice nurse (APN) intervention would benefit physical and emotional outcomes in caregivers of discharged older patients	Caregivers of frail rural elderly patient (>65years) currently in urban hospitals. Patient-carer dyad. Intervention Group: n=16, Control Group n=16)	Caregiver physical health and wellbeing (via Health and Daily Living form) and stress and burden (via Caregiver Burden Inventory - CBI) outcomes. Additional data on caregiver problems and APN visit time via Omaha Classification System. Taken via phone at 48 hours, 2, and 4 week after discharge	Intervention had significantly better health outcomes- less emotional symptoms at Week 4, less depressive symptoms at week 2 and 4 and lower thoughts and feelings stress at 48 hours than Control	Aim, intervention, outcome
Pugh et al 2001,[97] United States	Randomised controlled trial	To test impact of Partners in Care (PIC) model on quality of life and functional status; and determine its cost effectiveness for older people	Older heart failure patients >65 years who lived at home and admitted to acute hospital in 48 hours. Intervention: n=27, Control n=31	QOL (SF-36), Functional status - 6MWT, Costs (ED and hospital visits, readmissions, doctor and nursing visits) taken at baseline and 6 months	Positive effect of the intervention on functional status and QOL but no significant difference between groups. No significant difference in costs between groups	Intervention

Thompson et al 2005,[98] United Kingdom	Randomised controlled trial	To determine the effectiveness of a hybrid program of clinic plus home-based intervention (C+HBI) in reducing recurrent hospitalisation in Chronic Heart Failure (CHF) patients	Inpatients with CHF discharged home. Intervention: n=58, Control: n=48	Primary endpoint: death or unplanned readmissions, rate of recurrent, all-cause readmission withing 6 months of discharge. Secondary endpoints: QOL (SF-36) at 1 and 6 months	Benefits of C + HBI program on recurrent hospitalisation is consistent with home or clinic-based CHF programs; but not statistically significant	Intervention
Halling et al 2020,[99] Denmark	Randomised controlled trial (with economic evaluation)	To evaluate the cost-effectiveness of a systematic, fast-track transition process from oncological treatment to Specialised Palliative Care (SPC) enriched with a psychological intervention at home for patients with incurable cancer and their caregivers	Inpatients with incurable cancer and carers: Patient Intervention: n= 162, Control: n= 159, Carers Intervention: n= 126, Control: n=10	Cost-effectiveness ratio (ICER), including healthcare costs, intervention cost and informal care from carers. Quality-Adjusted Life Years (QALY) via EORTC QLQ-C30 for patients, SF-36 for carers	This model of fast-track SPC enriched with a psychological intervention yields better QALYs than usual care (p=0.026) with a large increase in costs	Intervention, outcome
Hastings et al 2020,[100] United States	Randomised controlled trial	To examine the effectiveness of a primary care–based, nurse telephone	Older patients discharged home from ED. Intervention: n= 257; Control: n= 257	Primary: Repeat ED use within 30 days. Secondary: engagement with	A brief primary care–based nurse telephone support program after an ED	Intervention

		support intervention for Veterans treated and released from the ED		primary care, mental health and chronic disease management programs; total healthcare costs. Healthy Days Measure (HRQOL) used at baseline 30 and 180 days	visit did not reduce repeat ED visits within 30 days (P=0.6), despite intervention participants' increased engagement with primary care (OR = 1.6, CI=1.1-2.3) and some chronic disease management services	
Schumacher et al 2021,[101] United States	Mixed-methods, RCT, multi-site	To determine if an ED-to-home transitional care intervention reduces hospital-based acute care in chronically ill, older ED visitors	Older chronically ill ED patients. Intervention: n= 406, Control: n=544	Primary - Hospital admission rate within 60 days. Secondary - clinic visits within 60 days	Did not significantly reduce re-hospitalisations or increase clinic visits. If returned to ED, Intervention less likely to be hospitalised than control. Coaching intervention viewed as not capable of reducing hospital use due to systemic factors	Intervention
Rezapour-Nasrabad 2018,[108] Iran	Experimental (case-controlled intervention)	To investigate the effect of transitional care on quality of life in patients with	Patients between 20 and 76 years, admitted with heart failure (HF).	QOL - Minnesota HF Questionnaire (MLHFQ), Participation rates intervention	Patient QOL in the intervention group is significantly higher than the control group	Intervention

	chronic heart failure in physical, emotional-spiritual, and socioeconomic dimensions	Intervention: n=84, Control n=84	elements (visits, phone calls)	in physical, emotional-spiritual, and socioeconomic dimensions (P <.05)

COPD: chronic obstructive pulmonary disease, HF: Heart failure; ED: emergency department, QOL: quality of life; GI: gastro-intestinal; ADL: activities of daily living, CI: confidence interval; GDS: geriatric depression scale; NYHA: New York Heart Association; CHF;: congestive heart failure; BMI: body mass index; CLD: chronic lung disease; 6MWT: 6 minute walk test; MoCA: Montreal Cognitive Assessment; EORTC QLQ-C30: European Organisation for Research and Treatment of Cancer Quality-of-life Questionnaire Core 30; SF-36: Short Form 36 Health Survey Questionnaire

2.4.3 Synthesis of results

2.4.3.1 Intervention characteristics via TIDieR

Table 3 presents the core elements of the intervention reported in the study using the TIDieR items. Studies described person-centred, multi-component interventions with variability in delivery mode, content and timing.

What (i.e., materials and procedures used in interventions)

Most of the studies described interventions (n=33) that aimed to target both patients and carers. Four studies reported interventions that targeted carers exclusively. These included practical carer training at bedside, (109, 110) individualised education and support before and after discharge. (58, 78) Interventions were primarily delivered across both hospital and home settings. (n= 35) Three studies described interventions occurring in one setting - hospital for practical carers skills training(110) and home-based for community pharmacy follow up program and carer phone support.(78)

Most studies adopted a combination of delivery modes – face to face and phone (n=31). Smaller numbers used phone,(58, 78) face to face (93, 98, 110) and automated response devices.(77) The time points at which these types of contacts occurred varied greatly and was dependent on the design of the intervention bundle. Persons responsible for delivery of the interventions sat primarily with nursing staff (n= 17), (58, 79, 80, 82, 86, 88, 89, 92, 96-98, 100-102, 107, 109, 110) followed by other disciplines such as treating physicians, (83, 85) social work,(111) psychologists, (78) and pharmacists. (93, 95) Some interventions (n= 8) were delivered by more than one discipline.(79, 81, 84, 87, 91, 94, 103, 106) Two studies did not explicitly report on who was delivering the intervention. (90, 99)

All studies described self-management as the core intervention approach used to improve care transitions for patients and carers. This was enacted using various techniques and combinations: (1) patient and carer education targeting disease and symptom management, (38, 77-89, 91, 92, 94, 96-99, 101-108) practical caring skills, (58, 109, 110) psychosocial support; (2) standardised needs assessments;(58, 87, 94, 102) (3) standardised discharge planning including, medication reviews(38, 80, 90, 91, 93, 104-106) and carer training, and (4) referrals to other healthcare providers. (94, 98) Interventions occurring after discharge continued to include education and support and

for some studies extended into rehabilitation (81) for patients; counselling(79, 80) and post-bereavement support for carers.(99)

Table 3. TIDieR table for included studies

Author	What	Comparator	Rationale and/or theory	Who provided	How	Where	When and how much	Adherence	Tailoring & Modifications
Piette et al 2020 (77)	Accessible Health Technology and Caregiver Support Post - hospitalisation. Interactive Voice Response (IVR) phone calls to patients, automated alerts to clinicians and structured email feedback to caregivers	Usual discharge information and medical follow up	IVR supported interventions can improve self-management of chronic illness and providing EB behaviour change education. Used with caregivers can decrease their distress	Staff provided with detailed protocol	Email; automated phone responses, fax alerts. Individual	Three hospitals; home setting	IVR CALLS - First 2 weeks daily calls, three attempts per day. Then 3 times per week for two weeks, then weekly for nine weeks. CLINICAL ALERTS - individualised for each patients; CP COMMUNICATION - After each IVR call, CP received email, feedback and alerts	76% of attempted IVR calls were completed Clinical alerts generated for 18% of completed calls	Individualised alerts and actions dependent on patient response to automated questions on IVR calls; and feedback from CP
Shaw et al 2016(78)	The Family Connect Telephone Intervention.	NR	Caregiver interventions can improve cancer patient	Experienced psychologist trained in oncology and	Phone-based	Four hospitals, home	10 week period, 4 phone calls at 14d, 4, 6, 10 weeks. Patient	High withdrawal rates pre-randomisation. High fidelity	Caregivers could reschedule phone calls.

	Caregiver needs assessment and education on supportive care strategies delivered after discharge		and caregiver wellbeing. Family Connect trialled in other studies. Qualitative pilot work revealed carers indicate time after discharge can be most stressful time	communicatio n skills			could reschedule if required. Required length of time per call not reported on	maintained via use of intervention recordings in training. High participation. Interviews at 3 months indicated caregiver acceptance -. satisfied with timing, content and mode of delivery	Strategies to address needs were tailored to individual participants needs
Toye et al 2016 (58)	Usual Care + Further Enabling Care at Home Program – Phone-based interventions between nurse and carer to review discharge information, needs assessment	Usual Care: Discharge letter, medications, prescriptions, referrals and outpatient referrals. "At risk" patients receive Social Work intervention	Based on UK care-led tool known to improve carer outcomes. Hospital discharge needs of caregivers poorly met. Telephone based intervention considered most effective	Dedicated nurse trained in needs assessment tool and overall intervention	Phone-based	600-bed hospital, home	Across 3 phone calls - Contact 1- within 1 week post discharge, Contact 2 - 7-10 days post discharge; Contact 3 within 14 days of discharge	56% consented to study. 13.5% Attrition for both groups	Change to timing of nurse contacts due to limited availability of caregivers

	and post discharge follow up								
Coleman et al 2006(58)	Care Transitions Intervention - Coaching and self-management model using hospital and home visits and follow up phone calls and person-centred record	Usual Care	Based on evidenced based conceptual domains develop via qualitative data from patients and caregivers in previous studies i.e. what is most valuable during care transitions	Trained transition coaches (nurse practitioners)	Face to face and phone	Hospital, home	Hospital visit pre-discharge, one home visits within 48-72 post discharge, then 3 follow up phone calls within 28 days of discharge	Participation rates. 67% intervention group received all components, 0.8% received none. 86% received at least home visit and phone call	Individualised via person-centred record
Utens et al 2014(79)	Community-based hospital at home scheme. Early discharge from hospital and nursing support across care transition via visits and	Usual care – 7 days inpatient treatment then home	Based on GO AHEAD intervention from earlier RCT. Caregivers important part of hospital at home scheme	Nursing	Face to face, phone	6 hospitals, home	First 7 days: 4 x home visits, 1 x hospital visit, then 90 day follow up. Access to 24-hour support. Education, counselling provided to	NR	NR

	phone support for patient and carer						patient and caregiver		
Naylor et al 2004(80)	Transitional Care Management Model – 3-month APN-directed discharge planning and home follow up via visits and phone support for patient and carer	Routine care - heart failure management, discharge planning and home care services	Evidence supports multidimensional, person-centred approach that occurs across hospital and post-discharge period	Led by APN. Trained and HF experience. Physician joined APN in pre-discharge and initial follow up visit	Face to face, phone	6 hospitals, home	Pre-discharge: daily visits; Post discharge: at least 8 x visits; 1 x within 24hours, then weekly, to bimonthly across 3 month period in total	NR	Intervention content adapted to individual (via goal setting and care plans)
Aimonino et al 2008(81)	Physician-led hospital level treatments at home. Medical and rehab services (nursing, medicine, physical therapy [PT], occupational	Usual hospital care	Physician-led substitutive clinical unit hospital at home model will reduce readmissions, mortality and other medical outcomes	Established multidisciplinary team and service, no additional training reported	Face to face, phone-based	Geriatric hospital, home	Daily nurse and physician visits, then daily nurse, and every 2-3 days intervals for physician. Additional urgent home visits available. Dosages of OT	Both groups received similar rates of COPD treatments. Intervention group received 14.1 nursing visits and 9.9 physician visits. ?NR	Amount of visits dependent on patient's medical needs.

	therapy [OT]). Patient and carer education on disease and symptom management						and PT not reported		
Angermann et al 2012(82)	Nurse-coordinated Disease management program (DMP) for patients and carers -via hospital visit, weekly phone follow up, medication adjustment and specialist care	Routine discharge planning and GP follow up	DMP can reduce hospitalisation and mortality rates. Intervention elements developed by MDT and current evidence	Led by trained nurses, supported by cardiologist and psychologist	Face to face in hospital, phone-based at home, with patient, carer and clinician	6 hospitals, home	Pre-discharge – hospital visit After discharge: Weekly contacts in first month, individualised frequency. Contacts 10-15 minutes. Emergency contacts available	High compliance with self-monitoring and drug adherence Training and supervision model applied for fidelity	Adapted to meet patient unmet need. Receipt of intervention modules and frequencies varied
Atienza et al 2004(83)	Comprehensive hospital discharge planning and outpatient HF management program for patients and	Usual care. Standard discharge planning and HF management	Evidenced-based physician-led clinical model used. Education pre -discharge and early after discharge	Treating physician. Training not described	Face to face in hospital, and clinic, telemonitoring via phone	3 hospitals, home, clinic	(1) Patient and family initial interview and self-management education pre-discharge; (2) Physician home visits 2 weeks	NR	NR

	families. Physician-led		important element for successful transition from inpatient to outpatient care				post discharge; and (3) Follow up clinic visits every 3 months. (4) 24 hour phone support line from discharge to end of study		
Casas et al 2006(84)	Standardised, integrated care intervention; Includes hospital visit, patient/carer access to post discharge support via home visits, web-based call centre	Usual Care: Discharge planning with routine follow up	Integrated/shared care may prevent readmissions by improving coordination among different settings/levels	Delivered by specialist nurse and GP. Training not described	Face to face in hospital, initial period home, then phone-based	2 hospitals, home	At discharge: (1) Initial assessment, (2)Patient/carer self-management education (2 hour duration) (3) Generate individual care plan. Post discharge: (1) Patient/carer access to specialise nurse via web-based call centre (2) In Spain - MDT home visit within 72 hours discharge;	Barcelona had 448 calls via call centre – 194 scheduled, and 254 (43%) scheduled Leuven had 201 calls, 128 (63%) (nurse-triggered). The mean duration phone calls was 20 min. for both sites. n Leuven, no home visits by hospital based specialised nurses were planned after discharge	Adapted to different health systems. GPs key role in one site, whilst nursing in other. Individualised care plans generated for each patient

							and ongoing support by respiratory nurse (3) In Belgium GPs provided case management. (4) Weekly phone call in first month (5) Non-schedule visits triggered via call centre as required		
Hendrix et al 2011(109)	Individualised experiential caregiver training and follow phone follow up after discharge. Based on Coleman's Transition Model	NA	Based on theory of problem based adult learning and designed to enhance self-efficacy. Improve self-efficacy can improved patient and carer outcomes	Nurse trained in protocol and supported with mock training, feedback and weekly consultation	Face to face, phone	4 medical units at Veteran Affairs (VA) Hospital, home	Before discharge: 1 or 2 interactive sessions at least 2 hours long. Follow up phone call 24-72 hours after discharge for mediation reconciliation	High completion rate (80%), Actual dosage range: 3-6 hours in one day; except one carer across 2d	Training individualised to patient and caregiver needs
LeGrain et al 2011(85)	OMAGE discharge planning	Standard care from the AGU	Intervention used evidence based self-	Trained geriatricians	Face to face and phone	6 acute geriatric units	4 x education sessions, mean duration: 98.7	Acceptance and fidelity reported. 92.7%	Individualised education session

	intervention using chronic treatment review, self-management education (patient and carer); and enhance transition of care communication		management education approach; and targeted three risk factors of preventable readmissions: DRPs (e.g. adherence), depression and malnutrition				min education, 70.7 min treatment review and 44.2 transition of care communication	participants eligible for education, 41.2& delivered to patient, 24.5% to patient and carer; and 34.2% to carer.	modified based on patient and carer needs
Hendrix et al 2006(110)	Individualised experiential caregiver training at bedside before discharge on symptom management. And home care skills. Carer-led	NR	Self-efficacy theory applied to caregiver training model. Self-efficacy (confidence) contextual factor to be able to provide care	Trained nursing specialists	Face to face	Extended rehabilitation centre, home	1 or 2 training sessions, minimum of two hours long; duration and frequency led by carer and their needs. Before discharge	Carers viewed training as effective. 22 patients referred; 15 had caregivers at home but half patients refused for caregivers to participate. 7/8 caregivers agreed to participate. Actual range: 3-6 hours in one day; except one carer across 2d	individualised based on patient and carer needs

Abad-Corpa et al 2013(102)	Multi-component, nurse-led, intervention. Includes patient/carer education and care-coordination pre-discharge; home visit and phone follow up	Usual care + follow up phone call at 2,6,12 and 24w	Discharge planning and multidisciplinary interventions reduce hospital utilisations, improve care coordination and HRQOL	Trained nursing	Face to face and phone	Two acute hospitals, home	PRE-DISCHARGE (1) Patient/carer education on disease (2) Needs identification (3) Referral to other HCP. Across 5 days. AFTER DISCHARGE: Care plan, follow up home visit <72hours and contact with primary care team. Phone follow up at 2,6,12 and 24 weeks	26% eligible participants recruited. Higher satisfaction with nursing care in IG	Individualised, person centred model
Aboumatar et al 2019(86)	BREATHE Program Transition and self-management via hospital, home and face to face pre - discharge and	Usual care - 30 day follow up from transition coach	Transitional care interventions can reduce ED visits and readmissions; and need to focus on long term outcomes.	COPD trained nurses	Face to face, home visits, phone	447-bed acute hospital, home	(1) Patient and family support for discharge (2) COPD Self-management support for symptoms (3) Behaviour change education. (4)	85% had at least 1 hospital visit, completed the intervention	Individualised, person centred model

	3-months after. Patients and carers		Co-developed with patients, carers and stakeholders; informing desired outcomes				increased access to community supports. Mean no. 6.1 sessions (1.4 in hospital, 4.7 as outpatient). Mean duration of 23.8 min; >half sessions with caregiver present.		
Chiang et al 2012(103)	Telehealth care model via hospital and home. Nurse led discharge planning, phone support; and patient-carer use of devices to monitor symptoms after discharge	Usual care - hospital based discharge planning	Advanced disease management models prevent readmissions. Guided by Meleis's transition theory. Transitions can impact on patient's wellbeing, their relationships and their family caregivers	Telehealth nursing specialist and referred to physician as required	Face to face, telehealth device and phone	Acute medical centre, home	Contact made within 48-72 hours, then daily contact and monitoring of symptoms. Duration and dosage individualised for patient's needs	No participants lost to follow up	Individualised for meet patient and carer need and respond to change in condition

Coleman et al 2004(104)	Multicomponent, coaching model across hospital and home. Phone support for 24 days post discharge. Targeting (1) medication self-management, (2) patient-centred and owned record (3) timely post discharge follow up and (4) Identify red flags	Usual care	Applied Evidence-based Care Transitions Intervention - constructs based on qualitative data from patients and carers. Self-management improves transitions	Trained Nurse practitioner	Face to face, phone	Hospital, home	(1) Hospital visit, (2) Home visit within 24-72 hours post discharge, at least 3 x phone calls across 24 days	High adoption and acceptance. 91% received home visits, 72% received >3 phone calls. Reported improved confidence and skills in self-management	Individualised according to patient and carer needs, details on health care record
Lainscak et al 2013(87)	Multi-component discharge coordination model across hospital and home.	Usual care	Little evidence supporting discharge coordinators for COPD patients. Transition programs	Discharge co-ordinator	Face to face, phone	Specialized pulmonary hospital, home	(1) Assessment of discharge needs (2)Involved patient, carers and communicated plan to other	High acceptance; only 18/118 did not receive follow up visits	No. of phone calls tailored according to patient need

	Discharge planning with patient and carer, follow up phone support and home visit after discharge		targeting discharge critical to reducing health care costs				providers (3) Phone contact within 48 hours after discharge; (4) Ongoing review via phone by discharge coordinator until needs met; engaging other HCP; (5) Final assessment via home visit 7-10d after discharge.		
Li et al 2014(88)	Two-stage self-management program across hospital and home. Included patient-carer psychoeducation in hospital, home and over the phone over 3 month period	Usual care	Transitional care interventions can enable continuity of care and has shown positive results in Western countries in discharge planning	COPD trained nurses	Face to face, phone, home visits	Hospital, home	1 x hospital visit, phone calls 3,5,7 and 9 weeks after discharge; and home visits 72 hours and 3 months after discharge	Low dropout ad withdrawals	Individualised assessment

Jenq et al 2016(105)	Individualised transitional care, including patient-carer education, medication reconciliation, follow-up telephone calls, home visits and linkage to community. Across hospital and home	Usual care	Evidence supports transitional care programs in reducing readmissions. Based intervention on proven models	Transition care coaches trained social workers delivered intervention	Face to face, phone	Hospitals, home	PRE-DISCHARGE: Patient-carer needs assessment; POST-DISCHARGE: (1) Minimum 1 x follow up phone call per week for medication/support review. (2) Home visits if functional assessment needed. Plus, usual practice of written discharge instructions	NR	NR
Kwok et al 2004(89)	Intensive community nursing (CN) supported discharge program. Pre-discharge assessment, home visits for	Usual care	Evidence suggest CNs improve discharge and reduce readmission for older people. Informed design for chronic lung	CNs with > 2 years' experience. Trained in care of CLD patients	Face to face, phone	Hospital, home	Pre-discharge initial visit. Home visits: 1 x within 7 days of discharge, then weekly for 4 weeks and monthly until 6 month. Access to	High adoption (87%) of home visits Average number of home visits per subject was 11.8 3.9 (range 2–24); the average number of tele-phone calls	Phone hotline based on need and self-directed by patient/carer

	disease management and psychoeducation for patient-carer. Access to support hotline		disease (CLD) participants				phone line as needed	per subject was 10.3 6.1 (1–24); and total time spent by CN per subject 9.9 3.3 (2.3–17.1) hours	
Preen et al 2005(90)	Evidence-based multi-disciplinary discharge care plan given to patient/carer before discharge and sent to GP and community providers. GP follow up 7 days post discharge	Usual care	Evidence gap in efficacy of multi-disciplinary discharge care plan. Inadequate discharge planning and poor communication to GP can increase length of stay, cause breakdown of care	NR	Face to face, phone	Two hospitals, home	Care plan provided 24-48hours before discharge, GP follow up 7 days post discharge	Intervention group general practitioners 90.1% compliance with discharge care plan return, 47.2% returned before discharge. Average (mean ± SD) care plan return time was 3.0 ± 3.2 days post-discharge	Care plan included patient/carers goals, individual needs. If GP hadn't followed up, research nurse would contact them

Shu et al 2011(106)	Integrated Post Discharge Transition Care Program (PDTC). Pre-discharge care plan, follow up phone call, access to hotline and referral to clinic. Patient-carer education for disease management, medication and care plan adherence	Usual care (post discharge care plan + patient/caregiver education on ward)	Based on Coleman's Care Transitions Intervention, Expected to reduce adverse events and readmission rates	Study nurse and treating physicians	Face to face, phone	Hospital, home	(1) Provision of care plan predischarge; (2) 5 x follow phone calls at days 1,3,7,14 and 30 post discharge. Hotline counselling and support as required	62% patients received all follow up phone calls; remaining were lost to follow up, died or readmitted. 20% of IG used hotline. 14% IG attended scheduled clinic visits, 2% unplanned clinic visits	Individualised interventions provided based on care plan
Watkins et al 2012(111)	Individualised Hospital to home transition program using social worker navigator. Home care services set-up pre-discharge,	NA	Model adopted from pre-established CTI. Targeting psychosocial needs of patients to improve IADL performance	Social workers	Face to face, phone	961-bed hospital, home	At least 30 days after discharge or up to 4 months. 1 x hospital visits, 1 x home visit within 72 hours after discharge; then visits and	Average of 63 days per patient in the program. Average of 2.7 visits, 3.5 phone calls, and 16hr of in-home assistance. Average of 12 days between	Individualised home care service provision and follow up

	patient and family support for after discharge via home visits		and ability to stay home				phone calls on need basis	discharge and their first primary care physician visit	
Zimmerman et al 2017(107)	Home-based transition care intervention (HBTCI) for multimorbid patients. Multi-component self-management model across hospital and home using coaching and teach back method	Usual Care	Patients need different dosages of CTI to enable change. Cognition and patient activation inform intervention design. CTI models and Activation Science as theoretical base	Nursing and nursing assistant trained in intervention	Face to face, phone	Acute hospital, home	Dosage and frequency varied by group. Included medication management, personal health care record development, red flag identification and action planning	Drop out rates recorded across four groups	Individualised to patient need
Enguidanos et al 2012(91)	Nurse practitioner and physician-led intervention Discharge planning and post discharge	Usual care	Hospital utilisation can be reduced if older people properly followed up after discharge.	Nursing and physician	Face to face, phone	Hospital, home	3 x home visits, 2 x phone calls. Duration not reported. First visit within 72 hours of discharge	High adoption and fidelity.70% received one home visit, 67.7 received 1-2 calls. All patients receive at least 1	Individualised care plan

	follow up via home visits and phone calls for patient-carer education, medication review		Based on pre-existing CT Model by Coleman and adapted for high-risk population					call or visit and no more than 6 contacts with NP. 94% received a home visit. Five patients refuse, one went to hospice. Average time 75 min spent with patients	
Laramee et al 2003(92)	Chronic Heart Failure (CHF) Hospital-based Case Management (CM) Program Early discharge planning, patient and family education, phone follow up and medication education	Usual care	CHF CM linked to better health utilisation and patient outcomes Core components based on evidence based guidelines	Nursing CHF CM, trained in cardiology and critical care	Face to face, phone	Hospital, home	Patient/family received phone calls 1-3 days after discharge and at weeks 1,2,3,4,6,8,10, 12. Duration from 5-45 min. CM also on call during Monday to Friday	70% acceptance rate, 86% completed intervention. Greater adherence to treatment plan and higher satisfaction with care for IG. Higher doses and use of medication for IG	Individualised care plan

Nazareth et al 2003(93)	Pharmacy discharge care plan. Medication education before and after discharge to patient-carer and follow up with GP, community pharmacist.	Usual care	Coordinated care between hospital and community pharmacists, patient and family can improve medication adherence for older people	Hospital and community pharmacists	Face to face	3 acute hospitals and 1 long stay hospital, home	(1)Pre-discharge: Medication management, information and discharge plan. (2): 7-14 days after discharge home visit follow up by community pharmacist	HOSPITAL:. 81% received only one discharge plan. 26%lost/unavailable COMMUNITY:71% patients received home visit. Mean no. of interventions 1.9 per visit; and 2.8 per patient. Mean duration of first home visit was 38min, 2nd visit was mean time 27 min. 32 min of extra clinician admin time	individualised based inpatient/carer and community care provider's needs
Lim et al 2003(94)	A post-acute care (PAC) program for older people after discharge. Short term case management and care-	Usual care	High readmission risk immediately after discharge. PAC program provides coordinated care and short	PAC coordinators (nursing or allied health)	Face to face, phone	Four acute hospitals, home	(1) Assessment of discharge needs and planning; (2) As needed: follow up phone call, available for crisis management,	311 received intervention, (293 followed up; 5 withdrew, 13 lost to follow up)	Individualised "as required" or "as appropriate"

	coordination pre and post discharge		term community follow to minimise risk				liaison with service providers, coordination of and access to extra service provision		
Naunton et al 2003(95)	Home-based follow up of high risk older patients after discharge. Patient-care education, compliance medication review, liaise with community	Usual care	Readmissions related to drug-related problems (DRP) can be avoided via system-based interventions involving patient and clinicians	Pharmacists	Face to face	400-bed acute hospital, home	Planned: 2 x home visit. 1st home visit (5 days) mean duration 50 minutes (range 25-120). 2nd Home visit (90 days) mean duration 30 minutes (range: 15-60)	57 received intervention, 8 withdrew or lost to follow up. High acceptance of recommendations (76%), information (84%) and contact (94%) with pharmacist	Medication review required categorisation of DRP to develop individualised plan and education
Dellsega et al 2002(96)	Advanced Nurse Practitioner (APN) intervention via hospital and home visits, phone calls.	Usual care (no APN)	Rural caregivers at higher risk of readmissions and adverse outcomes. APN models improve patient, caregiver and	APN (post graduate training)	Face to face, phone	Rural hospital, home	Standard care + APN intervention: 1 x hospital visit, 2 home visits at 48 hours and 1-2 weeks post discharge. Phone call between two	71% of caregivers completed interviews (not intervention) due to feeling overwhelmed	NR

	Psychoeducation model		service outcomes. Based on Brooten's transitional care model				home visits. Based on Brootens' transitional care model		
Pugh et al 2001(97)	Partners in care model (PIC) - long term patient case management. Enhanced discharge planning, self-management education for HF via workbook, nursing assessment and 6 month follow up by case manager	Usual care	Non-pharmacological longitudinal case management can improve outcomes for HF patients - including goal attainment, reduced length of stay, better resource utilisation, carer coordination	Nursing	Face to face, phone	Two acute hospitals, home	NR	NR	NR
Thompson et al 2005(98)	Nurse led, clinic and home based	Usual care (education + outpatient	Hybrid program of Nurse-led, Clinic plus	Two nurses skilled in heart failure	Face to face	Two acute hospitals,	1 x ward visit, 1 x visit within 10 days of discharge,	High acceptance. 98% receive home visit within 10	NR

	intervention (C + HBI). Across hospital, home and clinic. Patient-family education on disease management, referrals to support services	follow up 6-8 weeks)	home based follow up most beneficial for CHF patients based on other intervention studies	management and post graduate qualifications, using strict protocols		home, clinic	attend monthly regular clinic visits for 6 months	days, 79% attended all their clinic sessions	
Halling et al 2020(99)	Fast-tracked Specialist Palliative Care Transition Model with enriched psychological intervention. (across hospital and home for patient and carer/family)	Usual care	Earlier RCTS shown intervention improves patient QOL and carer outcomes (anxiety and depression).Fas t track nature likely to show economic benefits	NR (in protocol paper)	Face to face	Hospital, home, clinic	Hospital sessions not reported; team conference at home + 2 x psychology settings in first month then as needs. Carers received 3 additional sessions post bereavement	NR	NR
Hastings et al 2020(100)	Discharge information and support for	Usual Care	Evidence shows phone support improves	Nursing	Phone	Veteran medical	Call 1 - needs assessment ; Call 2 - referral for	High adherence (92% completed Call 1, 98%	Support based on

	patients receiving care in the ED (DISPO ED). Nurse phone support after discharge for disease management and counselling		continuity of care. Not tested in ED. Should improve transition via disease management and patient and family education			centre, home	chronic disease management and counselling. Optional call 3 - during week 2 for additional needs. Can initiate additional calls for 30 days	completed both calls; half completed optional and 3% initiated one call within 30 days. Low uptake from carers. 33% acceptance of recommendations	individual need
Schumacher et al 2021(101)	Colemans CTI - modified for ED. With added supports for meals and transport. Coaching model via phone and home 4 weeks after discharge	Usual care: Written instructions and GP follow up	Self-management approach of intervention will address factors that lead to patients seeking ED over primary care. Colemans' CTI proven effective for older inpatients	Coaches have bachelor's degree or completion of CTI. Not limited to nursing	Phone, face to face	Two ED's, home	1 x home visit. Within 30 days coach called patient weeks 1,2 and 4; lasting 60 minutes. Extra calls and visits based on need	37% did not receive intervention due to coach unable to schedule home visit, 8% received transportation, 26% received meals. None lost to follow up	Additional phone calls and visits based on need. Individualised program

Rezapour-Nazrabad 2018(108)	Nursing liaison transition care model CHF patients. Psychoeducation for patient and family across hospital and home. Phone call and visits tailored to individual need	NR	Based on Naylor's Transition Care Model (TCM) - improves patient outcomes via nursing support	Nursing	Phone, face to face	Hospital, home.	Nursing liaison support provided during admission and after discharge up to 6 months via phone or visit. Duration and number of times not reported	100% response rate. Nil other data reported	Dosage of phone and visits based on individualised need

EB: Evidence based; NR: Not reported; APN: Advanced practitioner nurse; CTI: Care transition intervention; CT: Care transitions.

*Some TIDieR items have been combined in the table for ease of reading: What = Items 1, 3 and 4; Adherence = Items 11 and 12, Tailoring & Modifications = Items 9 and 10.

How much (frequency and time period of interventions)

Most studies (n=36) reported on the number and frequency of clinician contacts across hospital and home settings. Eighteen studies involved contact within 72 hours of discharge(38, 79, 81, 84, 87, 88, 90-92, 94, 96, 102-104, 106, 107, 109, 111) and 14 studies involved contacts made more than a week after discharge. (58, 77, 80, 82, 83, 86, 89, 95, 98-101, 105) There was limited or no reporting of intervention frequency for two studies. (94, 97) The final contact in the intervention commonly was at three months, (79, 80, 83, 95, 102) but ranged from 7 days (87, 90, 93) to 6 months after discharge.(89, 98, 107, 108) Eight studies reported that the final contact was determined by individual need. (86, 94, 99, 101, 103, 105, 107, 111) The planned duration of intervention sessions was reported by twenty percent of studies (n=8).

Adherence

Adherence to intervention was commonly described as participant completion rates; including participation in different components of the intervention, (38, 77, 78, 81, 84-87, 89, 92, 93, 95, 98, 101, 103, 104, 106, 109-111) recruitment and retention rates,(58, 88, 93-96, 101-103, 107, 108) as well as acceptance and compliance with recommendations made. (82, 85, 91, 95, 100, 104) Seven studies (19%) did not report on adherence. Clinician adherence to proposed intervention delivery (fidelity) was reported as audio recording of intervention, and supervision/training models. (78, 82) Actual clinician adherence was described as rate of intervention delivery.(85, 90, 91)

Tailoring modifications

Reporting of specific modifications to core components of the intervention was limited to two studies. This involved altering intervention timing according to carers availability and adaptations to ensure applicability across different hospital settings.(58, 84) Most studies described interventions as tailored to meet the needs of the individual (n= 30) via individualised care plans,(38, 72, 77, 80, 82, 84, 90-95, 100-102, 104, 106, 110, 111) needs assessments, (78, 81, 82, 85, 87-89, 103, 107-110) and goal setting.(80)

Rationale

Rationale for the choice of intervention was reported as quantitative data from earlier controlled studies (n= 30). (58, 77-105, 109, 111) Adoption of established care models including Colemans Care Transition Intervention (CTI) (n=10)(38, 78, 91, 101, 104-108, 111) and Naylor's Transition Care Model (TCM);(73) alongside qualitative data from preliminary work and earlier studies (n=6)(38, 72, 78, 82, 86, 99, 104) were also presented as rationales for intervention choice. Well-described rationales relied upon a combination of these aspects. Only five studies referred to specific theoretical models to explain how their intervention worked and achieved proposed outcomes. These include self-efficacy theory, (110) problem based adult learning, (109) Melisis Transitions Theory, (103) Brooten's transitional care model (96) and activation science. (107)

2.4.3.2 Alignment to the CTF

Implementation measures

Table 4 illustrates how well the studies align with the CTF domain "implementation measures". These measures were derived when studies had reported on adherence data in the TiDIER checklist. All constructs except for penetration were reported on to varying extents: acceptability (n=31), (38, 77, 82, 85-93, 95, 98-112) adoption (n=31),(38, 77-79, 85-96, 98-111) appropriateness (n=27),(38, 58, 77-82, 85, 86, 88, 90-96, 101-106, 109-111) intervention cost (n=13),(38, 80, 81, 85, 89, 94, 96, 98, 99, 105, 107, 111) fidelity (n=24),(38, 58, 72, 77, 78, 80-82, 84, 85, 90-93, 95, 96, 98-101, 106, 107, 109-111) reach (n=3), (24, 78, 105) replicability (n=9),(77, 80-85, 88, 99, 100, 113) and sustainability (n=3).(82, 83, 109) Studies had alignment with an average of four constructs. Most studies reported data on the three constructs of acceptability, adoption and appropriateness. Alignment to the most common constructs of acceptability, adoption, appropriateness and fidelity were evidenced in two ways – by (1) descriptions of quantitative data related to participation rates, initial uptake, withdrawals and satisfaction with the intervention; and (2) describing data collected from earlier feasibility or exploratory studies that aligned with these constructs. Studies reporting both quantitative and qualitative data for these measures were given higher ratings (as per Table 3) than studies reporting on only one.

Table 4. Alignment to CTF implementation measure constructs

Citation	Acceptability	Adoption	Appropriateness	Intervention Cost	Fidelity	Reach	Penetration	Replicability	Sustainability
Piette et al 2020[77]	*	*	*		*			*	
Shaw et al 2016[78]	**	*	**		**	**			
Toye et al 2016[58]	*		*		*				
Coleman et al 2006[58]	**	**	*	**	**				
Utens et al 2014[79]	**		**						
Naylor et al 2004[80]	*	*	*	**	*			*	
Aimonino et al 2008[81]	**		**	**	*	**		**	
Angermann et al 2008[82]	**		**		**			**	*
Atienza et al 2004[83]				**				*	
Casas et al 2006[84]					*			*	

| | | |

Zimmerman et al 2017[107]	*		*				**		*											
Enguidanos et al 2012[91]	**		**		**				**											
Laramee et al 2003[92]	**		**		**				*											
Nazareth et al 2003[93]	**		**		*				*											
Lim et al 2003[94]			*		*		*													
Naunton et al 2003[95]	**		**		**				**											
Dellsega et al 2002[96]				*		*		*		*										
Pugh et al 2001[97]																				
Thompson et al 2005[98]		*		*				*		*										
Halling et al 2020[99]		**		*				**		*								*		
Hastings et al 2020[100]		**		**						**								*		
Schumacher et al 2021[101]		**		**		*				**										
Rezapour-Nasrabad 2018[108]		*		*																

No star – not described, *= poorly described, **= well described.

2.4.4 Outcomes

Outcomes were described at the individual level and service level in various combinations across the different studies. These are outlined in Table 5. The strongest alignment was with clinical outcomes construct (n=31). These included patient-specific (n=21), (77, 80, 82-84, 86-91, 93, 95, 97, 98, 100, 102, 106-108, 111) carer-specific (n=3),(103, 109, 110) and patient-carer combined (n=7)(58, 78, 79, 81, 94, 99).Common patient-related outcomes measures included health-related quality of life (HRQOL) (n=15) (81, 83, 87, 90, 94, 97, 98, 100, 102, 107, 108, 111), mortality (n=8), [80, 81, 83, 84, 86, 87, 93, 94]physical and psychological function (n=7).(58, 78, 80, 81, 89, 97, 107) Carer-related outcomes were mostly self-reported appraisals of caregiving preparedness and wellbeing(n=4),(58, 96, 103, 109) followed by burden or distress levels (n=8).(58, 78, 79, 81, 89, 94, 96, 103)

Table 5. Alignment with CTF individual and service-level constructs

	Patient and carer reported outcomes (PROMS)			Health service-related outcomes		
	Patient/Caregiver-Centred Outcomes	Patient/Caregiver experience	Clinical Outcomes	Provider Experience	HC Utilisation	Cost
Piette et al 2020(77)			*P	*	**	
Shaw et al 2016(78)	*	**C	**		*	
Toye et al 2016(58)	*	**C	**			
Coleman et al 2006(58)		*P			**	**
Utens et al 2014(79)	*	**C	**			
Naylor et al 2004(80)			*P		**	**
Aimonino et al 2008(81)		**	**			
Angerman et al 2008(82)			*P		**	
Atienza et al 2004(83)			*P		**	**
Casas et al 2006(84)			*P		**	
Hendrix et al 2011 (109)	*	**C	*C			
LeGrain et al 2011(85)					**	**
Hendrix et al 2006(110)	**	**C	*C			

Abad-Corpa et al 2013(102)		*P	*P		**		
Aboumatar et al 2019(86)			*P		**		
Chiang et al 2012(103)	**	**C	*C				
Coleman et al 2004(100)	*	**		*	**		
Lainscak et al 2013(87)			*P		**	*	
Li et al 2014(88)			*P				
Jenq et al 2016(105)					**	*	
Kwok et al 2004(89)		*C	*P				
Preen et al 2005(90)		**P	*P	**	**		
Shu et al 2011(106)			*P		**		
Watkins et al 2012(111)		**P	*P		**		
Zimmerman et al 2017(107)			*P		**	**	
Enguidanos et al 2012(91)		*P	*P		**		
Laramee et al 2003(92)		*P			**	**	

Nazareth et al 2003(93)	*P	*P	**	**	
Lim et al 2003(94)		**		**	**
Naunton et al 2003(95)	*P	*P		**	
Dellsega et al 2003(96)		**	*	**	*
Pugh et al 2001(95)		*P		**	**
Thompson et al 2005(98)		*P		**	**
Halling et al 2020(99)		**		**	**
Hastings et al 2020(100)		*P		**	**
Schumacher et al 2021(101)			*	**	
Rezapour-Nasrabad 2018(108)		*P			

No star – not described, *= poorly described, **= well described.

P = patient measures only, C= carer measures only, ** = well described patient and carer measures.

The second strongest alignment was with healthcare utilisation outcomes construct (n=29); specifically readmission rates (n=25), (38, 77, 80-84, 86, 87, 89, 91-93, 95, 97, 98) Emergency Department presentations (n=10),(77, 85, 86, 89, 91, 92, 97, 106, 107, 111) hospital days (n=3)(90-93)and clinic visits (n=3).(77, 101, 105) Fourteen studies aligned with the cost construct – describing measures of direct and indirect healthcare costs.(38, 72, 80, 83, 85, 87, 88, 92, 94, 96-100, 105, 107)

Data on individual experience was reported for 15 studies – 6 studies measures carer experience,(58, 78, 79, 89, 103, 109, 110) seven studies measured patient experience (38, 90-93, 95, 102, 111) whilst two studies measured patient and carer experience.(81, 104) Measurement tools used included satisfaction surveys (n=9),(79, 90-93, 95, 102, 111) rating scales (n= 2),(58, 104)and individual interviews (n=3).(89, 109, 110) Less experience data reported on for clinicians and service providers (n=6) (77, 90, 93, 96, 101, 104) A small number of studies (n=7)(58, 78, 79, 103, 104, 109, 110) demonstrated alignment with the CTF construct "patient/carer -centred outcomes", evidenced by links made between what patients/carers have voiced are their goals/needs and the chosen measures.

Most studies (n=24) used health service utilisation as the primary outcome, including two studies with patient-carer dyads. Clinical outcomes were used as the primary measure for 12 studies, and individual experience for one study.

2.5 Discussion

This is the first review to examine the reporting and methodological quality of CTIs for carers of patients with advanced illness and their alignment to a theoretical framework.

This review has shown that carers are under-represented in transition interventions as evident by the intervention content, delivery and selection of outcomes. Just one third of the studies that met the original inclusion criteria included carers, with most of these providing brief descriptions of carers only as they were considered as a component of patient directed interventions. Carers appeared to be considered as resources rather than recipients of care in many of these studies – something that has been identified in other literature(114) and consistent with clinical practice.

Studies predominantly reported on clinical patient-related and health utilisation outcomes. While these can be considered objective, easy to measure and well accepted as drivers for policy change, the dominance of these measures implies that carers are less

visible and their needs less influential upon clinical translation and policy change. The costs of caring - the individual and societal costs that are generated when a person takes on the caring role – are significant; yet measuring cost effectiveness and equity remains difficult. (37, 115)These could be important elements to consider integrating into an optimal research and policy frameworks for CTIs. However, operationalising this is likely to pose many challenges; and more research is needed to understand the extent to which this is already happening. Equally researchers should be more cognisant on the policy context in which their research is positioned, and consider moving carers' outcomes to greater prominence in order to drive change.

The UK has faced challenges in the implementation of the Care Act 2014 which highlights the needs of the carer.(39) This legislation stipulates that all carers should have access to assessment and support that is on par with the person they care for in health service design and delivery. How this is enacted and interpreted is up to individual health services and authorities. While this legislation is an important step in recognising the needs of carers, Carer UK found a national hospital discharge model fell short in supporting carers of people with palliative care needs, with carers reporting up to a six month wait for a carer assessment.(40)

This review has also shown there is an absence of theoretical discussion to inform transition intervention selection, with most studies relying on previous studies to justify their choice. The theoretical underpinnings of an intervention should form part of the preliminary development of a complex intervention, such as is required to support transitions, to ensure it effectively addresses the problem at hand. (74) The effectiveness of one study in one context does not guarantee it will work in another. Recent work by Thompson and colleagues highlights the importance of the need to better understand and report both theory and the mechanisms that underpin heart failure CTIs. (116) Practical advice that can help researchers "identify, disentangle and verify" mechanisms in complex intervention research was suggested way to achieve this.(117) Unfortunately, there is little

evidence that this advice has been adopted for heart failure transition interventions, and even less evidence evaluating carer needs. Applying the CTF in the design phase could improving the reporting quality at the evaluation stage and assist in addressing this issue.

Findings of this review, demonstrate the broader application of the CTF to the examination of the reporting quality of intervention studies, and its alignment with the TiDIER. It has highlighted specific constructs that may be common (and not as common) to interventions for hospital-to-home transitions in palliative care; and can be used by researchers in developing and evaluating studies in these contexts. It supports the inclusion of carers when reporting intervention content, delivery, and outcomes measures – equivalent to patients. It also offers the opportunity to position the carer as the primary recipient of an intervention that aims to improve the transition to home for end-of-life care. The CTF could also inform standardised reporting guidelines. Standardised reporting guidelines are available for an increasing number of methodologies and play an important role in facilitating study replication and translation into practice.(117, 118) It is important to note that not all CTF constructs will be relevant for each study, nor should they be applied or necessarily be reported in the one paper. For example, our review showed that the number and type of implementation measures reported varied greatly. This challenge has been addressed in the STARI reporting guidelines for implementation studies which follows dual strands – one for reporting of implementation strategy; and the other for the clinical or health intervention being implemented. (117)Future work on the development of a reporting guideline for CTIs could adopt this approach and use established methodologies for this process.

2.6 Limitations

This review has some limitations which require mention. There was an overrepresentation of chronic disease populations in the final sample compared to advanced cancer. This influenced the nature and timing of the interventions, lending themselves towards disease

and case management models. This is most likely due to the well-established care transition models (38, 73) for this population that have core principles and components that can be readily applied to intervention design and development, allowing researchers to test them in controlled studies. Although the number of intervention studies targeting carers of people with advanced cancer has increased in recent years,(35) these have been primarily in home-based settings rather than hospital discharge settings.

Mapping to a single set of constructs within the CTF was difficult; instead, content was mapped to all relevant subdomains. Published papers that detailed the development of relevant interventions such as protocols, and qualitative feasibility studies were excluded from this study. They may have offered additional information detailing the theory and mechanisms underpinning intervention design and choice of outcomes. Nevertheless, reference to this preliminary work in intervention papers is needed so that the research can be replicated.

The authors of this review also acknowledge that there are other transitions of interest including discharge from sub-acute settings like skilled nursing. or rehabilitation facilities to home. A review of these intervention models could also inform future intervention design and delivery.

2.7 Conclusion

There was considerable variation in the characteristics of CTIs due to their multi-component nature and the influence of contextual factors. This review has shown that carers are under-represented in CTI content, delivery and selection of outcomes. Health services, researchers and governments are faced with the challenge of how carers should be positioned in both the research and policy agenda. A standardised reporting tool that integrates the relevant constructs of the CTF could help address this challenge by offering the opportunity to include the carers in the intervention design and evaluation. Establishing a standardised reporting tool would also improve the reporting quality and

clinical translation of these complex interventions; especially for carers of people with palliative care needs where an optimal care model is yet to be established.

2.8 Summary

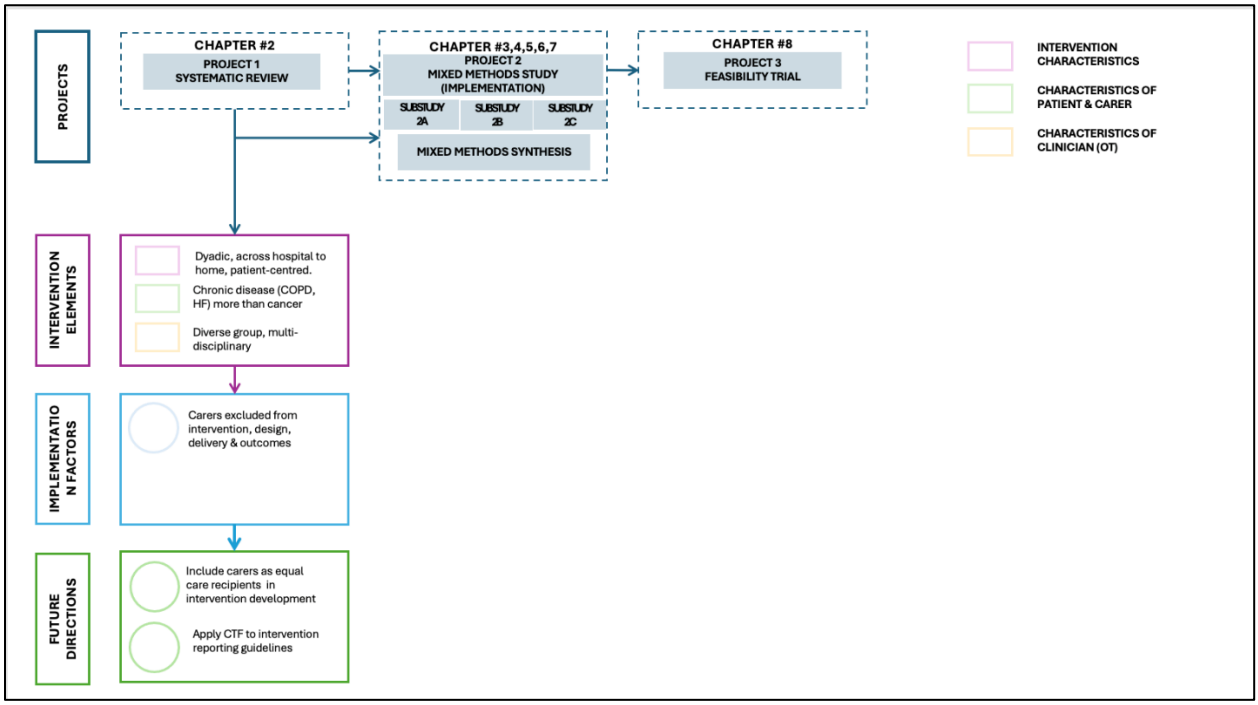
This systematic review allowed us to understand some of the key the characteristics that need to be considered when designing a CTI to improve hospital discharge for people with palliative care needs; and address the first objective – To identify the evidence gap related to the optimal CTI and components delivered to carers of people with palliative care needs. These findings and their alignment with other research components are illustrated in Figure 7 and will inform the intervention modelling that follows in subsequent chapters. Specifically, (1) the consideration of a dyadic intervention that is delivered across hospital and home, by multidisciplinary team and importantly, (2) the inclusion of carers in intervention design, content, delivery and outcomes

Findings from the review have also validated the anticipated gap between research, policy and practice; particularly in what is the best carer-focused model. Applying the CTF has revealed the absence of carers in the intervention design, delivery and selected outcomes in the current research; and limited theoretical discussion explaining what an intervention is designed to achieve. In addition, features of the interventions reported in the review were largely related to achieving change with people with longer chronic disease trajectories, rather than people with advanced cancer or approaching end of life. For these groups of carers, hospital discharge may be occurring in a different context and rely on different mechanisms; compared to someone with a chronic disease. These may be faced with the person they care for returning home with higher symptom burden, higher care needs and a higher degree of uncertainty. (68)

These findings generated from this review have informed the development and modelling of the carer-focused intervention that was piloted in Study 2; and the importance of

continuing to obtain a better understanding of the key components, and underlying mechanisms needed to influence outcomes.

Figure 7. Research components and findings for Project 1



Chapter 3. Project 2: study design and methodology

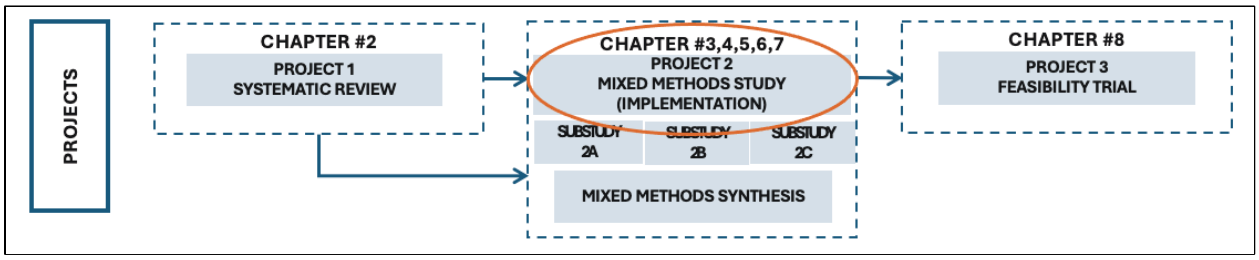
Findings from the systematic review in Chapter 2 revealed that carers are under-represented in intervention studies that seek to improve hospital-to-home transitions for the advanced cancer population. For those interventions that targeted carers, discussion of theoretical underpinnings was largely absent, and studies varied markedly in their design, outcomes and target population. Carers mostly participated as part of dyadic interventions (with patients), and study aims centred upon achieving patient or service-related outcomes such as improved symptom management or reduced hospital readmission rates.

In Chapter 1, the CSNAT-I was identified as a carer-focused intervention that had potential to support carers in the hospital discharge context. However, implementation of the CSNAT-I into a new context, such as at time of hospital discharge, requires targeted implementation modelling and evaluation. This fact and the systematic review confirm the need to conduct developmental research to fill the existing gap in evidence about the role of carer-focused interventions in practice.

This chapter describes the rationale, aims and methodology used to conduct Project 2, a mixed methods study evaluating the early implementation of CSNAT-I for carers of people with advanced cancer in a hospital discharge context. It includes a summary of the aims and methods of the three studies embedded within Project 2 – Two qualitative studies (2a and 2b) and one quantitative study (2c) . Detailed descriptions of the designs and methods of studies 2a, 2b and 2c are given in chapters 4, 5 and 6, respectively.

The components and processes of Project 2 and how it relates to the other parts of this doctoral research is diagrammed in Figure 8..

Figure 8. Research components and processes for Project 2



3.1 Rationale for developmental research

How an intervention will work in different contexts needs to be considered in the early or developmental stages of research. Such work is critical to decisions regarding progression of the research to subsequent stages, including testing the efficacy and sustainability of the proposed intervention and its eventual translation into everyday practice. (119) For this study, describing an intervention as working or not working refers to the extent to which people in the chosen setting engaged with the intervention and its elements. "Unpacking the black box" to see *why* an intervention works rather than *if* it works (116) is a critical step in determining whether the research can proceed to the stages of feasibility and efficacy testing, as recommended by MRC.(74) Understanding why an intervention works facilitates the selection of appropriate evaluation measures in subsequent research. This is an important part of complex intervention development and needs to occur each time a new or existing intervention is introduced to a new setting. (120)

Evidence shows that the implementation of a complex intervention like the CSNAT-I will transpire differently across different settings. (56, 62, 65, 121) Implementing the CSNAT-I into practice requires significant practice change at the individual and organisational level. (52, 121) Such practice change would involve clinicians including carer assessment and support as part of routine care alongside patient care, and organisations providing adequate support and resources to facilitate and sustain it. Qualitative studies of the implementation of the CSNAT-I in community and specialist palliative care settings (i.e., how the intervention was delivered) revealed several factors that have helped and hindered practice change with various degrees of success (see section 1.1.7).

To date, adoption of the CSNAT-I within the acute hospital setting has been rare (65) compared to the community and home-based settings. There is little published data characterising the carers receiving and clinicians delivering the CSNAT-I in this context, and limited discussion of how the CSNAT-I interacts with the hospital discharge context. Most available data relates to hospital nursing staff delivering the CSNAT-I, who questioned whether the CSNAT-I aligned with the organisational expectations of their clinical role (65)

In contrast, OTs view facilitating discharge and supporting patients and carers during this process as a core part of professional palliative care. (47) There is also broad recognition of the value of OT in discharge planning, with patients and carers viewing them as offering the practical help needed to feel prepared. (122) In addition, Rogers and colleagues(123) found that involvement of OTs in care is associated with reduced readmission rates for an older chronic disease population. These findings reinforce the need to explore an approach involving OTs implementing the CSNAT-I in real-world practice.

3.2 Aims and research questions for Project 2

Primary aim

To explore the implementation of an existing carer-focused intervention (CSNAT-I), administered by OTs, into routine practice to support carers of people with advanced cancer at hospital discharge.

Secondary aims

1. To understand people with advanced cancer and their carer's experiences and views on accepting [implementing] a carer-focused intervention into the hospital discharge context (Sub study 2a).
2. To understand clinician (occupational therapists') experiences with delivering carer-focused intervention before, during and after implementation (Sub study 2b).

3. To describe the behavioural and contextual factors that influenced clinician (occupational therapist) experience over time (Sub study 2b).
4. To examine how a carer-focused intervention is delivered and received when introduced into a real-life hospital discharge context (Sub study 2c).
5. To describe the key elements of a carer-focused intervention model and the requirements for successful implementation into hospital discharge context (synthesis of sub studies 2a, 2b and 2c).

The secondary aims were answered using analysis of three datasets collected within three sub studies:

- (2a) a qualitative study of patient and carer experiences, involving semi-structured interviews after CSNAT-I administration;
- (2b) – a longitudinal qualitative study of clinician experiences, conducted using focus groups and interviews throughout implementation; and
- (2c) – a quantitative study of intervention contents and processes occurring at patient, carer, clinician, and service levels, data collected during and after implementation using a project specific survey tool.

Detailed description of these studies and their findings can be found in chapters 4, 5 and 6.

3.3 Mixed methods

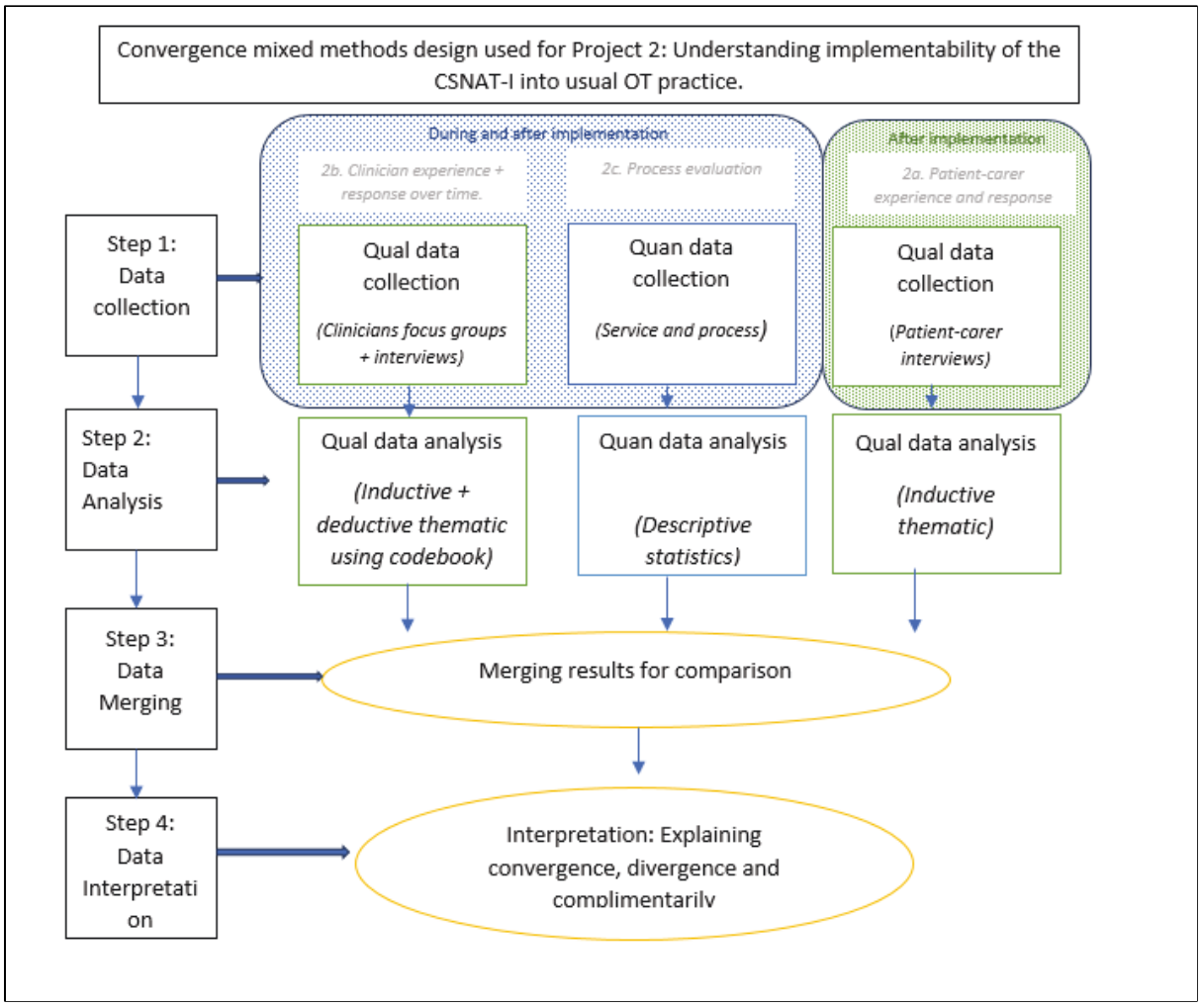
A convergent mixed methods design, underpinned by a pragmatic approach, was used in Project 2. Rationales for both methods are provided in the next section.

3.3.1 Rationale for and overview of convergent mixed methods design

A convergent mixed methods design was used to achieve the aims and answer the research questions for Project 2 (as detailed in Figure 9). Quantitative and qualitative data collection and analysis occurred separately, with the results compared to determine congruence or divergence. (124, 125)

Understanding complex intervention and factors influencing implementation warrants collection of data from multiple sources. Individual responses, behaviours and procedural and contextual elements can be explored qualitatively via individual experiences, and quantitatively via observed behaviours, and outcomes. Mixed methods allow for an integrated analysis and interpretation of qualitative and quantitative data and subsequently, an enhanced understanding of how an intervention may operate in a new context. (125, 126)

Figure 9. Convergent mixed methods design for Project 2



As illustrated in Figure 9, mixed methods data integration occurs in the study design, methods, interpretation and reporting phases, (127) represented by steps 1–4. A convergent design was chosen to allow for collection of quantitative and qualitative data

concurrently (step 1) and in parallel, with analysis and then integration occurring after the collection period had ended.

During the methods phase, a merging approach (step 2) was applied whereby each of the datasets was analysed separately (i.e., statistically and thematically), then brought together for a further merged analysis. Finally, during the interpretation and reporting phase, side-by-side integration (124) was applied (steps 3 and 4) using joint display tables to enable visual comparison of the qualitative and quantitative findings, identify shared themes and generate meta-inferences. (128, 129) Details and justification for the joint displays used are given in Section 7.3.

3.3.2 Rationale for the pragmatic approach and its relationship with mixed methods

The paradigm of pragmatism was adopted in the mixed methods study. A paradigm is a belief system that allows the researcher(s) to agree on the most important questions in their field and the most appropriate ways to answer them. (130) From a philosophical perspective, pragmatism relates to the central concept of "action"; (131) that is, how we think is linked to the actions we take. For example, we act based on what we think (or believe) will be the possible consequences of our actions, then use the outcomes to predict what could happen in similar scenarios. In addition, pragmatism posits that human actions cannot be separated from past experiences and the beliefs arising from them. (130, 131)

From a research perspective, pragmatism relates to the process of inquiry to guide the practical exploration and resolution of problems. (130) According to Dewey's Model of Inquiry, (132) inquiry is a form of experience that involves a decision-making process linked to actions and beliefs to resolve uncertainties. Steps involved in this process can be summarised as:

- identifying a situation as problematic;
- thinking about the difference it makes to define the problems one way or another;

- developing an action in response to the problem;
- evaluating actions in terms of possible consequences; and
- taking actions that are likely to resolve the situation.(130, 133)

Dewey also emphasises the importance of considering inquiry as a continuous rather than a linear process, whereby beliefs and actions are interacting towards reaching a solution. When we apply Dewey's model to research, the inquiry process involves addressing uncertainties—these take the form of research questions or problems we aim to solve.(130) Applying a pragmatic approach also involves researchers considering consequences of decisions they make in planning, conducting and evaluating their research. These decisions are also shaped by their beliefs and experiences and informed by the real-world constraints of limited time and resources in which the research is occurring. (130)

This iterative and flexible approach of pragmatism towards making practical decisions is favoured by mixed methods research designs, particularly in the areas of social sciences and health service research. (130, 133) Pragmatism and mixed methods share the pluralistic view of using as many sources as possible to obtain the best answers to the proposed research questions.(134) Creswell ((135), p.10) emphasises that: "Individual researchers have a freedom of choice. In this way, researchers are free to choose the methods, techniques and procedures of research that best meet their needs and purposes". Patton also argues that pragmatism and generic qualitative inquiry can be a theoretical framework that can be used for qualitative research "instead of framing the inquiry within an explicit theoretical, philosophical, epistemological or ontological tradition".((136), p.155)

A pragmatic approach was employed for this mixed methods study to inform the study purpose and process in the following ways:

- to understand individual experiences and responses to a complex intervention (the CSNAT-I) and to explore the influence of behavioural (beliefs and actions) and contextual factors;
- to provide the theoretical framework for the mixed methods approach, the analysis, and synthesis; and
- to offer an iterative approach to study conduct, in which decisions and changes could be made across data collection and analysis stages to accommodate real-world limitations including time, funding and workforce shortages.

3.4 Proposed intervention model and implementation process

The CSNAT-I was introduced into acute hospital settings in Australia (see Section 3.5.1 for specific sites) between 2020 and 2021, using an evidence-based implementation strategy and training toolkit developed by the UK-based CSNAT-I research team. (64, 137) Briefly, this involved planning for, executing and evaluating the implementation processes and outcomes related to adopting the CSNAT-I into a practice setting. Understanding the influence of specific implementation and behaviour change strategies (e.g., training, incentives, organisational change, feedback) is a critical part of ensuring a new intervention can be successfully embedded into usual care and sustained in the long term.(69) However, a detailed analysis of implementation strategies was outside the scope of this doctoral program; instead, the strategies are summarised in Appendix 4. Details of the proposed intervention model that was implemented into usual care are given below.

3.4.1 Who was appropriate to receive the CSNAT intervention in Project 2?

All carers of a person with advanced cancer and complex discharge needs were considered appropriate to participate in the CSNAT-I. A patient was considered to have complex discharge needs if the palliative care consult team and/or the treating occupational therapists was involved. Given the adaptive design of Project 2 criteria to determine if a carer was appropriate, evolved further to enhance acceptance (Appendix 4).

3.4.2 What was implemented?

The CSNAT intervention is a five-stage person-centred model led by carers and facilitated by occupational therapists to identify, prioritise, and meet needs related to caring for advanced cancer patients. Details about the elements of this intervention can be found at www.csnat.org. The five stages are:

1. Introduction of CSNAT-I (occupational therapist introduces the CSNAT-I to the carer during admission);
2. Carer consideration of needs (carer completes self-assessment and prioritises needs);
3. Assessment conversation (carer and occupational therapist discuss prioritised needs);
4. Shared action plan (carer and occupational therapist identify and follow up actions to meet needs); and
5. Shared review – (occupational therapist and carer schedule and complete shared review).

The CSNAT-I consists of a validated paper-based form (the “About Me” booklet) that includes 15 domains of need, criteria to rate and prioritise these needs, and a template to outline action plans to meet the needs. (138)Domains of need fall into two categories – support domains to enable the carer to care (e.g. “Do you need more support with understanding your relative’s illness?”) and support domains for carers themselves (e.g. “Do you need more support with having time for yourself in the day?”). The About Me booklet , became the record that carers kept, and occupational therapists summarised the paper in the electronic medical record. Refer to Appendix 5 for an example of the CSNAT-I stages and tool.

3.4.3 When and how was it implemented?

Occupational therapists who had completed the 2-hour online training module delivered the CSNAT-I as part of their usual care. The timing, outputs and delivery of the CSNAT-I stages were determined via occupational therapist feedback from training and discussion groups (as per the recommendations from the Training and Implementation Toolkit).(64) This feedback informed the development of a clinical guideline for each site. This guideline was modified iteratively based on findings from the data collected during the study (see Appendix 6). There was also a focus on commencing the CSNAT-I early in the admission and providing a second review after discharge as recommended in a feasibility study conducted in the acute discharge setting.(57)

3.5 Project 2: Study procedures

3.5.1 Settings and Timelines

The settings for the three studies in Project 2 were a 140-bed specialist cancer hospital (SCH) and a 571-bed acute general hospital (GH) in metropolitan Melbourne, Victoria, Australia. OTs comprised part of the interdisciplinary team servicing medical, surgical, haematology and specialist palliative care wards across both sites. At the time of the project, the OT workforce comprised both full-time and part-time employees and included nine occupational therapists at the cancer centre and approximately 80 occupational therapists at the acute hospital.

Project 2 was undertaken across 12 months, inclusive of a three-month pre-implementation planning stage (August to October 2020), an eight-month implementation stage (November 2020 – June 2021) and a four-month post-implementation stage (July 2021 – October 2021). Data collection and analysis for Project 2 occurred between November 2020 – October 2021.

3.5.2 Participants – eligibility

Patients and carers

Potential participants for Project 2 were patients with advanced cancer and their carers (patient–carer dyads) who received the CSNAT-I during their admission to one of two hospitals as part of routine care. Eligibility to receive the CSNAT-I is explained in section 3.4.

Carers were defined as "lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management"(139) – the definition used by the CSNAT-I development team.

Participation in Project 2 involved the following: access to patients' medical records, access to information recorded on the CSNAT-I and demographic details for carers, and (optional) interviews for patients and carers (study 2a). Both members of the dyad did not have to agree to participate in the interview to be deemed eligible for the study.

Inclusion and exclusion criteria

Patients and carers were eligible to participate if they were able to provide informed consent (based upon clinical judgement obtained from the treating team) and have sufficient English to complete the evaluation. Patients and carers were excluded if they did not meet the inclusion criteria.

Occupational therapists and carer consumers

Potential focus group participants were OTs who were trained to use the CSNAT-I in practice, clinical champions who had been selected by the lead researcher (CM), and two carer consumers. Carer consumers shared their lived experiences and influenced discussion and development of the CSNAT-I implementation processes and delivery model. Facilitators of the focus group included the lead researcher (CM), the research/project officer (AU), and a researcher/observer (CD) with expertise in focus group

research. Interview participants were OTs who had attended the focus groups. Eight of the 17 focus group participants also completed interviews. All eligible OT and consumer participants were required to have completed the online CSNAT-I training.

3.5.3 Ethical considerations

Approval was obtained from the ethics committee of the Peter MacCallum Cancer Centre, Royal Melbourne Hospital (HREC No. 66596) and University of Technology Sydney (ETH20-5542) (Appendix 7). The procedures used in this study adhered to the tenets of the Declaration of Helsinki. Informed written consent was obtained from all OTs, consumers, patient, and carer participants included in the study. Verbal consent was sought and obtained immediately prior to the focus groups and interviews. In the case of the patient being unable to consent, consent was obtained from their authorised representative. Additional details about the consent process are reported in chapters 4, 5 and 6.

3.5.4 Data collection

Qualitative data were collected in two studies (2a and 2b); using different methods as the research questions warranted it. Details on methods and findings are reported in Chapters 3 and 4. In study 2a, semi-structured interviews were held after the intervention to collect patient and carer experiences with, and views on, the acceptability of the CSNAT-I. In study 2b, OTs' experiences of and responses to the CSNAT over time were collected via a series of focus groups conducted before, during and after implementation, and via interviews after implementation. Quantitative data was collected in a third study (2c): prospective demographic and clinical data from the electronic medical record, and prospective service and process data, including participation and completion rates. Patient-related measures used in study 2a and 2c were the Australian Karnofsky Performance Scale (AKPS) (140) and Resource Utilisation Groups – Activities of Daily Living (RUG-ADL).(141) The features of these valid and reliable measures are summarised in Appendix 18. Briefly, the AKPS measures patient's overall performance status (a higher score equates to more independence and higher performance), whilst the RUG-ADL measures function according to levels of

assistance and resources needed when completing activities of daily living (a higher scores equates to more dependence and lower performance). (Appendix 18).

3.5.5 Data analysis

Data analysis occurred in three stages: thematic analyses of qualitative data in studies 2a and 2b, statistical analysis of the quantitative data in study 2c, and the integration of the results from all qualitative and quantitative datasets. Integration of the two forms of data was achieved using the "side-by-side" approach described in section 3.4.1; the results are presented and discussed in chapter 7.

Detailed descriptions of study design and methods employed for studies 2a, 2b and 2c are provided in chapters 4, 5 and 6.

3.6 Ensuring rigour in qualitative research

Considering and enhancing rigour was a critical part of ensuring the quality and contribution of the qualitative research. Researchers must maximise the validity and reliability of their study findings. Reliability refers to whether research findings are consistent and could be repeated in different circumstances, while validity refers to the accuracy of findings (i.e., are they capturing what is actually happening?) (142) In quantitative research, these constructs are readily assessed through objective measurement against rules and standards of the methods employed.(142) The reliability and validity of qualitative research is assessed by means of rigour or "trustworthiness". Criteria that can be applied to ensure rigour are introduced in this section, and processes employed for the qualitative studies are described in chapters 4 (Sections 4.2.4 & 4.2.5) and 5 (Sections 5.5.5).

Credibility refers to whether the research finding can be trusted. It relates to the degree of alignment between what participants are saying and the researchers' representation of these viewpoints. (143) Research is considered credible when it accurately reflects the diverse realities shared by participants. (143) This can be achieved through purposive

sampling of participants to reflect their unique experiences and contributions, a technique employed in both studies. Seeking clarification directly from participants on the accuracy of data collected is a key technique for gaining credibility.(142) Otherwise known as "member checking", this validation process involves participants checking or reviewing data collected for accuracy. In Project 2, all participants were offered a summary of interview and focus group transcripts to enable member checking (see sections 4.2.4 and 5.5.5).

Dependability refers to whether the findings are consistent or reliable and align with the data they came from.(142) Dependability can be gained through an auditing process that demonstrates the logic in the research process and the links between the data and reported findings. An audit trail should show evidence of steps taken throughout the research process and the reasoning behind theoretical, methodological and analytical choices . Auditing strategies used for this research are described in sections 4.2.4, 4.2.5 and 5.5.5. Examples include fieldnotes, thematic logs and coding strategies based on constructs from pre-existing frameworks.
Triangulation is the use of multiple sources to collate data and themes and expose multiple perspectives on reality.(136, 142) If these perspectives align, credibility and dependability will be enhanced. Three kinds of triangulation were used in this research: multiple data collection methods, multiple data sources (e.g., participant quotations), and researcher triangulation. Using researchers from different disciplines, across data collection and analysis process can enrich the research process.(144)

The role of the individual researcher's beliefs, knowledge and personal experiences in how data is shaped and interpreted must be considered in qualitative research. Reflexivity is the process of reflecting critically on the influence of the self as a researcher.(142) These influences were documented explicitly in the strengths and limitations of the qualitative studies to allow the reader to assess their relevance and value to the research and

enhance its credibility. The next section provides an overview of critical reflection on the roles of the researchers and the reflexive process (expanded upon in following chapters).

3.7 Roles of the researcher and research team

The primary researcher and PhD candidate (CM) conducted focus groups and interviews, data analyses and manuscript write-up. CM was a clinician researcher and clinical (OT) leader in oncology and palliative care at the specialist cancer hospital (SCH). CM was also research leader for the clinical occupational therapy team at the general hospital (GH). The studies in Project 2 were funded by a grant, giving additional impetus to produce rigorous high-quality work. Past experiences and knowledge of the intervention, patient/carer cohort, characteristics of the occupational therapists and hospital context were considered strengths for both CM and the assistant researcher (AU).(145)

The assistant researcher (AU) took fieldnotes during the interviews and focus groups and coordinated the consent process. She had research assistant and project management experience and held a senior clinician role in the main site and a master's in public health. AU reported directly to CM in the research team and the clinical team at the SCH. AU had also worked in a senior clinical role at the GH in the past so had pre-existing relationships with some of the participating occupational therapists and knowledge of the setting.
In the SCH, CM led the occupational therapy team in clinical, and research matters. AU was responsible for communicating and operationalising directions given by CM to the broader team, often in the absence of CM (CM worked part-time whereas AU worked full time). In addition to carrying out data collection and recruitment tasks for the research study, AU oversaw the implementation process occurring in the clinical setting. This included encouraging staff to use the CSNAT-I, with regular audits, incentives, and feedback loops.
In the GH, CM coordinated and facilitated research across a large cohort of 80 clinicians, and she held a consultative role, with no direct reports in this setting. This included

encouraging staff engagement in clinical research. She also had existing relationships with these clinicians from past research collaborations they had worked on. CM had also known some of the occupational therapy participants at the GH in past senior clinical roles where they had directly reported to her.

The relationship between the main researcher (CM) and the assistant researcher (AU) may have influenced AU's engagement with clinicians in research processes to encourage participation as well as and implementation as a commitment to successfully meet the study deliverables. This relationship may have also influenced how AU received feedback from staff and delivered feedback to CM. Specifically staff may have not felt comfortable to share negative feedback.

The researcher's personal assumptions, expectations and reactions to participants and data were recorded in fieldnotes during the research process, including positive and negative aspects.(145) Informal reflective exercises on similar themes occurred amongst the broader research team and with the original CSNAT-I developers, adding depth and validation to individual reflections and a better understanding of the impact of self-reflection on the findings.

3.8 Conclusion

This chapter described the theoretical approach, study design and methods employed for Project 2 – an exploration of the implementation of a carer-focused intervention into a hospital discharge context for carers of people with advanced cancer, delivered by OTs as part of routine care. Exploring how an existing intervention can be delivered into a new context requires a pragmatic mixed methods approach that uses multiple data sources to answer the research questions. This approach allowed procedural iterations as the study progressed to support the conduct of research in a real-life clinical setting.

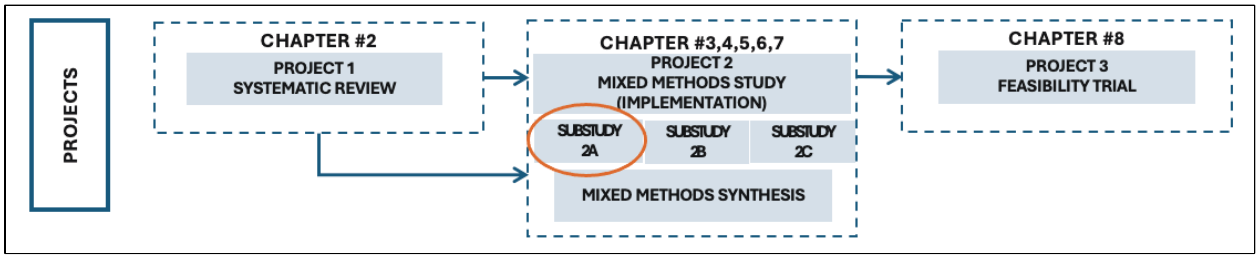
The next three chapters (4, 5 and 6) describe the design, methods and findings of two qualitative studies and one quantitative study. Synthesis and interpretation of these studies are reported in chapter 7, informed by the overarching framework applied to the doctoral program – the CTF.

Chapter 4. Project 2: study 2a (patient and carers' experience with the intervention)

Chapter 2 showed that carers are under-represented in interventions aimed at improving hospital-to-home transitions for people with advanced disease, and even more so in the advanced cancer setting. As explained in chapter 1, the CSNAT-I shows promise as a carer-focused intervention that could assist in hospital discharge for this patient–carer population. However, its implementation requires significant practice change, and major contextual and behavioural barriers to its success have been documented in the UK. Therefore, developmental work is required to understand how this type of complex intervention can work in an Australian acute oncology setting. This requirement underpinned Project 2 – a mixed methods sequential study with three components aiming to evaluating the implementation of the CSNAT-I into usual practice, at patient, carer, clinician and service levels. Study designs and methods for Project 2 were described in chapter 3.

Chapter 4 is the first of three chapters to report on the studies conducted as part of the overarching mixed methods Project 2. Specifically, chapter 4 reports on the qualitative study (2a) that aimed to understand patients' and carers' experiences with and views on the acceptability of the CSNAT-I being delivered by OTs in an acute oncology setting (see Figure 10). Findings from this study were integrated with those from studies 2b and 2c in Chapter 7 to address the main aim of exploring CSNAT-I implementation into usual care.

Figure 10.Research components and processes for sub study 2a: Patients' and carers' experience.



This chapter is based on an article published in 2023 (reference overleaf) in the Australian Journal of Occupational Therapy, a peer-reviewed journal with an impact factor of 1.8 and h-index of 53 (Appendix 8). This journal focuses on publishing evidence to influence policy, systems and OT practice locally and globally. The format of the article has been aligned with the rest of the thesis.

> **Marston C**, Morgan DD, Philip J, Agar MR. Experience and acceptability of a carer-focussed intervention in acute oncology settings: A qualitative study of people with advanced cancer and their carers. Australian Occupational Therapy Journal 2023 Oct;70(5):570-80.

4.1 Introduction

Carers of people with advanced cancer are critical to supporting patients moving from hospital to home. (11, 12) However, carers describe their needs being largely unmet whilst navigating distress and uncertainty (section 1.4).(33, 122, 146) There is growing recognition cancer carers need more support at international and national policy levels, but limited evidence of this in research and practice (Chapter 1, Section 1.6).(40, 41, 43) In most studies, the carer is overlooked or positioned as a patient resource during discharge rather than a recipient of care.(8, 147)

The Carer Support Needs Assessment Tool-Intervention (CSNAT-I) has proven effective in improving carer outcomes in palliative care.(55, 56, 58, 60) The CSNAT-I creates opportunity for carers to communicate and prioritise their needs, and to develop action plans with clinicians (Section 1.7). However there is limited evaluation of the CSNAT-I in the hospital context. (58, 137) To our knowledge, no studies have evaluated the lived experience of carers receiving the CSNAT-I in an acute oncology setting. Understanding lived experience from the lens of intervention acceptability, in this case a carer discharge intervention, is an important phase of complex intervention development.(74, 148)

This study sought to understand advanced cancer patient and carers' experiences with the CSNAT-I and views on acceptability in the hospital discharge context when delivered by occupational therapists. Acceptability was defined as the "extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experiential cognitive and emotional responses to the intervention".(148)

4.2 Study design

This study employed a qualitative design underpinned by a pragmatic and generic qualitative inquiry approach. This approach enables researchers to seek answers to practical questions that can inform actions, . and the freedom to choose what methods or procedures will work best(136) This study sought to understand carers' experiences of receiving an intervention in usual everyday practice; specifically, their views on acceptability i.e. how they thought it worked and how it made them feel. A pragmatic approach also enables decisions to be made during the research process within real world constraints.(136) Real world constraints can be defined as time and resource limitations related to conducting research in a natural clinical environment. Findings were mapped against the Theoretical Framework of Acceptability (TFA).(148) Consolidated criteria for reporting qualitative research (COREQ) guidelines guided reporting.(149) This study was part of an evaluation of a program of work whereby the CSNAT-I was implemented using the evidence-based toolkit (1) with other components of the evaluation occurring at health professional and service levels (Intervention model and Implementation strategy; Section 3.4).

4.2.1 Setting

Refer to section 3.5.1.

4.2.2 Participants

Refer to Chapter 3, section 3.5.2 for details. Briefly, participants were patients with advanced cancer and their carers (patient-carer dyad) who received the CSNAT-I during admission Determining carers suitability to receive the CSNAT-I was based on a local clinical pathway that was developed as part of the implementation strategy (Appendix 6). Both members of the dyad did not have to agree to participate in the interview to be deemed eligible in the overarching study. Of the fifty patient-carer dyads who consented for the main study, ten carers and two patients agreed to participate in interviews.

4.2.3 Sampling and recruitment

Patient-carer dyads were approached within the overarching study after being identified by treating occupational therapists. A researcher (AU) obtained consent during face-to-face or phone contact with eligible participants during hospital admission. Participation in the study involved: (1) Researcher access to medical records for patients; (2) access to information recorded on the CSNAT-I and demographic details for carers: and (3) and an optional interview for both patient and carers. (Chapter 3, section 3.5.2). Researchers (AU or CM) repeated verbal consent via phone prior to scheduled interview. Participants were purposively selected to obtain a variation and diversity in participants, specifically different cancer diagnoses, length of time caring and social situations. Opportunistic sampling technique was used, allowing the researcher to remain open to new circumstances unfolding during the research process e.g. participant availability; different context. (138). . For this pragmatic study, data saturation was limited to the level of analysis needed to answer the overarching research questions. This was reached for the main themes when new codes or themes supported the study findings.(8, 150)

4.2.4 Data collection

Data collection occurred between November 2020 to June 2021. Patient and carer semi-structured interviews were conducted via phone by CM within two weeks post hospital discharge. Semi-structured interviews elicit participant perspectives, meanings and

experiences. An interview guide is used to allow the researcher to address a specific topic, but also allows for conversation to flow and take unexpected directions.(142) For this research, interviews explored participant experiences and views on the purpose, benefits and drawbacks of the CSNAT-I. The interview schedule was based on past CSNAT-I qualitative studies and piloted with carer consumers (Appendix 9). The schedule consisted of open-ended and probing questions. Additional introductory questions were used after the first three interviews to provide more detail about the CSNAT-I e.g. you were provided with a green handout from the occupational therapist to take home. Interviews were audio-recorded and transcribed verbatim. Transcription summaries were given to participants for review. Interviews lasted between 12 and 43 minutes. Field notes were also recorded by CM.

4.2.5 Data analysis

Data was managed using NVivo software. Inductive thematic analysis was used to examine participants' experiences, thoughts and behaviours arising from the interviews and recorded field notes. Data analysis used an inductive thematic analysis approach as described by Kiger and Varpio.(151) This approach involves an adapted process outlined by Braun and Clarke:(152-154)

(1) Interviews (transcript and fieldnotes) were read and re-read individually and then as a whole to ensure familiarisation with data;

(2) Initial codes were identified and defined from three interviews and used to develop a coding manual. These codes were then applied to the entire data set. Additional notes were made regarding any potential patterns that may inform future theme generation. These two steps were conducted by two experienced qualitative researchers (CM, AU);

(3) Codes were analysed and organised into themes and an audit trail of theme development was maintained;

(4) Researcher triangulation with another two other researchers (MA, JP) ensured that themes reflected the data and focus of study; and

(5) Final theme and subthemes were constructed and interrelationships between themes articulated by CM and DM . TFA constructs and qualitative findings from other CSNAT-I studies were used to inform coding and early theme development. This was to align with timeline for project and responsiveness needed to identify and address any emerging issues along the way.

4.3 Findings

Demographic and clinical characteristics of interviewed participants are outlined in Table 6 and Appendix 10. Most carer participants were female, and ages ranged from twenty-seven to sixty-nine years. Partners and adult children made up most of the cohort. Time spent in caring role for eight carers ranged from three months to ten years, with two carers reporting “a few months” and “since diagnosis”.

Table 6. Participant demographics, study 2a

CARER (n=10)	
Gender	Female: 7; Male 3
Age	Range: 27 - 69
Relationship with patient	Spouse: 4, Adult Child: 4, Parent - 1 Friend - 1
PATIENT (n=2)	
Gender	Female: 1, Male: 1
Age	42; 69
Diagnosis	Glioblastoma, metastatic melanoma

Carers described their experience with the CSNAT-I in the context of preparing for the return home of person they were caring for. The following themes were constructed from the data: (1) Covered

everything, (2) Increased awareness of needs; and (3) Wrapped in care. Themes and subthemes are described below.

4.3.1 THEME 1: Covered everything

4.3.1.1 It centralised everything

Patients and carers described the CSNAT-I as a coordinated process which enabled identification of carer needs relating to discharge home and practical ways to address them. For most carers the process of identifying their needs using the "About Me" booklet was central to their experience. Carers often referred to the booklet as the "green form" [CP35] and viewed it as a valuable resource that assisted them in navigating the hospital discharge process. This carer appreciated how the booklet offered a starting point to accessing what was needed for discharge for his mother; and was also something he and other family members could refer back to:

> *"*...it was good that [name] provided that 'cause at least I'm able to centralize and go back and forth, OK this is how we're supposed to start.... *" [CP8]*

Another carer described how the booklet was instrumental in navigating their new role as a carer and how to prepare for the future:

> *"It helped me to understand what kind of thing I need 'cause this is the first situation we met and I've got no idea what kind of thing I need maybe in the future and the green form let us know everything we may need in the future." [CP35]*

One carer found it difficult to recall the "green form"; however, the process of needs assessment and support was still a central focus of their experience:

> *"Yeah, no I did understand the form. To be honest I can't remember exactly what it said.... So I...went home with the confidence that everything was gonna be good and we'll do as much as we can and, yeah, it was all available, oxygen, anything, any questions that we've had were answered." [CP21]*

4.3.1.2 Comprehensive way of working through needs

Most carer participants valued the structured approach around pre-determined domains to work through their specific needs, offering a smooth coordinated approach to an overwhelming situation described as a comprehensive process that "covered a lot" [CP21]. The pre-determined domains included in the "About Me" booklet were considered thorough and relevant; except for one carer [CP35] who suggested an additional section was needed to record support with ambulance insurance.

> *'I can't really think of anything else that you could put on there that's going to … 'cause it's really got everything, it did have, you know, whatever you needed. "[CP33]*
>
> *"…it was very thorough like to the point so I was happy with that…I was happy with the sentences because I've usually found the ones what was important to us." [CP8]*

The checklist format was described by one carer as a key feature that made the CSNAT process easy to understand and respond to:

> *"…I think the tool is very good, I think anyone would probably like it as well 'cause it helps a lot. You know, you just tick what you know already or if you need anything else you just mark it down, it's pretty straightforward so it's really helpful… I have an admin job so I'm pretty into ticking boxes…" [CPRMH8]*

One carer found the comprehensive nature of the CSNAT-I initially overwhelming but useful over time:

> *"Overwhelmed – with everything that is happening so it was good to have time to reflect on. I sat down with coffee and breakfast next day to complete; then went through again with (AD) – and realised that some things had been addressed or changed." [CP20]*

In contrast, the process of how these steps were enacted were not always clear to the patients and carers; particularly the process after discharge. Carers recalled this process in different ways, ranging from not knowing who should contact who, to having

contact with various different health professionals involved in their care. This carer had pre-established relationships with the lung cancer nurse:

"About two weeks ago he was struggling big time and I rang Mary, although I didn't speak to her I spoke to another person there and they were able to fix my problem actually which was good and Mary sent me a message saying, you know, what she thought I needed to do as well. So I feel very supported." [CP21]

4.3.2 THEME 2: Increased awareness of care needs

4.3.2.1 Self awareness

The CSNAT-I facilitated an increased self-awareness of carers' own current and future care needs and priorities but also improved occupational therapists' awareness of carer needs. This was mostly centred around the practical needs of caring, such as "what I need to be able to care" (CP11) and "making sure you're doing things the right way" [CP11] to support both the carer and the patient after hospital discharge. Needs included help with fast tracking funding applications for additional care, obtaining equipment and knowing who to contact for assistance in the future. One carer, new to the role, explained how the CSNAT-I provided them with the information and knowledge needed to navigate what was to come:

> *"I think it just highlights, you know, to people what's available and what's possible and, you know, I think it's a knowledge thing, just to know what's there and what could help you and things like that." [CP8]*

The CSNAT-I also alerted two carers to consider and attend to their own personal needs, at a time when these were often not prioritised:

> *"Make me stop and think – how I am going to manage myself…. Thinking of her needs not mine; financial, own needs." [CP20]*

This awareness could also be overwhelming. The CSNAT-I was confronting for one carer, whose husband was rapidly deteriorating, with the reality of the situation "*It just makes everything real*" [CP11]. Another carer new to caring for her adult daughter, needed time to

adjust and understand what was needed and valued the support of the occupational therapist during this adjustment.

> *"Sitting down with occupational therapy was better than doing it on your own – to help you navigate." [CP20]*

4.3.2.2: Validation

Working through the care needs was validating for most participants. This occurred by confirming that there was help available that they wouldn't otherwise know about; and a way to acquire knowledge or information.

> *"But…it had sections on there that made you think about other options that we may not have known of because…we've never been in that situation. So… you can actually get someone to help you at home or help you, [with]… the garden or whatever it may be like, you know, extra help,… that sort of thing,…and assistance…some of the things [I] probably wouldn't have known of, so that would be a big benefit…" [CP2])*
>
> *"Oh no it's always useful to know what's available too to help you should you need. I mean you can't ask for help if you don't know what's available." [CP11]*

In other cases, becoming aware of their own capability in responding to needs was affirming . For some carers, using the CSNAT-I verified that they were managing aspects of their caring role more proficiently than they thought.

> *"Validating things I thought I wasn't sure of; that I actually was." [CP20]*

4.3.2.3 Needs don't stop

Several carers spoke of their awareness of their changing needs, mostly once they returned home. One carer realised that the hospital bed that she didn't think was necessary was actually *"really beneficial"* [CP11]. Another carer witnessed her father become more dependent once he was home and felt the CSNAT-I was needed beyond hospital discharge; stating "*Needs don't stop after going home…" [CP21].*

One carer participant spoke of how some needs became less important over time:

> *"There was problems- … on the form that were relevant and that became irrelevant within a day or two." [CP11]*

4.3.2.4 Helping others understand what we need

Carers reported that working through the CSNAT-I with occupational therapists, enabled occupational therapists to gain immediate insights into what was needed, and carers to better understood what areas the therapists were likely to be able to help them with.

> *"I think it is beneficial to them so they understand, you know, where we come from as well and they can see what we need and what they can assist on too, so I think it helps?…" [CP8RMH]*

One patient recognised the benefit of the CSNAT-I for the OT and their work structure*:*

> *"I guess it's to help the OT staff learning ahead and give them an idea about what to do next day". [PP5]*

4.3.3 THEME 3: Wrapped up in care

4.3.3.1 Feeling cared for

Increased awareness of care needs triggered emotional responses for all carers. They described feeling more supported, cared for, and reassured that they would be able to cope. Some participants reported a noticeable shift from feeling "panic" [CP33] to feeling more prepared for caring for their loved one at home. Knowing there was someone to contact was reassuring.

> *"We were very nervous bringing him home. It…was comforting to know that they were there and ringing and making sure that everything is going well… I was very pleased." [CP33]*

One carer described how the CSNAT-I may have also elicited a sense of reassurance and comfort for the patient – knowing that the carer was being cared for:

Yeah I think it would definitely benefit the patient as well 'cause, you know, they're rest assured that the carer is getting that backup..., so they don't get stressed like everything's on that carer obviously, and they're making sure that the carer gets assistance at the same time as well as they're getting assistance too, so kind of like a balance..." [CP8RMH]

4.3.3.2 Receiving support from all sides

Carers described feeling surrounded in this extra care that extended across hospital and home. Care ranged from systematically working through the "green form", access to required equipment they needed so "they wouldn't injure themselves" [CP11], to the support from the community-based palliative care nurses provided once they got home:

"...It's been really quite good because we had the [home nurses]... that brought all the tools that we need for [unclear]... the chair, the bed, and they were... excellent. So we didn't really need to panic on how are we going to, ...move him around the house and take him to the toilet....It was really quite easy because.. they came, set it all up for me...." [CP33]

Carers described a sense of relief in knowing that there were people they could contact if they had questions and could help them with the unexpected. This support contributed to a sense that they were not alone in preparing for the return home of their loved one.

"It's a good thing to happen because it's two things for us, it's like firstly the empathy and communication that you're following something through to making sure that everything's OK in one end, and then from our perspective it's an opportunity also to ask questions that we forgot to ask the hospital, or maybe if my mum is a bit unwell maybe they can provide us with other guidelines. So it works both ways." [CP8]

4.3.3.3 Care coordination

Carers described the experiences of support from a coordinated team across hospital and community rather than a specific person. Most carers could specify the nature of the support - *"bringing all the tools – the chair, the bed..."* [CP33] but only a few accurately

identified the specific discipline of the person providing care. Although individual disciplines of team members were rarely identified, there was a shared sense of appreciation and comfort in knowing that the support was available and accessible.

> *"I wouldn't put that down as a negative that you had multiple calls because at least you know that's checking in, at least if there was an issue then you've got these people calling and they can be like OK, that's OK, we'll help you or we'll do this or whatever, you know. But if no one calls then you'd be like oh my gosh, we've just left and they've just left us with nothing sort of thing." [CP33]*

However, one carer preferred to have one key contact person:

> *"Cause one of the things I said it's too much information overload. You nearly need one person, again too many people." [CP33]*

4.4 Discussion

This is the first study to examine carers' experiences of using the CSNAT-I delivered by occupational therapists in an acute oncology setting. Overall carers described the CSNAT-I positively, experienced as a comprehensive process that increased awareness of care needs and generated responses to practical aspects of caring, resulting in them feeling more supported and surrounded in care as they moved from hospital and home.

4.4.1 Working through the practical needs

Our findings provide new evidence highlighting how carers address their needs in the hospital discharge context. A prominent benefit was the process of working through needs related to practical aspects of caring. The function of the CSNAT-I in systematically identifying and addressing carers' needs has also been reported when evaluated in other clinical settings, including home based community palliative care settings(53, 60) and carers of people with motor neurone disease.(61) Like this study, other carers have recalled this needs assessment process as making them feel listened to, validated and more confident in the caring role.(60, 61)

A changing and uncertain environment demands that carers adapt quickly to new or higher caring responsibilities when their loved one goes home.(19, 155) Carers spoke of the CSNAT-I primarily addressing their practical needs with less reference to their emotional needs. This is not surprising in the context of discharge where obtaining information and practical resources to carry out the caring role is at the forefront of carers' minds; and recognised as key domain of unmet need.(33, 58) Carer prioritisation of practical over emotional needs has also been reported in a trial testing of an outreach model that used the CSNAT –I to support carers of older people following discharge from a short stay medical unit.(33, 58) Carers most prioritised knowing who to contact, what to expect in the future and how access to practical help in the home. The practice scope of the occupational therapist may have also influenced carers' focus on the practical aspects of caring. Facilitating discharge is core practice of occupational therapists working in oncology and palliative care (47) and carers have viewed occupational therapists as providers of practical solutions in other palliative care research.(19) That said, carers still acknowledged how the CSNAT-I created opportunities to address emotional needs (e.g., asking carers if they needed support with their own feelings, worries or spiritual concerns). This suggests that even in a discharge-focused context, the comprehensive nature of the CSNAT-I and its ability to reach across a broad range of needs is still favoured by carers.

4.4.2 Embedded within the discharge process

Our study has provided insights into positioning this intervention in interdisciplinary care. Carers viewed the CSNAT-I as part of the usual discharge process, rather than a separate, exclusive model of care. This was evident in two ways. Firstly, participants perceived the CSNAT-I as part of a bundle of care that was not specific to one discipline. It was a supportive model where they could determine what was needed, what options they had for support in the future, obtain support from "all sides", and across hospital and home. Carers did not link their experience exclusively to the occupational therapist. Instead, they perceived their experience involving different people and across various time points. Secondly, carers viewed themselves as active recipients of care within the discharge planning model. Carer descriptions of feeling surrounded by care, and actively addressing

their own needs as well as the patients; suggests that they were engaging as care recipients. Other qualitative studies have suggested inclusion of the CSNAT-I in the discharge planning process is likely to be well received(58, 137) but our study show this to be the case.

Carers have expressed a need to be included and positioned as partners in the discharge planning process (114) – but unfortunately often feel unrecognised and excluded.(33, 156) For carers to fulfil their caring role and prevent breakdown of care once their loved one returns home, they need to be engaged with multi-disciplinary, multi-component interventions that reach across hospital and home and facilitate optimal information provision, care coordination and communication.(33, 156) Carers' experiences reported in our study align with these characteristics; and build on the existing evidence that the CSNAT-I can contribute to better hospital-to-home transitions for carers and the people they care for.

Our study also builds on the notion that carers wish to receive further support beyond discharge. Carers' appreciation and positive response to follow up after discharge supports the evidence that the final review stage of the CSNAT-I is best completed once the patient has returned home to ensure needs have been addressed.(57) Some needs may not be identified by carers prior to the patient's discharge home, especially if the caring role is new or the nature and complexity of care have changed. Findings demonstrated that carers were looking beyond that initial transition period and sought follow up of new and outstanding needs via the CSNAT-I – aware that needs would continue to arise, and more support may be needed. This could also include more support for their emotional needs once the person is home from hospital. These findings echo other studies which demonstrate that access to ongoing support and a review of their needs as carers is important to carers but often remains unclear or unaddressed at both patient and service levels.(57) The CSNAT-I developers recommend that the CSNAT-I should be repeated at key points in the care trajectory such as following discharge.

However, these key points are dependent on the context in which the CSNAT-I is delivered in and the preference of the carer's needs.(53, 59) For example, there may be key points after discharge where carers' emotional needs become more of a focus.

4.5 Strengths and limitations

The primary investigator had a dual role as the clinical lead for the service and interviewer with the potential to influence the collection and interpretation of the data. This was managed by rigorous discussion with experienced qualitative researchers outside the clinical service. These discussions along with field notes and reflections about their clinical role also assisted with the overall analysis and confirmation of themes (see section 3.5.6). This dual role also served to benefit the analysis by offering a real life understanding of meanings and patterns generated from the data i.e., how the intervention worked in this context and potential clinical implications. The sample may have not included carers who were experiencing more complex situations, as discharge planning can be a distressing and overwhelming time for carers. The lack of critical or negative feedback also potentially was a limitation, as carers may have felt less able to express these views during care transition, particularly as this was conducted during the COVID 19 pandemic. The researcher and assistant researchers were occupational therapists, however they did not deliver the CSNAT-I at the time of this study to any of the patient-carer participants. The research team's roles in clinical care may have influenced participants willingness to openly criticise the intervention. Nevertheless, how to capture data from this specific group of carers is still an important consideration for future research.

4.6 Implications for clinical practice and research

This study has highlighted the adaptability of the CSNAT-I and its capacity for implementation in different contexts with similar outcomes – that is, to generate more support for carers as they navigated the hospital discharge process.

The CSNAT-I can be integrated into existing discharge models and delivered by several clinicians in the multi-disciplinary team. Its natural synergy with discharge planning helps to address known implementation challenges by providing support to carers within their

existing scope of practice and offer efficiencies by embedding it into existing models and supporting more economical adoption into practice. At a practice and policy level carers need to be considered “receivers” of care and support, not just providers of care for someone else.

Further research is needed to further examine the drivers for carers to accept and engage with interventions. Acceptability relies on the cognitive and emotional response of people receiving and delivering the intervention (148)– i.e., “if it feels good, I will use it”.

4.7 Consent to participate

Informed written consent was obtained from all patient and carer participants included in the study. Verbal consent was reported immediately prior to the interview. In the case of the patient being unable to consent, consent was obtained from the authorised representative.

4.8 Conclusion/summary

This study demonstrated that carers like receiving the CSNAT-I and favour the individualised support it offers across hospital and home and as part of the discharge planning process. It can also be delivered by occupational therapists and other clinicians with a natural synergy to discharge planning. These findings start to build evidence of what may be the key features of a carer-focused intervention that is most likely to be accepted by carers in this setting. In addition, the findings informed development and testing of a modified delivery model of the CSNAT-I in the feasibility trial reported in Chapter 7.

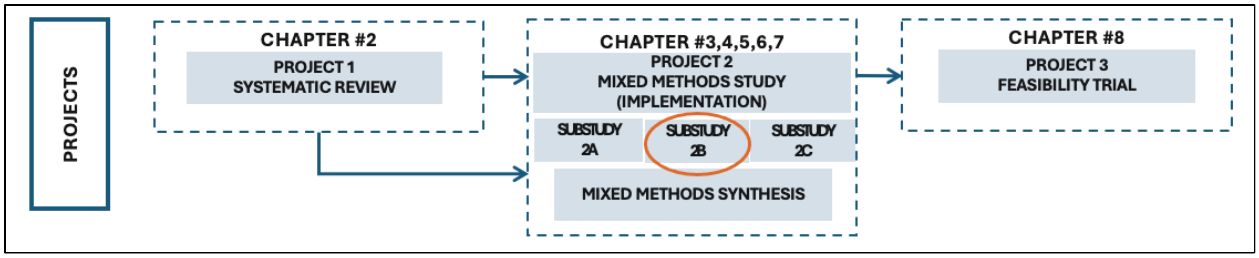
The next three chapters build on this evidence by reporting on occupational therapists’ experiences over time (Chapter 5), patients’, carers’ and occupational therapists’ adherence and interaction with the CSNAT-I (Chapter 6), and the overall success of the implementation and influencing factors (Chapter 7).

Chapter 5. Project 2: study 2b (qualitative study of clinician experience)

Chapter 5 is the third chapter reporting on a mixed methods study of how the CSNAT-I can be implemented into usual OT practice to assist carers in the process of hospital discharge of people with advanced cancer. This chapter describes the findings of study 2b, which was designed to understand OTs' experiences with delivering the CSNAT-I as part of routine practice over time.

Chapter 4 showed that patients and carers accepted the CSNAT-I as part of usual discharge planning processes delivered by occupational therapists. Use of the CSNAT-I also increased awareness and support for carers across hospital and home. These positive findings implied that occupational therapists are well positioned to deliver the CSNAT-I. However, successfully embedding the CSNAT-I into routine care is dependent on clinicians and organisations shifting towards a more carer-focused practice model (137) and maintaining it in the long term. Therefore, it was critical that this mixed methods study examined occupational therapists' individual experience and behavioural responses to adopting the CSNAT-I into routine care and how this occurs over time. This data was collected in study 2b using a series of focus groups (n=6) before, during and after implementation, followed by interviews (n=10) and interviews with occupational therapists working across two acute oncology settings (see Figure 11). The focus groups and interview data worked together to provide an in –depth and comprehensive view of clinicians experiences both during after CSNAT-I implementation. Study design, methods and results are reported and discussed in this chapter and then integrated in chapter 7 with the findings of studies 2a and 2c to describe the overall implementation of the CSNAT-I and the factors that contributed to it.

Figure 11. Research components and processes for Sub study 2c: Occupational Therapists' experiences


PROJECTS
CHAPTER #2
PROJECT 1
SYSTEMATIC REVIEW
CHAPTER #3,4,5,6,7
PROJECT 2
MIXED METHODS STUDY
(IMPLEMENTATION)
SUBSTUDY 2A
SUBSTUDY 2B
SUBSTUDY 2C
MIXED METHODS SYNTHESIS
CHAPTER #8
PROJECT 3
FEASIBILITY TRIAL

Occupational therapists who deliver the CSNAT-I will be required to undergo significant practice change – shifting their focus towards consideration of carers' needs alongside patients' needs (see section 1.7). (52, 57, 59, 60) To date, there are no published studies of OTs' use of the CSNAT-I in practice. An important first step to understanding how well an intervention can be implemented is to evaluate the experience of the people delivering the intervention, and to identify factors that may be helping or hindering this practice change.(119)

5.1 Aims

- To understand occupational therapists' experiences in delivering a carer-focused intervention before, during and after implementation into usual practice
- To describe the behavioural and contextual factors that influenced occupational therapist experience over time.

5.2 Research questions

- What were the occupational therapists' experiences with implementation of the CSNAT-I before, during and after implementation?
- What were the perceived factors influencing clinician behaviour or practice change over time?

5.3 Study design

5.3.1 Theoretical framework

A longitudinal qualitative design, underpinned by a pragmatic approach, was employed to achieve the study's aims. Pragmatism informs qualitative inquiry by enabling researchers to seek answers to practical questions that can inform actions in real-life settings.(136) This study sought to understand occupational therapists' experiences of embedding a new intervention into their everyday practice and how behavioural and contextual factors influenced this over time. A pragmatic approach also allowed for practical decisions to be made to best answer the research question.(136) Specifically, this related to applying

behavioural change strategies to overcome implementation barriers as they arose. Data was collected via a series of focus groups before, during and after implementation, and individual interviews in later stages of implementation.

The Theoretical Domains Framework (TDF) informed the data collection and thematic analysis of data for this study(157) and provided a suitable lens to explain the contextual and behavioural factors influencing practice change. The TDF is a determinant framework used in implementation science research to explain the influence of individual determinants (e.g., clinician knowledge and beliefs) on implementation outcomes (e.g., acceptability).(158) The TDF is validated and consists of 14 domains that can be used to understand the contextual and behavioural factors influencing clinician practice change.(159) The TDF was used to develop an initial coding framework for use in analysis and early theme development. Consolidated criteria for reporting qualitative research (COREQ) guidelines were followed.(149)

This study ran parallel to an implementation process using the evidence-based CSNAT-I implementation and training toolkit.(64) The processes used are reported in Appendix 4. The focus groups served a dual purpose across this program of work: to support decisions related to the development of a proposed delivery model for the CSNAT-I that was relevant to the setting, and to collect data to inform evaluation of the implementation process and occupational therapists' lived experiences. Focus group data also informed iterative modifications to the implementation process to improve acceptability and potential for practice change.

5.3.2 Sampling and recruitment

Potentially eligible occupational therapists were identified by clinical champions, then approached by the researchers. Purposive sampling was used to select participants for focus groups across the early, mid-way and late implementation periods of the CSNAT-I, and for individual interviews after CSNAT-I implementation. Senior occupational therapists/team leaders were appointed as clinical champions at each site as

recommended in the evidence-based implementation and training toolkit .(64) All occupational therapists completed the online training. Invitations to participate in the focus groups and interviews were sent via email along with written information and consent forms. Verbal consent for the interview was obtained at the final focus group session and confirmed via a follow-up email. Recruitment ceased when data saturation was achieved. For this pragmatic study, data saturation was limited to the level of analysis needed to address the aims for sub study 2b . This was reached for the main themes when new codes or themes informed the study. (150)

5.3.3 Data collection

Data collection occurred between November 2020 and June 2021 (during the COVID-19 pandemic). Focus groups and interviews were used to achieve the research aims (see section 5.1). These allowed researchers to explore the real-world experience of occupational therapists using the CSNAT-I in everyday practice and evaluate what helped or hindered their use of the CSNAT -I.(160) Focus groups facilitated rapid, in-depth exploration of participants' experiences and promoted interactive discussion.(138) Occupational therapists with varying levels of expertise contributed diverse perspectives on the shared use of the CSNAT-I. Focus group data informed the development of a CSNAT-I delivery model for each setting, iterative modifications to the proposed model, and the evaluation of the implementation process and occupational therapists' lived experiences. Online focus groups were conducted with clinicians (occupational therapists). The primary researcher (CM) was the moderator for the focus groups to guide the collection of comprehensive information and active engagement in discussion by the participants.

The focus group guide (Appendix 11) was based upon the Implementation Toolkit) and relevant constructs of the TDF (161) to allow exploration of behavioural factors that may have helped or hindered implementation. Focus group questions were reviewed by occupational therapist, consumer beforehand and minor changes made to language,

explanations of the CSNAT. The first focus group was observed by a co-design expert who recommended the ninety- minute session be split into two sessions to avoid participants' fatiguing. Furthermore, the embedded training content was moved onto an online platform and to maintain an exploratory approach to data collection. Fieldnotes were documented by both researchers (CM and AU) during and after the sessions. Each focus group was captured via audio-recording and transcribed word-for-word. A summary of responses provided during the focus group was sent to group members for member checking.

Semi-structured interviews were conducted both face-to-face and online across both sites in the late implementation stage of the project. The interview guide (Appendix 12) was informed by past CSNAT-I implementation studies(52, 137) and relevant TDF (161) constructs, earlier focus group data and quantitative data (collected prospectively as part of the larger mixed methods study). Interviews guide included open-ended questions and probes to elicit responses that centred around therapists' experiences with using the CSNAT-I and adopting into their usual practice. Interviews were conducted by the primary researcher (CM), audio-recorded and transcribed. CM conducted interviews as part of her PhD, using her prior knowledge and focus group data to explore key issues in depth. Fieldnotes were taken during the interviews. A summary of the transcript was returned to each participant for member checking prior to data analysis.

5.3.4 Data analysis

Data were managed using NVivo software.(162) Inductive thematic analysis using a codebook approach (163, 164) was employed to examine data arising from the focus groups, interviews and field notes. A codebook approach allowed for efficient charting of the developing analysis, and early theme development that aligned with the timelines for the project. A structured coding framework based on relevant constructs from the TDF(161) was used for initial coding and theme development, as well as inductive engagement with the data through the process to refine and construct final themes (Appendix 13).(163) Both focus group and interview data were mapped against the TDF. A step-by-step process was

undertaken based on guidelines for analysis of data related to implementation problems, as outlined below.

Clinician focus group data analysis procedure (adapted from Atkins(159))

1. Two researchers (AU and CM) independently read and re-read datasets.
2. The coding strategy was developed (based on TDF constructs) from review of independent coding of first transcript by AU and CM.
3. This coding strategy was applied to independent analysis of second transcript and AU and CM reviewed alignment.
4. AU and CM completed independent coding for the second transcript and reviewed alignment. Consensus was reached via discussion and modifications to coding strategy.
5. Remaining focus groups were coded independently but peer-checked and the coding strategy adapted as required.
6. CM generated initial themes.
7. MA, DM and JP checked and revised themes with CM.
8. Themes were refined and finalised and descriptions generated. Steps 6 and 7 were repeated as required.

After the first and second set of focus groups, additional steps occurred concurrently to identify barriers to behaviour change and generate and apply behavioural change strategies across the implementation period. These strategies are summarised in Appendix 5.

Analysis of interviews followed the same 8-step process but was conducted separately from the focus groups. Researchers examined each data set, by comparing constructed themes. The relationship between these data sets is described in the results section.

5.4 Research team and reflexivity

The primary researcher and PhD candidate (CM) conducted focus groups and interviews. As an experienced clinician researcher and clinical (OT) leader in oncology and palliative care at the SCH and research lead for the GH, CM was subject to several potential biases in data collection and analysis. This included CMs personal and professional reasons for wanting the study to succeed (i.e. to achieve her doctoral degree, fulfill grant deliverables), and the power relationship between CM and occupational therapist participants. This potentially influenced occupational therapist participants' decisions to participate (i.e., because a senior staff member asked them to) and to give overly positive responses to be supportive of the project. Moreover, participants may have felt like they did not have the freedom to choose to participate or not. During data analysis, the researchers may have leaned towards themes that supported the success of the study, specifically the uptake of the intervention by the OTs into their practice, and helped to create conclusions about the two sites and participants.

A reflexive approach was incorporated into the data collection and analysis to identify and overcome some of these biases. (142) This included fieldnotes documenting personal experiences and reactions to responses received in focus groups, interviews and stages of analysis. In addition, fieldnotes on emerging themes were documented and discussed with the research team, informing ongoing revisions to the interview schedule. Validation was also sought by seeking input into data collection and analysis process from supervisors with non-OT backgrounds, members of the steering committee for the implementation part of the project, including carer consumer representatives., and the original CSNAT-I developers – Professor Gunne Grande and Dr Gail Ewing.

As noted in chapter 3, the assistant researcher (AU) took fieldnotes during the interviews and focus groups and coordinated the consent process. AU had research assistant and project management experience and a master's degree in public health, and held a senior occupational therapist role in the SCH. AU reported directly to CM in the research team and the clinical team, which may have influenced her approach to engaging other occupational therapists in the consent process and a desire for the project to be successful. Rigorous discussion and regular supervision sessions between CM and AU allowed for further reflections and awareness of potential influences on the outcomes for this project.

5.5 Results

Six focus groups were conducted across the project, two groups at each stage (before, during and after implementation), representing each hospital setting. Participant attendance and characteristics are summarised in Table 7. Ten interviews were conducted with OTs, three from the GH and the remaining seven from the SCH. Focus groups lasted between 22 and 71 minutes, and interviews from 13 to 34 minutes. The first focus group conducted with participants from the SCH was broken into two parts (based on feedback from a co-design expert observing the process) to reduce participant fatigue.

Four themes were constructed from the data, representing participants' experiences and behavioural responses to adopting the CSNAT-I into their practice (Figure 12). The three themes "Patients used as conduits to carers' needs", "How well do I meet carers' needs?" and "Looking entry points to approach carers" represented the longitudinal changes in participants' clinical practice in their work with carers and how well they believed they did this before and after adopting the CSNAT-I. The fourth theme, "Fitting the CSNAT-I into my practice", was an overarching theme and represented what participants did to modify their behaviour or the intervention to fit the CSNAT-I into their everyday practice. The interaction between these themes is illustrated in Figure 12 and described in the following section.

5.5.1 Theme 1: Patients used as conduits to carers' needs

A recurrent theme was participants describing carers as inherently linked to patients. OTs responded to carers' concerns primarily to facilitate meeting patients' needs. Participants described carers as the patients' "extra limb" (Focus Group 1, SCH) that needed to be considered in the process of assessment and intervening. While doing so was believed to achieve better care for the patient upon their return home, the carer was viewed as a resource rather than a recipient of care.

> *Every hospital would probably regard the carer as part of the team, they're an intrinsic part of how we treat the patient and what happens to the patient during and after their hospital stays. (Focus Group 1, GH)*

However, one focus group participant expressed concern at focusing on carer needs.

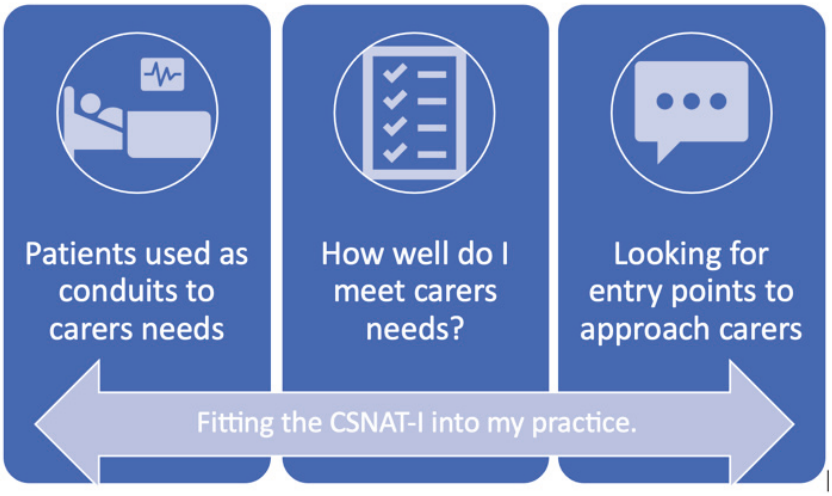
> *I would be a bit hesitant [how] far you go with the carers' needs as well. I mean they aren't our patient. (Focus Group 1, SCH)*

Table 7. Participant information and involvement

Hospital	ID	Level of expertise	Online Training 1	Online Training 2	Focus Group	Interview
SCH						
	COT1	Grade 2	Yes	Yes	1,2	Yes
	COT2	Grade 2	Yes	Yes	1,2,3	Yes
	COT3	Grade 2	Yes	Yes	1,2,3	Yes
	COT4	Grade 2	Yes		1	
	COT5	Grade 2	Yes		1,2,3	Yes
	COT6	Grade 1	Yes		1	
	COT7	Grade 2	Yes		1,2	Yes
	COT8	Grade 1	Yes		3	Yes
	COT9	Grade 2	Yes			Yes
GH						
	AOT1	Grade 2	Yes	Yes	1,2	
	AOT2	Grade 3	Yes	Yes	1,2,3	Yes
	AOT3	Grade 3	Yes			
	AOT4	Grade 3	Yes		1,2	
	AOT5	Grade 2	Yes		1,2,3	Yes
	AOT6	Grade 3	Yes	Yes	1,3	Yes
	AOT7	Grade 3	Yes		1	
	AOT8	Grade 1	Yes		1,2	
	AOT9	Grade 1	Yes		1	
	AOT10	Grade 2	Yes		1	
Consumers	C1		Yes	Yes	1,2	
	C2		Yes	Yes	1,2	

Levels of experience: Grade 1= ≤ 2 years, Grade 2 = ≤6 years, Grade 3 = ≥ 7 years

Figure 12. Themes representing occupational therapists' experiences and behavioural responses to using the CSNAT-I in usual discharge planning practices



Several participants reported that, over time, using the CSNAT-I enabled them to shift from working with carers to meet patient needs towards working more directly with carers and their individual needs in the process of discharge planning. This was evident for participants across both settings.

> *I think before the CSNAT I think my mind automatically went to carer training, …Where I think this just sort of opens it up more, it's not just "can the carer look after that person?" (AOT5)*
>
> *It's quite a holistic approach where we've been able to touch base with the carer more, or support person and actually taking them aside to find out… their agenda and what their support needs are versus us leading our own. (COT2)*

One experienced participant reflected that she had always seen patients and carers as equal recipients of care:

> *Carer and client are both clients – [I have] always had that approach. (COT7)*

5.5.2 Theme 2: Looking for entry points to approach carers

Participants described a process of looking for entry points or opportunities to approach carers. Determining the right time, place, and clinical context in which to engage with

carers was a routine part of their practice that continued throughout their use of the CSNAT-I and how they adapted to this practice change.

For most participants, the discharge planning context offered guidance about when and how they could connect with carers. There was a sense of confidence in working with carers when there was a clear plan for the person to be discharged home from hospital. The discharge context gave participants an opportunity to start talking about the needs of carers; this carried over to their use of the CSNAT-I. Participants actively looked for patients with planned discharges home to inform their decision about whether to use the CSNAT-I or not.

> *...when you're going into doing discharge planning with a patient without the CSNAT tool... you never know what you're...going to walk into, and ... the carers might be in different stages, some of them might be in more denial, might not be prepared to have those conversations, and even before the tool trying to get that information out of patients was really hard... (COT3)*

While some participants positioned the CSNAT-I as a discharge planning tool, others recognised that it may help them to meet carers' needs at multiple points in care. Sensitivity and judgement were required to determine appropriate times to introduce and when to follow up. One participant described this as "*keeping an eye out for the sensitive moments"* [COT2]. In contrast, consumer participants wanted to be approached as early as possible.

Establishing rapport with the carer was also considered a way of determining the right time to approach carers. Knowing a carer's situation made it easier for participants to recognise when they may be reaching crisis point. In other instances, participants looked for visual and non-verbal cues from carers to identify when they may need additional support.

> *...once you've got your rapport...with the carer, ...you can notice that they might look a little bit more rundown or that they don't look as good as they were at the start or*

there might be some other red flags so it leads you to that more caring conversation as well... (Focus Group 2, SCH)

The CSNAT-I offered a new entry point for facilitating conversation, trust, and rapport with carers. Less experienced participants described how using the CSNAT-I improved their confidence and rapport with carers.

I think I'm probably just better at having some of those emotional conversations... It's also sort of helped me shape my communication. (COT5)

However, some participants believed that using the CSNAT-I to approach carers was not always appropriate. Participants noted that using the CSNAT-I for research purposes meant that OTs were approaching carers that they perceived as not requiring support at that time.

...you don't want to be sort of doing this with a person who's independent, self-caring, going home with a carer who might be helping out with a few little things during the day but there hasn't been any sort of real report of concern, and having too much time spent on a patient like that with the CSNAT where you could be spending that extra fifteen, twenty minutes with a patient who's actually struggling. (COT3)

5.5.3 Theme 3: How well do I meet carers' needs?

Participants evaluated their ability to meet carers' needs before and after using the CSNAT-I. Prior to using the CSNAT-I, they believed that they were missing carers' needs by focusing on patient and discharge-related needs. This focus group participant described how carers were largely absent from her work with neuro-oncology patients:

...it's not focused on carer needs, it's [on] patient's needs, it's often over the phone and on discharge... and it's more risk mitigation from an OT perspective and that it's not structured. (Focus Group 1, AH)

Some participants expressed apprehension that exploration of a broader range of needs with carers, as suggested by the CSNAT-I, would *"open up a can of worms"* (Focus Group 1,

AH) and identify needs they could not meet due to limited time, resources, and skills. One participant was concerned that the CSNAT-I would create undue distress or burden on the carers.

> *... I'm always really conscious of not making it an extra stress for that carer either, that like they feel like they haven't had a chance to have a look at it, they almost feel a bit like they haven't done their homework... (Focus Group 2, SCH)*

However, after gaining some experience using the CSNAT-I, participants described an increase in confidence in their ability to work with carers' needs. They highlighted the value of applying a more structured and comprehensive approach to assessment, described by some participants as moving from just seeing what "came up" to sitting down for a conversation.

> *And it gives them that permission, that space to actually have a think about ... and you put it on the plan so when you actually go back to it they're empowered to kind of follow up and do something about it as well. (PMCFG2)*

These changes in confidence were more likely to be described by participants from the CH than the GH. One participant from the GH felt that the CSNAT-I was not needed because they considered their current work practices with carers on the palliative care ward to be sufficient:

> *I...from an experienced point of view just quickly get in and do my stuff, that sounds really awful doesn't it, but it's a shift for me to incorporate something when I'm in such a rhythm of feeling like I've got it anyway... [AOT6]*

5.5.4 Theme 4: Fitting the CSNAT-I into practice

Participants described several ways they adopted the CSNAT-I into their everyday practice, including how they contended with barriers, responded to the implementation process, and used a problem-solving approach to adapt the CSNAT-I.

5.5.4.1 Contending with lack of time for carers

The participants acknowledged that working with carers required precious time and was not necessarily considered core by the institution and some workers. For participants working in the GH, discharge planning was *a "whirlwind process"* (Focus Group 1, AH) resulting in no opportunity to meet with carers. They expressed concerns that their current way of working would not allow for additional time to complete all aspects of the CSNAT-I and *"provide enough time for the carers to…absorb that information"* (Focus Group 1, SCH). This included shared concern across several participants there would be insufficient time to complete the final review stage –an integral part of the CSNAT-I. Over time, these perceptions changed for some participants; they found it quicker than expected to complete the CSNAT-I and a valuable addition to the care they provided.

> *Follow up phone call. Look I think the majority of the ones that I've done the phone call hasn't been longer than ten minutes, like ten minutes in the day isn't that much. (Focus Group 2, SCH)*

However, acute hospital participants were still trying to determine if CSNAT-I would ever align with what they described as a "survival mode" of working – where there was not enough time and support to complete the CSNAT-I. Consequently, participants considered involving other members of the multidisciplinary team. They appreciated how even in time-pressured circumstances when a CSNAT-I could not be completed, carers' needs had become more "front of mind" and they saw themselves "thinking like CSNAT-I".

5.5.4.2 Findings ways to fit the CSNAT-I into my work

A recurring theme was how participants adapted work practices and CSNAT-I elements to fit into their roles. Examples of this included adding CSNAT-I onto daily task lists, embedding it into existing discharge planning and assessment processes, and developing ways to deliver parts of the CSNAT when circumstances did not allow them to complete it in its entirety.

...so we kind of use it ad hoc...we have those conversations and then they start to talk about some issues, we can say we have another tool if you want to sit down and we can maybe formalize it and use it in that way....it's... taking out those bits that are really useful on a ward basis. (Focus Group 3, SCH)

At the end of implementation phase, specialist cancer centre participants recognised changes in their practice towards carers. However, overall, there was a sense that carers assessment and consideration of their needs had become more visible and routine in their practice. One participant reflected on how the CSNAT-I has extended her scope beyond usual OT practice:

I think the biggest thing that's changed for me is giving that time and space for those carers to actually voice what their needs are through the CSNAT, 'cause usually I follow my own agenda. ...Well I think without that tool I don't think I would've really switched my practice.. (Focus Group 3, SCH)

5.5.4.3 Impact of the implementation processes used

In addition to their own reflections on practice, participants described the value of other strategies used in the implementation process that helped them adopt the CSNAT-I. They highlighted the opportunities provided by group reflective practice and case study discussions led by occupational therapists. These shared clinical discussions were viewed as learning opportunities and an important part of embedding the CSNAT into everyday use.

However, some participants considered that encouraging staff to complete the CSNAT-I as often as possible was unhelpful in sustaining practice change. The pressure of using the CSNAT-I for research purposes was viewed as counterproductive for individual therapists:

...people start to feel guilty if they haven't done it and then...get a bit like anxious like I should be doing more. And then when you're doing it you might not have that positive connotation between doing it and having positive outcomes. (Focus Group 2, SCH)

Similarly, an interview participant, who was also a clinical champion, described the challenge of encouraging use of the CSNAT-I in the research context:

> *...to keep...that energy going within the team...which was really important, rather than making it kind of a chore which ...when we were so busy ....it was just something that we had to do... But now that's been integrated a lot more and just in a regular discussion where it doesn't feel like it's false.... (COT3)*

Participants did not believe widespread use of the CSNAT-I would be sustainable in the long term. Rather, they anticipated the CSNAT-I would become part of a suite of intervention models to be used based on determination of need rather than used with every carer. Extending the use of the CSNAT-I to other members of the multidisciplinary team, particularly social workers, was a recurrent theme in both the SCH and GH settings. A multidisciplinary approach to using the CSNAT-I was thought to have the potential to improve adoption and sustainability, including early assessment and support of carers needs that participants could not offer within their current scope.

> *...having it...like how we have the COPM[1] and the NUCOG[2]...in the office somewhere. We have a patient, oh this carer seems a bit stressed, come down, pick one up, go to the ward, go through it with them, and...having that...the trigger to stat that conversation, as opposed to having it as a standard for every single patient I see that's like high needs. (Focus Group 3, SCH)*

5.7 Discussion

This is the first longitudinal qualitative study of OTs' experiences and behavioural responses to implementing the CSNAT-I into their usual practice in an acute setting. Findings offer new insights into the use of the CSNAT-I. Firstly, the OTs' overall experience with using the CSNAT-I was positive; they viewed it as a valuable approach to improving

[1] *COPM = Canadian Occupational Performance Measure*
[2] *NUCOG = Neuropsychiatry Unit Cognitive Assessment Tool*

carer support at discharge. Secondly, the study produced novel information about OTs' response to this new intervention, which they regarded as outside from their routine practice scope or clinical setting.

5.7.1 Understanding and valuing the principles of an intervention

Participants valued the principles of the CSNAT-I and viewed it as a positive addition to practice, in that it could improve their confidence when communicating with carers and offered a structured way to meet their needs separately from those of the patient. This positive finding is similar to those of other qualitative studies of hospital-based clinicians' experiences with the CSNAT-I. (57, 60, 65) It is also supported by theory related to intervention acceptability. According to the TFA, (148) better understanding of how an intervention works and a positive emotional response to its introduction into practice can enhance the acceptability of an intervention.

The participating OTs were initially apprehensive about adopting a carer-focused intervention in a patient-focused and time-pressured environment, consistent with previous research about employing a carer focus in hospital settings. (65) The study provides new evidence about how OTs can adjust an intervention in response to clinical needs. They drew upon their clinical judgement and resources available to them from the implementation process, and modified the intervention to accommodate patient and carer needs. This commitment to achieving practice change could be explained by the leadership roles and influence of the clinical champions and researchers. Clinical champions and researchers held clinical leadership roles within the OT teams at the SCH and GH, which may have helped to maintain optimism and promote use of the CSNAT-I. A large-scale implementation study supports this notion, whereby the allocation of internal facilitators with authority and reach was found to result in higher adoption rates.(121) However, in our study this could also have served to inflate outcomes, because occupational therapists would want to be seen as "good citizens" and meet the expectations of their leaders.

5.7.2 Modifying an intervention to fit into usual practice

The findings herein demonstrate that occupational therapist can respond to an intervention that may be incongruent to their setting by seeking to make it (more) congruent. Rather than rejecting the intervention entirely, the occupational therapists modified the intervention to align it with their practice settings. Such adaptations reflect a creative response to bringing about practice change in the face of broader challenges such as organisational culture and time constraints.(125, 165)

Adaptation is a common behaviour in end-of-life care practice setting

Modifying or adapting an evidence-based intervention to make it fit into a new context is a common response for clinicians working in real-world settings. (166, 167) The findings of study 2b show this is also characteristic of how occupational therapists in cancer and palliative care settings approach assessment and intervention. Clinicians working in these settings, including occupational therapists, need to be responsive to the changing and unexpected needs of patients and families when planning for end-of-life care at home and adapt their assessment and intervention accordingly.(168) Occupational therapists have demonstrated similar behaviours with respect to the needs of carers of people with stroke; although valuing the options for formal carer assessment, they adapted their approaches to accommodate time and resource restrictions. (169)

The occupational therapy practice scope when working with advanced cancer patients with palliative care needs can also explain their response to working with carers. Occupational therapists' core business is to enable people to participate in their valued occupations or everyday activities. This is achieved through person-centred practices, and modifying the person's social, physical and relational environment. (47) Occupational therapists perceive carers as the relational environment that can help patients do what they need to do (in this instance, return home). Patients are central to therapists' practice, and in this study, they modified the intervention to align with this principle.

Adaptation can be planned, responsive and at system and individual level

Adaptation can occur before implementation (planned) or during implementation (responsive).(125) From an implementation research perspective, adaptations made prior to implementation are preferred and should occur at both the individual and system levels .(125) This will avoid proceeding with an intervention in which fidelity is compromised and successful outcomes unlikely, and consequently contributing to low-quality research and resource waste.(167) In study 2b, the delivery mode of the CSNAT-I was modified initially as part of the planned implementation strategy, driven by participating occupational therapists and local support for the practice change. However, during the implementation period, individual occupational therapists made further ad hoc adaptations, implying that earlier modifications were insufficient to support practice change. Furthermore, the environment in which they worked changed significantly over the course of the study. Given the study was conducted during the COVID pandemic, it is likely that occupational therapists found it difficult to adopt a new and systemised intervention into an unpredictable clinical setting and altered how they used the CSNAT-I according to their competing demands.

Ad hoc modification of interventions may compromise their outcomes, and in turn, the quality of care delivered to carers and the likelihood of sustaining practice change. For example, a CSNAT-I trial in stroke rehab suggested that clinicians who did not deliver the CSNAT as intended reported no improvement in carer outcomes.(62) However, it is important to note that in sub study 2b, occupational therapists perceived that providing parts of the CSNAT-I, and in some instances just “thinking” like the CSNAT-I, improved their typical interactions with carers.

Understanding how much an intervention can be modified before it starts to erode fidelity and the desired outcomes is an important part of determining how “implementable” an intervention is. (119) The CSNAT-I developers support clinicians and researchers applying flexibility in how and when it is delivered. (64) However, they offer little further guidance,

and fail to specify how much of the features or contents of the CSNAT-I can be changed without compromising its benefits for carers. Moore and colleagues (170) recently developed a tool that use a traffic light system to categorise adaptations that do not reduce intervention fidelity. When used in conjunction with intervention development processes, this tool could be helpful in determining whether the CSNAT-I loses its fidelity when modified and is the correct intervention, or whether other interventions should be considered.

If adapting an evidence-based intervention to usual practice is an expected behavioural response for clinicians, a systematic approach to support this process would be beneficial to maximise use of scarce time and resources. Ad hoc delivery of the CSNAT-I, without consideration of system-level modifications to support practice change, is unlikely to be sustainable. The original developers of the CSNAT-I (137) addressed this issue by identifying the organisations required to support, implement and sustain a carer-focused support model. Their recommendations constitute a comprehensive guide to assessment of the characteristics of both setting and practitioners prior to proceeding to large-scale intervention trials and implementation.

5.8 Strengths and limitations

This study had several limitations. Firstly, the primary investigator (CM) and the project officer/researcher (AU) held dual roles as clinical leads for the SCH and focus group facilitators and interviewers. Thus, their authority and widespread identification with the project may have influenced CSNAT-I implementation, individual occupational therapists' responses, willingness to participate and interpretation of findings. For example, the researchers' roles may have influenced occupational therapist participants' decisions to participate and to give overly positive responses about the project. During data analysis, the researchers may have leaned towards themes that supported the success of the study, specifically occupational therapists' uptake of the intervention into their practice, and reach conclusions about the two sites and participants that supported their personal

and/or professional interests. However, fieldnotes about the researchers' reactions and feelings during focus groups, interviews and thematic analysis served to mitigate these limitations by acknowledging researcher's influence on the research process and allow for tracking of how interpretations develop over time (i.e. capturing transparency). Seeking peer review and validation from researchers with non-occupational therapy background, the original CSNAT-I developers and steering committee members (including carer consumer representatives) also enhanced the credibility and dependability of the findings. (142) Importantly, these studies informed CM's doctoral work and were funded by a grant, providing further impetus to produce high-quality, rigorous research. Past experiences and knowledge of the intervention, patient/carer cohort, characteristics of the occupational therapists and hospital context could be regarded as strengths for both CM and the assistant researcher (AU), enabling them to view the findings objectively and enhance the research authenticity.

The restrictions on CSNAT-I implementation due to a strict grant funding period and intermittent pauses during the COVID-19 pandemic were unavoidable limitations. They meant attempting to change clinicians' practice in the COVID-19 context undoubtedly imposed additional personal and professional demands on staff, patients and carers, which may have influenced occupational therapists' adaptive responses and experiences. However, implementing an intervention that created opportunities for conversations with carers and enhanced engagement with them in a period when they were less visible than usual (due to COVID-19 restrictions) was arguably a strength of the study.

5.9 Conclusions

Occupational therapists' overall experience with the CSNAT-I was positive; they viewed it as a valuable addition to practice that could improve their work with carers. Although there was an intent to change practice and embed the CSNAT-I into usual care, participants were faced with circumstances (largely out of their control) that limited how much they could change. OTs responded to these limitations by modifying the intervention to make it

fit into their practice, rather than rejecting it completely. This study provides new evidence about how occupational therapists behave when invited to adopt an intervention that may not fit with their practice and is not supported at a system level. More exploratory work is needed to improve understanding of the features of health services that are likely to help or hinder the success of embedding the CSNAT-I, and what needs to happen at a system level to create a patient–carer dyad approach to all discharge interventions.

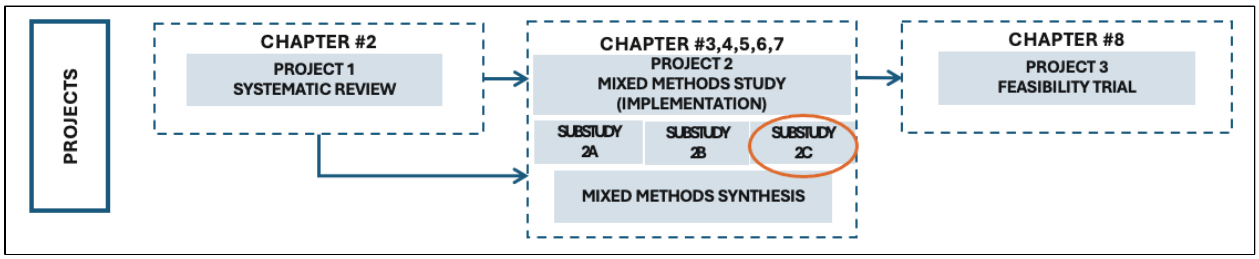
Findings from this sub study (2b) have provided evidence of occupational therapists' experiences and response to CSNAT-I implementation over time and the contextual factors that influence this. These findings, along with sub study 2a findings in Chapter 4, will contribute to mixed methods synthesis in Chapter 7 and the primary aim of exploring the implementation of the CSNAT-I into usual practice. The next chapter (6) will report on the third and final sub study 2c – a quantitative evaluation of how the CSNAT-I is delivered and received in a real-life hospital discharge context.

Chapter 6. Project 2: study 2c – a process evaluation of the delivery and reception of a carer-focused intervention to assist with hospital discharge from an acute oncology setting

This chapter reports on study 2c – the third and final component of the mixed methods study (Project 2). This quantitative study examined how the CSNAT-I was delivered and received when introduced into a real-world hospital discharge and OT practice setting. Methods employed to conduct this study are summarised in in the first section of this chapter. Data was collected prospectively at patient–carer, clinician and service levels, and analysed descriptively.

The last two chapters (4 and 5) reported on qualitative findings (studies 2a and 2b) related to patient–carer and occupational therapists experiences and responses to the CSNAT-I. These qualitative studies showed that patients, carers and occupational therapists valued the CSNAT-I and understood how it could benefit carers in this setting. Carers appreciated the support received across hospital and home and accepted it as part of usual discharge planning practices. The OTs found it difficult to adopt the CSNAT-I into usual practice and consequently adapted it to align with the demands of the fast paced and patient-focused environment. This chapter builds upon these earlier findings by presenting observational data related to how patients, carers and OTs responded to the CSNAT-I and the processes and outputs generated from the intervention itself (Figure 13).

Figure 13. Research components and processes for sub study 2c: Process evaluation.



6.1 Methods

Table 8 shows the research aim ,questions, design, methods for sub study 2c.

Table 8. Synopsis of aim, research questions, design and methods, study 2c

Title	**A process evaluation of the delivery and reception of a carer-focused intervention to assist with hospital discharge from an acute oncology setting**
Aim	To examine how a carer-focused intervention is delivered and received when introduced into a real-life hospital discharge context
Research questions	1. What types of patient–carer groups used the CSNAT-I? 2. What elements of CSNAT-I model were used by carers and occupational therapists? 3. How was the CSNAT-I model integrated into routine practice?
Design	A multi-site prospective observational study design was employed to examine the characteristics and behaviours of patient–carer dyads and occupational therapists, and processes occurring at individual and service levels during implementation of the CSNAT-I
Participants and setting	Described in sections 3.5.1 & 3.5.2 Consenting patient-carer dyads admitted to the general hospital or the specialist cancer hospital
Sampling	This was not an efficacy study; therefore, a minimum sample size was not calculated. The sample represents the pragmatic limitations of patient flow throughout the hospital at each site
Measures/outcomes	The main outcome was to describe how the CSNAT-I is delivered and received at patient, carer, clinician and service levels during implementation. Appendix 14 outlines specific clinical and process data collected to answer relevant research questions and the time points when data collection occurred. Patient measures included demographic data and clinician-rated assessment tools recorded in the electronic medical record. – the Australian Karnofsky Performance Status (AKPS)(140) and the Resource Utilisation Groups – Activities of Daily Living (RUG-ADL).(141) Features of these measures are described in Chapter 3 and Appendix 18. Carer measures included demographic and information recorded on the CSNAT-I tool (i.e. needs identified and action plan).
Data collection	Prospectively collected quantitative data included: (1) patient demographic and clinical data via the electronic medical record;

	(2) carer demographic and clinical (CSNAT-I) data via short interview and whilst using the CSNAT-I, respectively; (3) prospective service and process data via project specific-CRF; including participation and completion rates at clinician and patient-carer levels, before, during and after implementation.
Data analysis	Data analysis of the quantitative data (demographic, patient-carer related, service and process measures) was descriptive (means/SD or frequency/percentage as appropriate). This data was analysed using SPSS (version 24)

6.2 Results

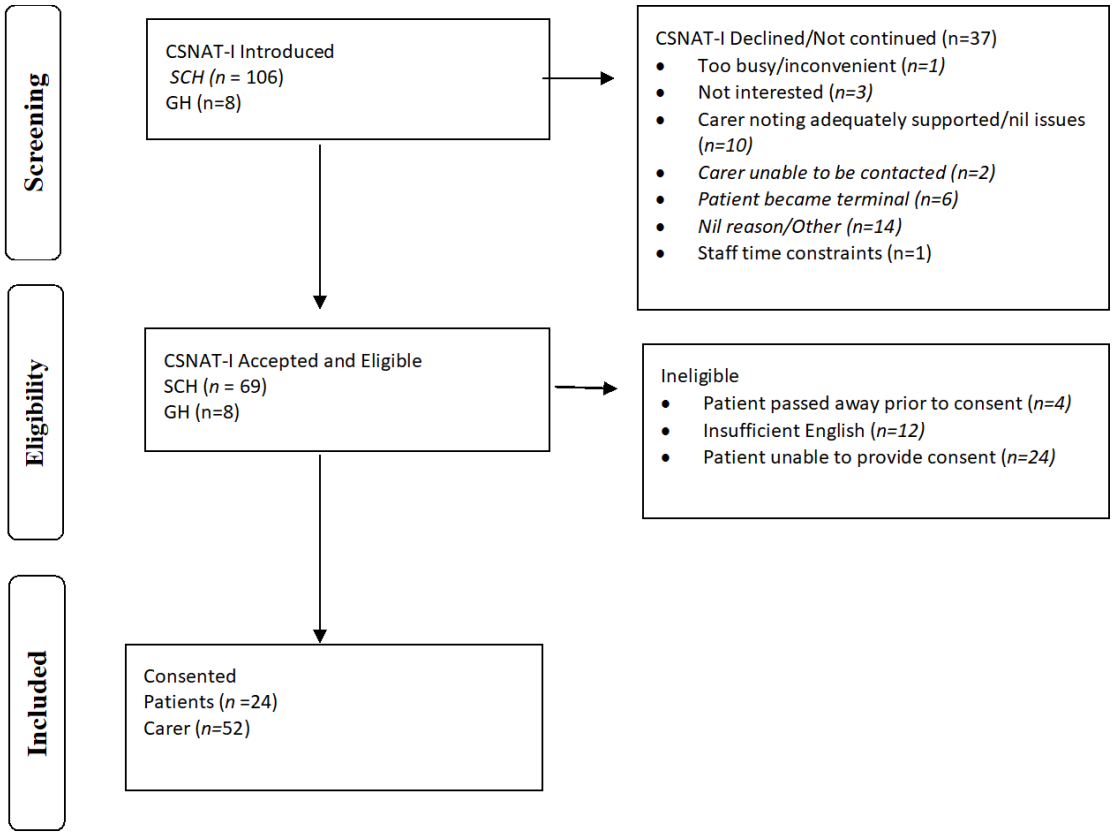
The CSNAT-I was introduced to 106 carers at the SCH and eight carers at the GH. Sixty-nine (65%) of carers at the SCH completed the CSNAT-I, and 100% at the GH. Fourteen of the 37 carers who declined to complete the CSNAT-I gave no reason; the others cited reasons such as already having adequate supports in place (n=10), their patient was nearing death (n=6), time constraints (n=2), not interested (n=3) and two were unable to be contacted.

Most carers (90% at the SCH and 50% at the GH) completed the first four stages of the CSNAT-I (needs assessment and action plans). Less than half (46%) of the carers at the SCH completed the review of their needs after discharge (stage 5) and 38% carers at the GH. Reasons for incomplete sections were not recorded.

6.2.1 Consented participant characteristics

Fifty-two patient–carer dyad participants consented to participate in the study, totalling 50 participants from the SCH and 2 from the GH. See Figure 14 for recruitment and drop-out rates. Reasons for drop-outs were both clinician and patient-carer related.

Figure 14. Combined eligibility and recruitment rates: general hospital and specialist cancer hospital



The demographic and clinical characteristics of patient and carer participants at both sites are outlined in Table 9. Most carer participants were female, with a mean age of 56.7 years (SD = 17.5). Spouses (48%) and adult children (37%) of the patient made up most of the carer cohort. One quarter of the carers were working. Time spent in caring role for carers ranged from 0 to 10 years, with an average of 2.2 years.

Table 9. Characteristics of consenting participants

Characteristics of participating carerss	
	Total (n=52 carer/patient dyads)
Gender	
Male n (%)	9 (17)
Female n (%)	38 (73)
Missing n (%)	5 (10)
Age (years)	
Mean (SD)	56.7 (17.51)
Median (range)	62 (24–84)
Missing n (%)	7(14)
Relationship to the patient	
Spouse/partner n (%)	25 (48)
(Adult) child n (%)	19 (37)
Other (e.g., parent, sibling, friend) n (%)	8 (16)
Level of education	
Secondary n (%)	25 (48)
Tertiary n (%)	22 (42)
Missing n (%)	5 (10)
Employment status	
Employed n (%)	13 (26)
Unemployed n (%)	17 (33)
Retired n (%)	17 (33)
Missing n (%)	5 (10)
Country of birth	
Australia n (%)	31 (60)
Other n (%)	16 (30)
Missing n (%)	5 (10)
Availability of carer	
Lives with patient	44 (85)
Lives with others	2 (4)
Missing	1 (2)
	Related to patients with
Gender	
Male n (%)	32 (61.5)
Female n (%)	20 (38.5)
Age (years)	
Mean (SD)	68.5 (12.9)
Median (range)	69 (30–94)

Primary language spoken at home	
English n (%)	21(84)
Other n (%)	3(12)
Missing n (%)	1(4)
Country of birth	
Australia n (%)	16 (64)
Other n (%)	9 (36)
Type of cancer	
Gynae n (%)	5 (10)
Lung n (%)	11 (21)
Haem n (%)	9 (17)
Skin & Melanoma n (%)	6 (12)
Lower GI n (%)	2 (4)
Upper GI n (%)	2 (4)
Breast n (%)	5 (10)
Uro n (%)	4 (8)
Sarcoma n (%)	1 (2)
Pancreatic n (%)	3 (6)
Neuro n (%)	2 (4)
RUG-ADL Score**	
Median (IQR, Q1,Q3)	8 (4.0, 14.0)
Australian Karnofsky Performance Status (AKPS) Score**	
Median (IQR Q1, Q3))	50 (30.0, 50.0)
Patients with AKPS 50 or more(%)	57.7
Patients with AKPS 40 or less (%)	42.3
Patient length of stay (days)	
Mean (SD)	21.1 (20.8)
Median (range)	12 (2–78)
Readmissions	
Patients readmitted within 30 days n (%)	13 (26)*
Palliative Care Unit(PCU) admissions	
Admitted to PCU during hospital stay n (%)	19 (76)
Actual discharge destination	
Home n (%)	37 (72)
Passed away in hospital n (%)	6 (11)
Still in hospital at end of study n (%)	5 (10)
Aged care Facility n (%)	1 (2)
Transfer to rehabilitation n (%)	1 (2)
Missing n (%)	1 (2)

The mean age of patient participants was 68.5 years. Patients whose carer received the CSNAT-I had high care needs, with over 42.3% reported as having an Australian Karnofsky Performance Status (AKPS) score of 40 or less.(140) This means they spent more than 50% of the time in bed, and required considerable assistance with their self-care. Seventy-six per cent of patients had been admitted to the specialist palliative care unit, and home was the most common discharge destination (72%), followed by transfer to other wards. Eleven per cent of participants died prior to discharge.

6.2.2 Receiving the CSNAT

The 52 carers who completed the CSNAT-I indicated the domains in which they wanted more support, all linked to the practical aspects of caring. These included "equipment to help care for your relative" (n=25); "knowing what to expect in the future when caring for your relative"(n=20); "knowing who to contact if you are concerned about your relative(n=16); and "managing your relative's symptoms including giving medicines" (n=14). The numbers and percentages of carers citing domains in which they wanted more support are shown in **Error! Reference source not found.** Carers citing CSNAT-I domains in which they wanted more support

Domain	**Number of carers (%)**
Equipment to help care for your relative	25 (17)
Knowing what to expect in the future when caring for your relative	20 (14)
Knowing who to contact if you are concerned about your relative (for a range of needs including at night)	16 (11)
Managing your relative's symptoms including giving medicines	14 (10)
Providing personal care for your relative	13 (9)
Financial, legal or work issues	12 (8)

Dealing with your feelings and worries	9 (6)
Having time for yourself during the day	8 (6)
Practical help in the home or elsewhere	7 (5)
Understanding your relative's illness	6 (4)
Anything else?	5 (3)
Talking with your relative/loved one about his/her illness	4 (3)
Looking after your own health (physical problems)	2 (1)
Getting a break from caring overnight	2 (1)
Your beliefs or spiritual concerns	0

Needs identified by carers triggered action plans determined by the carer and facilitated by the OT. The most common action plans generated were referral to another service (48%), followed by direct OT interventions (31%), carer-led interventions (seeking support independently, such as from family members) (9%) and signposting (the OT informing the carer about how to obtain additional support or information) (11%). Direct OT intervention related primarily to the prescription and provision of assistive equipment, followed by carer training and education and referrals to community services for assistance with patients' personal care on discharge. Referrals to another service (48%) was the most common action plan, and involved referrals mostly to hospital-based teams, specifically social work, medical, pharmacy and nursing teams.

6.2.3 Delivering the CSNAT-I

Data describing the timing, mode and nature of the delivery of the CSNAT-I to the 52 consented participants is outlined in Table 10. Average time taken to complete the pre-discharge component of the CSNAT was 32 minutes, and 17.3 minutes to complete the after-discharge component. Of the carers who received the shared review, 50% received it within 48 hours of discharge, whereas the remaining half received this component more than 48 hours after discharge. Face-to-face delivery was the most common mode (77%), followed by phone, and a combination of both. The CSNAT-I was introduced during patient review for 67% of carers, with smaller numbers being introduced to it during initial patient assessments and after family meetings.

Table 10. Timing and delivery mode for the CSNAT-I

CSNAT-I details	**N=52**
Time taken to complete stages 1–4 (mins)	
Mean (SD)	32 (16)
Median (range)	30 (10–75)
Time taken to complete Shared Review (mins)	
Mean (SD)	17.3 (9.3)
Range	15 (5–55)
Timing of Shared Review	
<48 hours after DC	16 (32)
48 hours or more after DC	16 (32)
Missing	18 (36)
Timing of CSNAT-I introduction, n (%)	
Initial Assessment n (%)	14 (27)
During a Review n (%)	35 (67)
Post family meeting n (%)	3 (6)
Mode of delivery (stages 1–4)	
Face to Face n (%)	70 (77)
Phone n (%)	8 (15)
Phone and Face to Face n (%)	4 (8)

6.3 Discussion

This is the first study to explore how the CSNAT-I may work when introduced by treating OTs into usual care across two acute settings to assist carers of people with advanced cancer in preparing for discharge. Findings demonstrated higher uptake of the CSNAT-I in a

specialist cancer centre than a generalist hospital. Overall, OTs delivered the CSNAT-I to a range of carers providing care for people with complex care needs and a planned discharge location. Assessing and actioning carers needs before discharge was easier to achieve than following up carers after discharge. Most eligible carers engaged with the CSNAT-I prioritised needs related to the practical aspects of caring, and received additional care from the OT and hospital multidisciplinary team to meet these needs and facilitate patient discharge.

6.3.1 Mismatch of implementation processes across settings

The substantially higher numbers of CSNAT-Is completed in the SCH than the GH poses questions about how an intervention can operate differently across two hospital settings in an Australian healthcare context, despite using recommended evidence-based implementation processes. The differences in the adoption of the CSNAT-I across these settings may have arisen because of a mismatch between the implementation processes needed and applied. (171) OTs at both sites received the same education and training, but there were fewer suitable patients and larger caseloads at the GH, resulting in less time and opportunity to practise delivery of the CSNAT-I. The clinical champions were less accessible at GH, and the lead researchers were part of the clinical OT team at the SCH, which most likely meant the quality of support and training offered at the SCH was higher. These findings are consistent with earlier research on the CSNAT-I, which associated less opportunity for practice and informal discussions, and facilitators without authority, with low adoption.(121)

The difference in uptake across the settings could also be explained by the characteristics of the organisations. The SCH had a higher volume of acute oncology patients with complex needs and advanced illness, and a larger proportion of participants were introduced to the CSNAT-I in the palliative care setting in the SCH than in the GH. Supporting carers in this context to facilitate end-of-life care at home is closer to the SCH's usual practice, and most likely demanded less practice change than in the GH. The GH services' acute medical oncology patients were dispersed across treating teams and

potentially less aligned to carer support, contributing to less opportunity to practise using the CSNAT-I. This mirrors findings from an earlier process evaluation of CSNAT-I delivery by nursing teams in community settings.(63, 121) Home hospice day therapy programs saw carers more frequently and had more opportunity to use the CSNAT-I, whereas the community nursing services had longer intervals between visits and less opportunity to complete the CSNAT-I. Other evidence has suggested that if a new intervention is too closely aligned to usual practice there is less motivation to embed it, and clinicians may argue that their current practice is sufficient.(63, 121)

6.3.2 Prioritising practical aspects of caring over the personal aspects

This study builds on evidence that carers of people with advanced cancer will prioritise needs related to the practical aspects of caring in the context of hospital discharge. Carers preparing for someone to return home from hospital commonly cite unmet needs related to information about the illness, medical treatment and practical aspects of caring. (33)This differs from carers in the community, who typically want more emotional and psychosocial support.(172, 173) In previous CSNAT-I studies, carers prioritised domains of need related to personal aspects of caring, including getting a break during the day and dealing with their own feeling and worries.(56, 60, 61) In an Australian trial in which the CSNAT-I was delivered to carers of older people after the latter's discharge from a short-stay medical ward, carers prioritised practical needs related to feeling supported upon their initial return home, specifically information on who to contact, what to expect and practical help in the home. (58)

In study 2c, carers were preparing for the person they care for to return home, so it is not surprising that their primary needs were patient focused. Most carers wanted more support with patient equipment, symptom management, and who best to contact for information or help after their family member or friend returned home. This finding reflects the experiences of carers revealed in the qualitative study in chapter 4; they described needing to know they were prepared, and set aside meeting their own needs until later.(174) The discharge planning role of the OT could also explain this finding. Carers

valued and identify OTs as the “practical help” needed for discharge. (19, 175) This may have influenced the direction and outcome of the supportive conversation carried out as part of the intervention and the subsequent focus on patient equipment needs. This prompts consideration of whether occupational therapists (OTs) delivering the CSNAT-I in Study 2c may have overlooked carers’ emotional and psychosocial needs. However, this may not be entirely the case, for two reasons. Firstly, most referrals generated from the CSNAT-I were to social workers, creating a pathway for assistance with psychosocial problems. Secondly, the review of needs that occurred after discharge would have served as a safeguard for carers’ psychological wellbeing, which is known to be at more risk once the care recipient returns home. (173)

Only two thirds of carers received follow-up after discharge. Examination of reasons for this shortfall was beyond the scope of study 2b, but behavioural and process factors are likely to be responsible. For example, carers may have already received follow-up from another hospital staff member or responsive community service and did not require additional support. Alternatively, time constraints and inadequate practice change support may have prevented OTs from delivering this aspect of the intervention (as the findings reported in chapter 5 suggest).

It is well known that interventions aiming to improve hospital-to-home transitions for both patient and carers with advanced disease should reach across both settings (57, 176) and should include consistent communication, handover, information provision and needs assessment.(1, 8) Carers interviewed for the qualitative component of Project 2 (Sub study 2a) also appreciated the support that followed them from hospital to home, regardless of who was delivering it.(122, 174) Therefore, it is important that review of carers needs after discharge is considered a critical element of carer-led discharge interventions, and that researchers seek to understand factors influencing its implementation and sustainability in different contexts.

6.4 Implications and conclusions

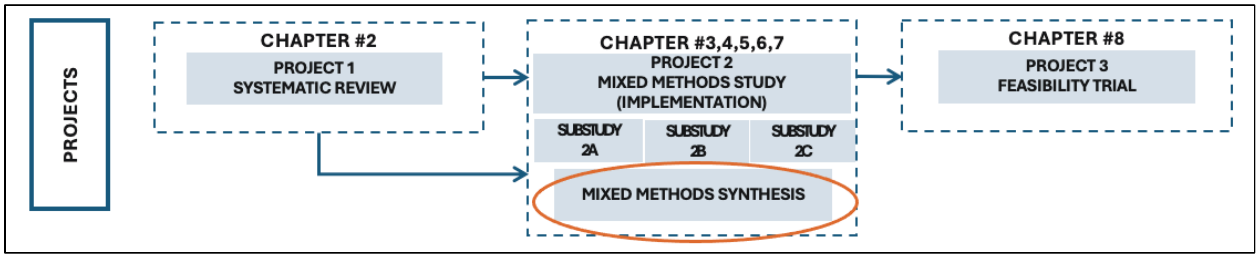
In summary, in this research, adoption of the CSNAT-I into routine practice in a hospital discharge setting occurred at a much higher rate in a specialist cancer setting than a general hospital setting. Carers prioritised the practical needs related to preparing for the caring role on discharge over their personal needs. Consequently, most care generated from the CSNAT-I related to actioning practical support, assistive equipment and education related to symptoms and medication management. The review stages of the CSNAT (after discharge) were completed less than the assessment and action stages (before discharge).

The next chapter (7) describes the merging of Study 2c's findings with those from the qualitative components (studies 2a and 2b) of the larger mixed methods study to obtain a more in-depth understanding of the implementation of the elements of the CSNAT-I and factors influencing this process in an acute hospital discharge setting. .

Chapter 7. Project 2: mixed methods synthesis of studies 2a, 2b and 2c – An evaluation of implementing a carer-focused intervention into routine care to assist with hospital discharge

This chapter describes the synthesis of the qualitative and quantitative results from project 2 (studies 2a, 2b and 2c). The synthesis stages, sequence and outcomes are diagrammed in Figure 15.

Figure 15. Caption cpation caption



Before presenting the findings of the synthesis, the aims and methods of the mixed methods study are revisited in section 7.1, followed by a summary of the key findings of the three embedded studies (2a, 2b and 2c) in section 7.2.

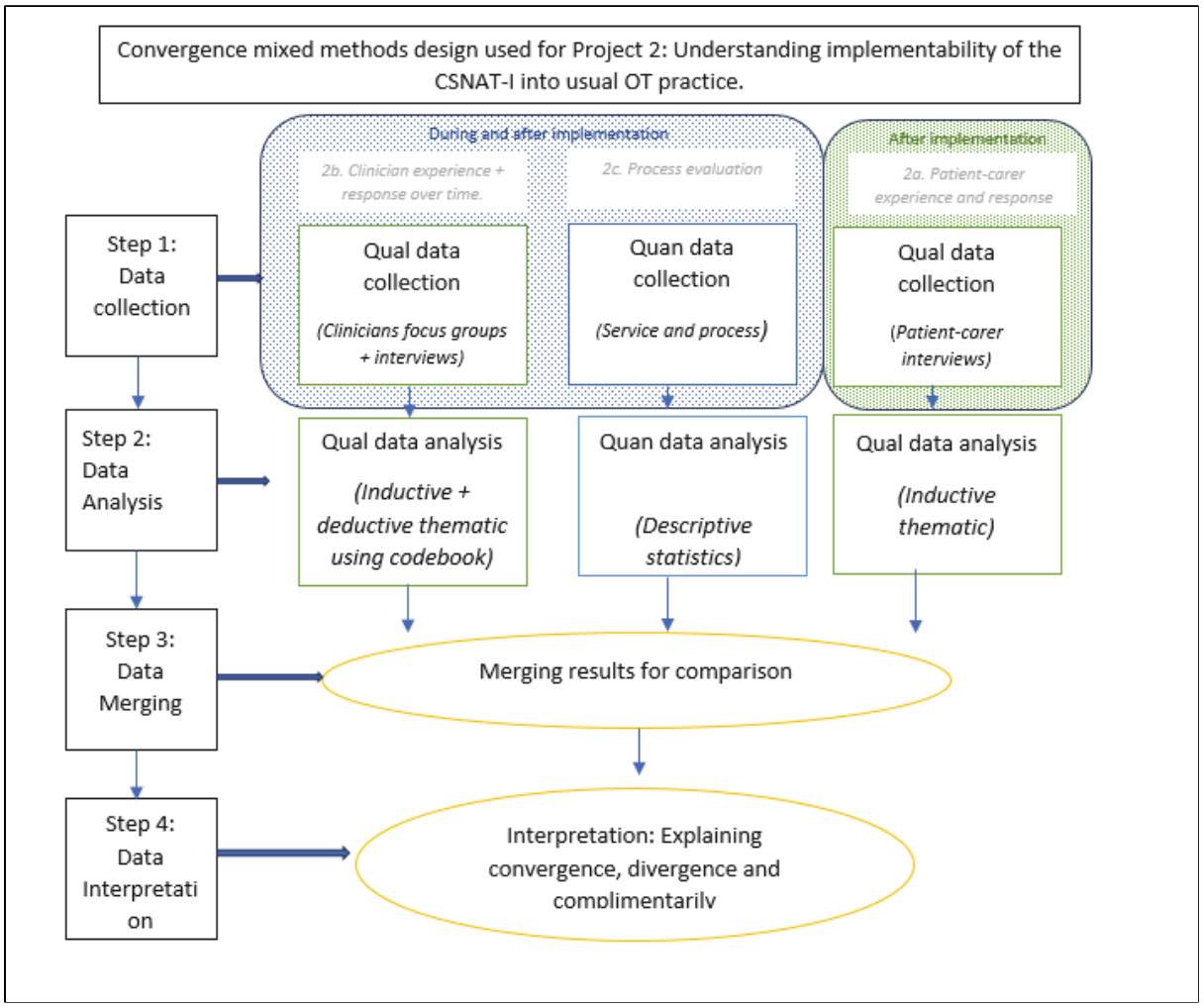
7.1 Synopsis of aims, study design and methods of Project 2

Project 2 aimed to explore the implementation of an existing carer-focused intervention (CSNAT-I) into routine practice to support carers of people with advanced cancer at hospital discharge. Secondary aims were to obtain an understanding of how patients, carers and occupational therapists responded to and experienced the CSNAT-I, and what contents and mechanisms of the CSNAT-I were delivered and generated in this new context. A convergent mixed methods study was employed to achieve these aims.

Data collection occurred in studies 2a, 2b and 2c (Figure 16). Study 2a involved the collection of patient and carer experiences and views of the CSNAT-I via semi-structured

interviews conducted after the intervention. Study 2b involved collection of OTs' views on the acceptability of the CSNAT-I as part of their usual practice via a series of focus groups conducted before, during and after implementation, as well as in interviews after implementation. Quantitative data was collected prospectively in study 2c – demographic and clinical data via the electronic medical record, and service and process data via the project specific-case report form. Participation and CSNAT-I completion rates were calculated.

Figure 16. Mixed methods design for Project 2



Data analysis consisted of thematic analyses of qualitative data from studies 2a and 2b, statistical analysis of quantitative data from study 2c), and, as presented in this chapter,

the integration or merging of the results from both qualitative and quantitative datasets. Integration of the two forms of data was achieved using the "side-by-side" approach as proposed by Creswell and colleagues (124) Comparison of datasets occurs in the discussion section of this chapter, and is illustrated in a series of joint display tables.(124, 129)

As explained in Chapter 3, the synthesis allowed for convergence across datasets and final interpretation to achieve the study aims.(128) This final analysis stage was structured using the CTF,(68) divided into the following domains: Intervention characteristics, Characteristics and roles of providers, and Characteristics and roles of patient and carers. In section 7.4, findings are mapped against a set of constructs to reflect these three domains, with the most relevant constructs then identified, leading to inferences being drawn and points of discussion raised. For example, the construct of *adaptability* – the perceived degree to which the intervention could be adapted – featured strongly across the study and was an important characteristic of CSNAT-I implementation. It should be noted that findings and inferences are not exclusive to particular constructs but overlap and interact with each other. For example, the characteristics of the treating OT influenced how the intervention was delivered in the acute setting.

7.2 Merging of results for comparison

Findings from these three sub-studies are reported in chapters 4, 5 and 6. To align with step 3 (Merging results for comparison) in Figure 16, the three datasets were assembled and are reported in Table 11.

Table 11. Summary of findings of sub studies 2a, 2b and 2c

2a: QUAL + (patient/carer)	2b: QUAL + (occupational therapist)	2c: QUANT +(process)
• Viewed by carers as an integrated part of usual discharge practices • Carers found CSNAT-I useful and highly acceptable because it assisted them to work through practical needs related to discharge, and offered support spanning hospital and home • Increased carer awareness of their needs	• Affirmed the CSNAT-I principles and found that it benefited carers • CSNAT-I improved how care was provided for carers • Over time OTs tended to modify the CSNAT-I to conform with existing scope of practice and setting. These modifications enabled ongoing use of the CSNAT-I that otherwise would have ceased in clinical care delivery • CSNAT-I was used to meet carers needs related to achieving patient and discharge-related outcomes • OTs led processes in CSNAT-I rather than carers	• Higher OT acceptability in the SCH than the GH • Delivered within existing patient care processes and workflow • Completing elements was more difficult after the patient was discharged • OTs prioritised practical needs and integrated multidisciplinary responses to need

7.3 Data merging and interpretation (synthesis)

The following joint display tables represent the final side-by-side integration of the qualitative and quantitative findings, specifically key themes and inferences. Each table represents a relevant construct from the CTF: (1) Intervention characteristics, (2) Characteristics and role of clinician (occupational therapist) providing the intervention and (3) Characteristics and role of the patient and carer receiving the receiving the intervention).Next to the constructs in this table in the brackets are relevant domains from the CTF that are most closely aligned to the findings from this final synthesis. For example, the domain of “authority” in Table 13 aligns with the clinician’s role of initiating the delivery and modification of the intervention.

7.3.1 Intervention characteristics

Table 12 shows the core components of the CSNAT-I that were confirmed across all three sub studies, including specific contents and mechanisms of the intervention, and preferred modes of delivery.

Table 12 .Mixed Methods Synthesis: Intervention characteristics

Convergence	**QUAL Carer ("Do they like it"?)**	**QUAL Occupational therapist ("Do they like it?")**	**QUANT ("How does it work?")**
Intervention characteristics (adaptability, compatibility, location of intervention activity)			
The CSNAT-I targeted practical needs related to preparing for discharge and care at home	Viewed by carers as helping them work through needs related to discharge and offered support across hospital and home	OT participants used the CSNAT-I to meet the practical needs of carers related to achieving patient discharge	Carers' greatest needs related to seeking more support with symptom management, medications, knowing who to contact, and assistive equipment
Assessment and response to carer support needs.	Increased awareness of support needs for self and others and offered a comprehensive way of working through needs	Improved confidence and ability to talk about and meet carers' needs as part of discharge planning	High adherence to needs assessment and support Low adherence to systematic review of carer needs
Delivered across hospital and home	Felt supported across the continuum, appreciated the follow up after discharge	Viewed follow up of needs after discharge as important but this was more difficult to achieve for general hospital OTs compared to cancer hospital OTs	Low adherence to completing follow-up after discharge (45% across both hospitals)

Embedded in existing discharge processes	Viewed as integrated into the bundle of care they received for the patient during the discharge planning process	Adaptations made to the CSNAT-I to fit into existing discharge planning models of care	Generated care related to discharge planning interventions and unmet needs
Inferences			
CSNAT-I could be delivered and was acceptable as an **integrated part of discharge and patient care processes** that offered timely responses to needs, reaching across hospital and home, and generating support for the practical aspects of caring. This finding implies that the CSNAT-I be embedded as part of a bundle of care. It also suggests that the CSNAT-I be delivered as a dyadic intervention for patients and carers transitioning between hospital and home. These proposals align with the key characteristics of CTIs reported in the literature for people with palliative care needs and their carers. (177) **Delivering carer support after discharge** was a critical part of the CSNAT-I, valued by both carers and OTs; however, this was more difficult to achieve.			

7.3.2 Characteristics and roles of clinician providing the intervention

Table 13 shows the key characteristics and roles of the clinician (occupational therapist) that arose from the synthesis, specifically in the domains of knowledge, skills, practice scope and authority.

Table 13. Mixed Methods Synthesis: Characteristics and role of clinician.

Convergence	**QUAL Carer ("Do they like it?")**	**QUAL Occupational therapist ("Do they like it?")**	**QUANT ("How well does it work?")**
Characteristics and role of clinician providing the intervention (provider) (knowledge, beliefs, skills, roles, authority)			
OT must have an aptitude for discharge planning	Carers did not identify specific clinicians or professions that helped them, but did refer to the need for a coordinated approach to care for discharge planning	Intervened with carers by meeting needs related to preparing for patients' discharge home	Generated a list of practical needs related to preparing for discharge home. This list guided direct intervention from OTs and other multidisciplinary team members in the hospital
OT understands and values the principles of the CSNAT-I and how it is intended to work to improve carer support at discharge	Carers recognised that the CSNAT-I helped others (i.e., OTs) become aware of what they needed, which prompted offers of support	OTs valued the principles of the CSNAT-I, how it increased their confidence and their ability to respond to carers' needs.	More CSNAT-I interventions were introduced to carers in the SCH (n=106) than the GH (n=8) High completion rates for carers presented with the CSNAT-I – 69% at SCH and 100% at GH

OTs are responsible for initiating the intervention, leading its delivery, and modifying intervention to fit into setting	Carers accepted the intervention as part of hospital system and discharge planning processes	Adapted intervention and behaviour to make CSNAT-I align with setting, apply clinical judgement	High participation in training and implementation program but lower uptake in SCH than GH OTs working in the SCH commenced CSNAT-I after initial contact with patient and provided direct intervention (31%) or referral to other services (48%)
inferences			
Carers and OTs viewed the role **of provider as someone with an aptitude for discharge planning,** able to fulfil patients' needs related to discharge and carers' capacity to care when they return home. **Carers were discipline agnostic –** not concerned with who provides support at hospital discharge if they adequately met their needs. The provider took on **the role of leading** the delivery of the intervention and **modified or adapted the process and the elements included t**o match their scope and capacity for practice change			

7.3.3 Characteristics and role of patient and carerr receiving the intervention

Table 14 shows key characteristics and roles of the patients and carers that arose from the synthesis and converged across data sources. Similar to the occupational therapists, syntheses findings were centred around patients' and carers' knowledge, beliefs, perceived roles and levels of authority.

Table 14. Mixed Methods Synthesis: Characteristics and role of patient and carer.

Convergence	**QUAL Carer ("Do they like it?")**	**QUAL Occupational therapist ("Do they like it?")**	**QUANT ("How well does it work?")**
Characteristics and role of patient and carer receiving the intervention (knowledge, beliefs, roles, authority)			
Patients and carers understood and valued the principles of the CSNAT-I and how it worked to improve the care they receive	Increased carers' awareness of their own needs and surrounded them with care	Improved OTs' confidence and ability to work with carers' needs by offering a structured and comprehensive process	High participation rate when CSNAT-I was offered Carers were able to identify their most important needs
Clinicians moved from regarding carers as a resource for providing patient care to a recipient of care in and of themselves	Carers valued contact initiated by the OT (as part of the CSNAT-I) and assisted them in acquiring what was needed to care for the patient Carers linked their own needs to those of the patients	OTs initiated and led intervention delivery, looking for entry points to approach carer and (in some cases) to minimise their burden OTs met patients' needs by intervening with carers using the CSNAT-I	The CSNAT-I process generated additional support for carers as part of hospital discharge planning Data showed carers prioritised needs related to caring for the patient first
Implications/Inferences			
Role shift occurs for carers when they enter the hospital environment. They change from the role of "conductor" or care coordinator of the person they care for to the role of "second fiddle" (36) and a resource rather than a person with their own needs. Similar to carers in the community, carers preparing for a patient discharge from hospital still value the CSNAT-I and			

how it works to increase support for them as carers. (57) However, as seen across the datasets, their views of and response to the CSNAT-I still reflects the patient-focused and discharge-focused environment of which they are part

7.4 Discussion

This mixed-methods study evaluated the implementation of CSNAT-I into routine practice to support carers of advanced cancer patients to prepare for discharge from hospital. The findings highlight the CSNAT-I components that are more easily delivered, how people experience the CSNAT-I's introduction, and how these interactions shape its implementation. Patients, carers, and OTs accepted CSNAT-I as a practical support tool. OTs led its delivery, adapting aspects for better integration into usual practice, while carers focused on supporting discharge home. The acute oncology setting and the adaptation process were powerful influences on interactions between the intervention, patients, carers and therapists, and are discussed in the following section.

7.4.1 Influence of the setting

The key theme underlying much of this work is the influence of the hospital context upon how the CSNAT-I intervention was delivered, and the response of clinicians (OTs) and carers during implementation. This theme reflects the theoretical proposition raised by the CTF that outer settings (i.e., organisational contexts) can affect the interaction between the intervention, the provider, the receiver and the process of implementation itself (see section 1.3.3).

Acute hospitals that provide palliative care differ from other hospitals in many important respects; in this research, the two settings also differed (as explained below). Palliative care principles are represented by a holistic, family and goal-centred approach to care, driven by optimising quality of life and improving symptom management at end of life, regardless of the setting.(178) This holistic, inclusive approach challenges the traditional, medical and patient-centred model of acute hospital care delivery. In practice, as evident in this study, there is a demonstratable intersection between the principles of palliative

care and medically and patient-driven discharge planning practices. (8) While acute hospitals primarily (sometimes exclusively) focus on the patient and facilitating discharge from hospital as quickly as possible, this research revealed that these activities may be delivered with ongoing reference to palliative care imperatives. This means clinicians' must work with more uncertainty, being responsive to unexpected changes to patients' goals and plans, modifying their treatment approach accordingly, and seeking to include families, friends and carers throughout the process. (122) Carers must cope with uncertainty and constant change, and adapt quickly to their new caring roles and responsibilities amidst distress and grief.(122)

These features of acute palliative care settings can explain the adaptive responses occupational therapists and carers invoked when using the CSNAT-I – an intervention originally developed for a more predictable home-based palliative care setting. (51) Care was conducted in an environment of constant change. This required modification of how care or the intervention was provided and received to allow both occupational therapists and carers to accommodate the constant changes in care plans and pathways home. For occupational therapists, this environment of rapidly evolving change was considered usual practice and familiar. This environment and occupational therapists' confidence within it may also explain carers' acceptance of the lead role OTs took in the delivery of the CSNAT-I in hospital, as well as the prioritisation of patient- and discharge-related support needs.

Differences in the service models of the two hospital settings could explain the differences observed in CSNAT-I implementation. For example, the SCH routinely facilitated many more home discharges for people with palliative care needs, and patients stay longer in the facility, allowing more time to provide a holistic approach to care and involve carers and families in the process. The acute GH provided multiple medical and surgical services and patients' hospital stay was routinely much shorter. During the research, the GH was also responding to the COVID-19 pandemic, with rapid and major redesign of its service model and heightened pressure to discharge patients quickly. As a result, GH occupational

therapists had minimal ability to increase their scope of care to include carers, or support practice change. During the same period, care at the SCH continued largely as usual. As described in the longitudinal qualitative study (2b), occupational therapists from the GH expressed intention to use the CSNAT-I, but these features of the GH were not congruent with being “implementation ready.

7.4.2 Adaptations of evidence-based interventions to fit into new settings

This study highlights how adaptations to an existing carer-focused intervention to align with a new context can occur as part of implementation. Adaptation can be defined as the degree to which an evidence-based intervention is intentionally modified in the process of adoption or implementation into a new context. (167, 179) Adaptation commonly involves changes or modifications made to intervention content, context and delivery, followed by modifications made to training and evaluation models. (167)

Adaptation can occur for various reasons. Firstly, adaptation may occur when there is a mismatch between the intervention and the setting, (166) and may be inevitable when introducing a new intervention into an existing setting. For example, time and/or personnel limitations may require the conditions or the intervention to change to enable adoption. Sound understanding of the environment and context allows the intervention to be modified before it is introduced. However, unplanned or reactive modification may occur in response to contextual issues or obstacles that arise. (166, 180)

Secondly, intervention adaptation may occur to reduce inequities in access for key groups, including underserved populations(181) such as people with serious mental illness. This may involve socio-economic measures such as reducing the cost of a program or translating resources for people from cultural and linguistically diverse backgrounds. Adaptation can improve implementation of an intervention in a new setting by making it more relevant to local needs, but it is important to consider whether doing so will compromise its overall effectiveness.

Different types of adaptations can influence the fidelity and overall effectiveness of the intervention. Wilstey Stirman and colleagues (180) described fidelity-consistent and fidelity-inconsistent adaptations. Fidelity-consistent modifications of an intervention maintain core components that are needed for effectiveness. Fidelity-inconsistent modifications can compromise the core components of the intervention and its efficacy. (166) An adaptation's classification can be determined based on the literature, input from intervention developers, and study data.(180)

In the current study, planned and fidelity-consistent adaptations occurred as part of a standardised implementation strategy created by the original intervention developers. Fidelity-consistent adaptations occurred with respect to delivery modes, physical settings and providers, but did not alter the five stages of the CSNAT-I. However, once the CSNAT-I was introduced into the real clinical setting, fidelity-inconsistent adaptations occurred. Review stages of the CSNAT-I were not completed, and the CSNAT-I delivery process moved from a carer-led to a clinician-led model.

The impact of these unplanned adaptations on the research outcomes was not formally assessed. Occupational therapists believed that even partial delivery of the CSNAT-I was beneficial. However, in this program of work there was no feedback or data from carers who had only received part of the CSNAT-I. This is an area that requires attention in future implementation research.

Balancing fidelity and adaptation

To date, there is no evidence supporting the notion that partial delivery of the CSNAT-I will be effective in achieving desired outcomes such as improving carers levels of preparedness to care, quality of life and reduce distress levels. However, in other settings such as primary mental health care, where fidelity-inconsistent adaptations are made to increase access to specific interventions, research exists to show that intervention efficacy is preserved and better healthcare outcomes delivered.(166) This has been reported in scenarios where social determinants meant an intervention could not be

delivered as intended. For example, Aschbrenner and colleagues(166) evaluated national implementation of a lifestyle intervention for people with serious mental illness living in the community. To overcome social and economic obstacles (e.g., societal stigma of serious mental illness and related costs) to accessing the program, researchers changed the setting from a community fitness facility to a mental health agency. Even though the developers considered community-integrated fitness participation to be a core component, participation in the adapted program was associated with reduced cardiovascular risk. The modification also increased access to under-serviced groups.(166)

Finally, fidelity-inconsistent adaptations may have few negative impacts upon the desired outcomes of "intervention bundles"(170) – multifaceted and highly individualised interventions in which concern for adherence to dosage is low. Instead, the effectiveness of the intervention can rely on the personal experience and meaning of the intervention to the recipient: what is the intervention doing for them? This has been described as "fidelity of enactment[3]".(182) Given that the underlying mechanism of the CSNAT-I relies on the individual responses of carers and their perceptions of whether their needs are met,(137) fidelity of enactment could be an alternative end point for carers in future studies, rather than relying upon protocol adherence as has been the case to date.

7.5 Recommendations for future research

Project 2 provided new evidence and raised new avenues for intervention development and implementation for the CSNAT-I (and other carer-focused interventions) in the hospital discharge setting for carers of people with advanced cancer. The following methodological modifications should be considered and evaluated.

[3] Enactment is the degree to which the skills acquired from the intervention translate into daily life.

1. Integrate an adaptation framework into CSNAT-I implementation

A systematic approach is required to plan, conduct and evaluate adaptations made to improve intervention implementation. To date, reporting of adaptations and application of frameworks in implementation research has been rare, occurring mostly in public health programs.(117) This recommendation could be operationalised by embedding the Model for Adaptation, Design and Impact (MADI)(113) into the CSNAT-I Implementation Toolkit. Based on earlier modification frameworks - a Framework for Reporting Adaptations and Modifications-Enhanced (FRAME)(180) and the ADAPT guidance,(170) MADI is a process model that clinicians and researchers can use to understand the characteristics of and the relationship between planned and unplanned adaptations, along with their impact upon outcomes. MADI has three domains: adaptation characteristics (what is modified, how, by whom, for whom/what and when), potential mediating or moderating factors (e.g., relationship with fidelity, influence of systematic factors) and implementation and intervention outcomes (intended and unintended impact). The ADAPT guidance tool(170) offers a traffic light system that outlines elements of intervention that can be adapted and those that should not.

The application of an adaptation framework and guidance tool could be considered in future CSNAT-I developmental studies and integrated into the planned implementation strategy. In the event of any modifications to CSNAT-I content and delivery, studies evaluating the impact of these modifications on the outcomes of interest should be encouraged and reported using a systematic framework. This will ultimately assist researchers and clinicians to determine whether it is possible to achieve a balance between adaptation fidelity and impact that supports the implementation of CSNAT-I into real-world acute hospital settings.

2. Reconceptualise core components of the CSNAT-I when aligning with hospital context

Implementation researchers have noted the challenge of keeping core components recommended by developers intact when implementing an intervention into new and

dynamic contexts.(182, 183) It has been suggested that those developing interventions reconceptualise the form and function of their interventions' core components and consider what may be altered to overcome social, economic and environmental obstacles faced in real-world clinical settings. Interventions such as the CSNAT-I appear to need modification in order to co-exist with established workflows in a fast-paced acute hospital setting. Early developmental consideration would enable a more flexible approach to implementation rather than, as currently occurs, placing expectations on the health service to undergo significant transformation to adapt to the tool.(184) This is an important consideration for future work with the CSNAT-I and subsequent collaborations with its developers.

This reconceptualisation process may involve developers considering if it is acceptable for the CSNAT-I to be a clinician-led intervention when delivered in a hospital setting. To date, developers have not explicitly defined clinician-led and carer-led processes. However, the nature of the CSNAT-I process facilitates carer-led decisions around needs assessment and resulting activities.(138) In this model, clinicians' capacity to lead the intervention is limited to assessing when to approach the carer and how support may be sourced or provided. In this mixed methods study in acute hospital settings, clinician-led interventions were an accepted part of routine care, acceptable to both occupational therapists and carers. Studies exploring engagement with the CSNAT-I(185) and a person-centred needs assessment(186) suggested that the parameters defining clinician and care-led models are influenced by the context and preferences of individual carers and patients. If this is the case, then an approach that designates different levels of delivery according to and aligned with individual preference may be adopted, while still preserving fidelity and impact.

Another consideration is the need to identify the CSNAT-I stages that are either essential or inessential to achieving the outcomes of importance to carers. This question needs to be tested in future studies, in which researchers should consider the fidelity of receipt and

enactment as the implementation outcomes rather than dosage. Both receipt (the degree to which participants understand and engage with the intervention) and enactment (the degree to which the skills acquired from the intervention translate into daily life) relate to participant engagement with the intervention.(187) Even though consensus has not been reached in the literature regarding the best way to measure enactment, there is shared opinion that high enactment equates to good outcomes,(187) and therefore should be considered in future feasibility studies.

3. *Assessment of local needs of the setting throughout the implementation process*.
The third recommendation arising from Project 2 findings relates to the assessment of local needs prior to and during implementation to determine the compatibility of the intervention and the degree of adaptation required. This aligns with the CTF recommendations and is a core part of most implementation frameworks. (Damschroder et al 2009, Rojas-Smith et al 2014) The CSNAT-I Implementation Toolkit involved an assessment of organisational readiness for including carer support into usual practice in the planning stages of the project. However, it does not mention further assessment of when it is okay to pause, proceed or stop, or of enablers of and barriers to implementation. The IDEA framework proposes that organisations adopt a "voltage drop" approach, (Miller et al 2020) in which they may not be implementation-ready but are willing to accept principles of the intervention and review capacity for full implementation later. Future CSNAT-I implementation processes could include these approaches to enable early decisions about whether to proceed.

The approach described above was informally applied to the third and final component (Project 3) of this doctoral program – a feasibility trial (Chapter 8). The implementation problems encountered at the GH indicated that it was not ready to proceed to the trial stage, and that the concept should be reviewed or other intervention models explored. However, the high acceptability and more favourable implementation of the CSNAT-I in the

SCH led to further modifications to the intervention delivery model and implementation strategy and to the SCH being deemed a suitable trial site.

7.6 Strengths and limitations

This mixed methods research had both strengths and limitations. First, the triangulation of three data sources, the application of an evidence-based implementation strategy and theoretical frameworks (the TDF, TFA and CTF) enhanced the rigour of the studies and provided a detailed understanding of the multiple contextual and behavioural factors influencing implementation success. The inclusion of the CSNAT-I developers in the implementation planning and evaluation processes and peer review of study design served as both a strength and limitation. A strength of their inclusion was that their guidance ensured high quality in study design and implementation, particularly with respect to staff training and ensuring intervention fidelity. A limitation of the close collaboration was that the original developers were resistant to changing the original CSNAT-I model.

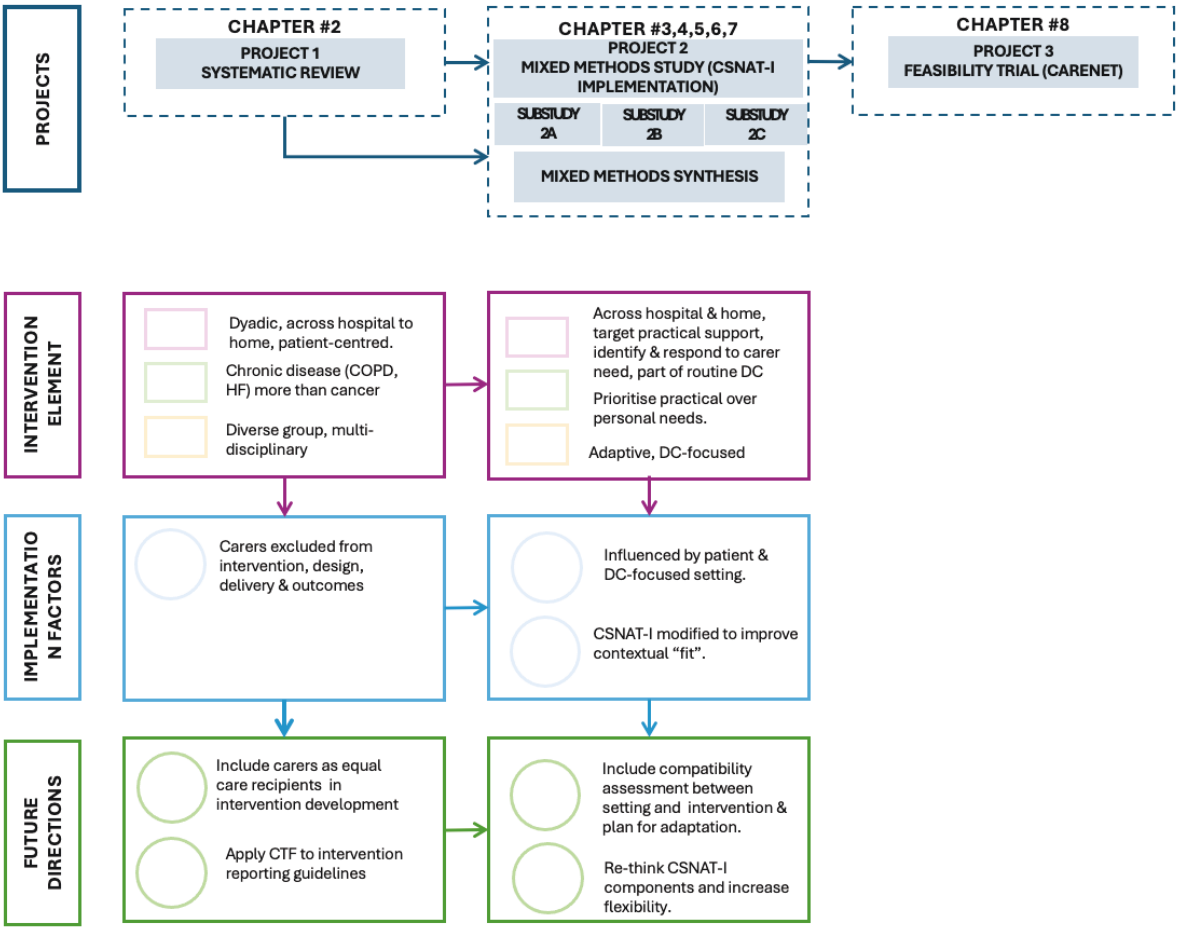
Conducting this research during the COVID-19 pandemic most likely influenced the researchers' views of caring and discharge planning. The uncertainty of the pandemic was also likely to have made the participating carers, occupational therapists and organisations less responsive to using a new intervention. These potential limitations were discussed amongst researchers and occupational therapists as part of the implementation strategy and acknowledged in the overall interpretation of the findings.

An additional limitation, unrelated to the investigator team, was the exclusion of some carer groups, specifically bereaved carers, carers from non-English speaking backgrounds, and carers whose patients were not receiving palliative care or OT during hospital stay. Research suggests that all of these groups have high levels of unmet needs and should not be overlooked in intervention design and delivery. (National Carer Strategy 2025). Future study designs could explicitly seek to include these carer populations.

7.7 Conclusion

This mixed methods study (Project 2) sought to understand what occurred when the CSNAT-I was implanted into routine care to assist carers of people with advanced cancer at discharge from the acute hospital setting. Its findings included identification of the specific intervention elements that carers and occupational therapists responded to, experienced, and the influence of the acute palliative care context on the way in which the CSNAT-I was delivered and received. Most importantly, the study highlighted that implementation of new carer-focused interventions into real-world clinical settings will undoubtedly involve adaptations to fit the practice context. As depicted in Figure 17, findings from Project 2 and the earlier systematic review (Project 1) have contributed to the overall doctoral aim of characterising core elements of a carer-focussed intervention that can assist carers of people with advanced cancer at hospital discharge. Both projects have provided evidence of specific intervention elements and implementation factors for consideration, and future directions required before proceeding to the next stages of research. Importantly, findings have informed the development of a refined care-focused intervention model (CARENET) that was tested in the third and final project - a feasibility trial (and described in Chapter 8).

Figure 17. Research components, processes and findings: Project 1 & 2.

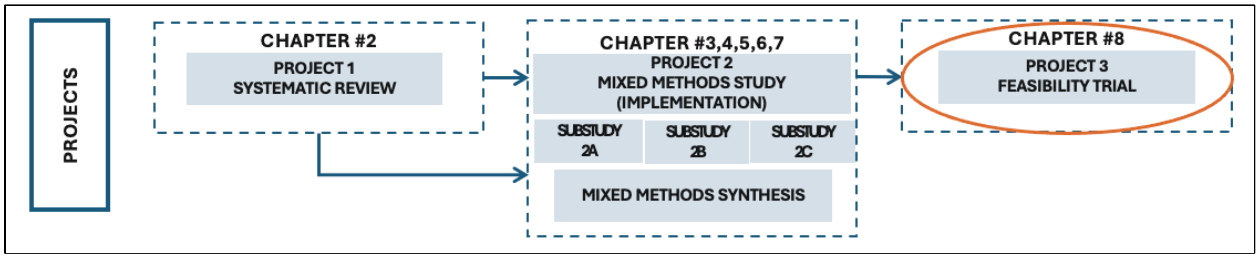


Chapter 8: Project 3: Findings from a phase 2 clinical trial (CARENET)

This chapter reports on the third and final component (Project 3) of this research. The first project was a systematic review that revealed a gap in the literature with respect to quality reporting and inclusion of carers in CTIs. This finding justified the conduct of developmental work in Project 2 (reported in chapters 3–7). Project 2 involved a concurrent mixed methods study of the implementation of a carer-focused intervention (the CSNAT-I) into usual care for supporting carers of people with advanced cancer at hospital discharge. The CSNAT-I was accepted as an integrated part of existing discharge planning models. Patients, carers and occupational therapists valued the CSNAT-I as way of responding to and actioning practical needs of caring and offering support across hospital and home settings. Occupational therapists' adapted the delivery and content of the CSNAT-I to fit into their practice scope and the acute discharge setting.

Findings from Projects 1 and 2 were applied to the development of a refined carer-focused intervention model – the CARENET. Project 3 was a phase 2 trial testing the feasibility of delivering CARENET to carers of people with advanced cancer and a planned discharge home. (Figure 18 shows the relationship and processes between all three projects.

Figure 18. Research components and processes for Project 3.



This chapter provides a synopsis of Project 3's aims, design and methods, followed by presentation of results, discussion and a conclusion. The discussion was informed by the

outcomes of an expert stakeholder group meeting held at the conclusion of the trial to consider translation of the findings at consumer, organisational and societal levels.

This chapter is derived from a manuscript submitted for publication in 2025 in Palliative and Supportive Care (submitted/under review; see Appendix 15). Palliative and Supportive Care is a peer-reviewed open access journal with an impact factor of 2.4, which focusses on publishing evidence to influence clinical practice, policy and research that enhances the psychosocial spiritual and symptom management aspects of palliative care. Formatting has been changed to align with the rest of the thesis.

8.1 Introduction

Moving from hospital to home can be a time of heightened stress and uncertainty for people with advanced cancer and their carers, because most of the care responsibility shifts onto family or friends.(32) This transition of care is associated with uncontrolled symptoms for patients and excessive burden on carers, many of whom are unaware of what to expect when caring for people with advanced cancer,(11) who typically undergo a rapid and sudden decline in function in the last 40 days of life.(16)

Carers are critical to successful discharge from hospital to home at the end of life.(34, 188) Firstly, they provide most of the care when a person returns home from hospital, often at substantial emotional, physical and financial cost.(32, 33) Secondly, their capacity to provide care remains one of the main factors that influences a person's ability to remain at home and avoid readmission to hospital.(34, 188) Thirdly, they have unique needs that differ from those of the patient and routinely remain unmet, such as detailed information related to support and practical aspects of caring.(33, 35)

International policy recommends that carers are included in discharge planning models and their support needs are met across the continuum of care.(1, 37, 40, 139) However, carers of people with advanced disease are under-represented in interventions and service

initiatives aimed at improving hospital discharge. A recent systematic review of the reporting quality of hospital-to-home transition intervention studies found that only 22% of studies included carers in intervention design, delivery, and outcomes, and even less so for people with advanced cancer.(189)

The Carer Support Needs Assessment Tool – Intervention (CSNAT-I) has shown promise as an intervention model that could be delivered in the hospital discharge setting.(57, 60, 65) Originally developed for community palliative care settings, the CSNAT-I is a systematic 5-stage process that creates opportunities for identifying and meeting carers' needs and has been demonstrated to improve their ability to cope with care at home.(55, 58, 60) These improvements include significant reduction in prolonged grief,(55) strain (54) and sustained increased preparedness and quality of life.(58)

Carers and clinicians in a UK study recommended that CSNAT-I be implemented in hospital settings to expand the discharge planning focus to include carers. Their intention was to combat "unrealistic expectations" of what care at home would entail and reduce the likelihood of breakdown of care at home after discharge.(57) Carers in this study also recommended implementing this tool as early as possible during hospital admission, with a review upon the initial transition home.(57) Recent evaluation of the CSNAT-I, implemented by palliative care nursing staff in a UK hospital, revealed behavioural and organisational challenges to its delivery.(65)The structure and focus of the CSNAT-I was considered acceptable; however, there was uncertainty regarding the "fit" of carers' needs in the health systems and which health professional should be responsible for delivery of the CSNAT-I.(65)

To investigate this further, we examined the CSNAT-I in an Australian inpatient acute cancer setting as part of routine care by OTs.(174) OTs play an important role in facilitating discharge home at end of life through interventions that optimise patients' functional performance and carers' capacity to care. (19, 47) The CSNAT-I was accepted by patients,

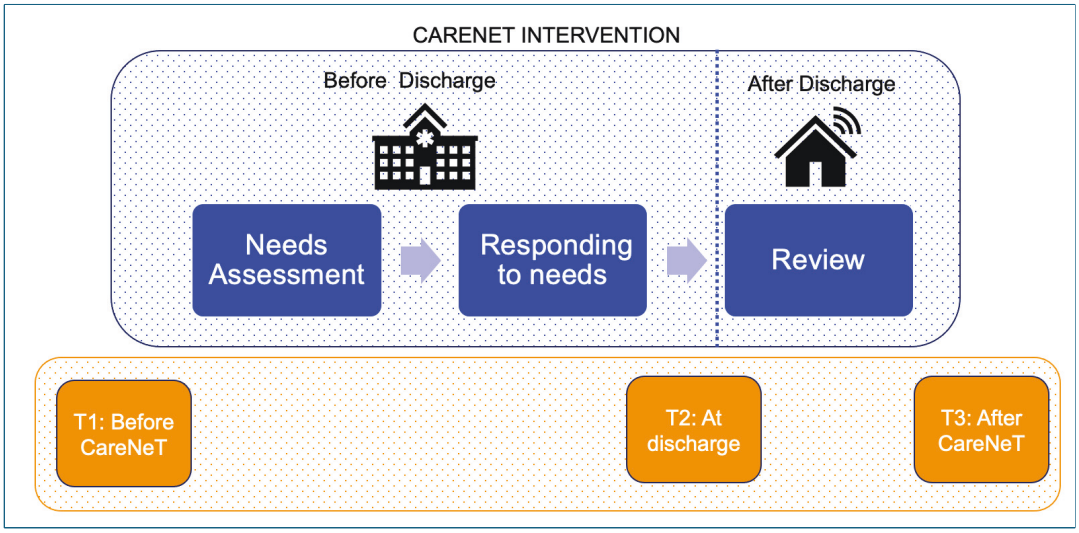
carers, and occupational therapists as an integrated part of existing discharge planning that should reach across hospital and home and target practical needs of caring.(174) Study findings informed the development of a modified delivery model for the CSNAT-I – **CAR**ing for car**E**rs of people with adva**N**c**E**d cancer at hospi**T**al discharge (CARENET). The CARENET model was then used to proceed to the next phase of feasibility testing in a controlled trial. Feasibility refers to the practicality of an intervention – whether it is fit for purpose in a specific context.(119, 190) Three key areas of feasibility were assessed: practicality, implementation and limited efficacy, based on Bowen's framework.(190) Practicality refers to the extent to which an intervention can be delivered within existing resources and circumstances. Implementation refers to the extent to which an intervention can be delivered as intended within a defined context or according to protocol (i.e., fidelity). Limited efficacy refers to the intended effects of an intervention on relevant outcomes.(190) Thus, this study aimed to determine the feasibility of delivering the CARENET intervention to carers of advanced cancer patients in an acute oncology setting, and the feasibility of the study design, to inform a possible phase three trial.

8.2 Methods

8.2.1 Design

A single-arm open-label study design was employed to determine the feasibility of the CARENET intervention and the study design. The selected study design aligns with the feasibility and piloting stage recommended in the MRC framework for design and evaluating complex interventions.(74) Feasibility was assessed using three key areas of focus recommended by Bowen's framework for feasibility studies (190)– practicality, implementation (fidelity) and limited efficacy, linked to the trial aims and measures detailed in Figure 19. Quantitative data were collected prospectively to achieve trial aims. CONSORT guidelines were used for reporting structure.(191)

Figure 19. Intervention components (needs assessment, responding to needs, and review) and data collection timepoints (T1 – before CARENET, T2 – at discharge, and T3 – after discharge)



8.2.2 Participants

Participants were adult inpatients with advanced cancer and informal carers (patient–carer dyad). For the purposes of this study ,carers were defined as “lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management” (139) All people with advanced cancer and identified carers admitted to a medical oncology ward were eligible and screened for the study. Eligibility criteria included English language competence, identification as a carer of a person with a diagnosis of advanced cancer with a planned discharge home, and ability to provide informed consent. Carers were excluded if their patient had a planned discharge to residential care or a subacute setting. Patients who were part of a dyad and able to provide informed consent (or proxy written consent) were eligible and invited to participate.

8.2.3 Procedure

The study protocol was prospectively registered with the Australian New Zealand Clinical Trials Registry, Registration No: ACTRN12622001325796. Ethical approval was obtained from the Peter MacCallum Cancer Centre Ethics Committee (HREC No. 83438, EC00235

and UTS Ethics Committee (ETH22-7440), (Appendix 16). From November 2022 – July 2023 potential participants were identified and referred for eligibility screening. Eligible carers and patients were invited to participate in the study, and if willing to do so, to provide formal consent. Once carers consented, the patient's consent was sought. The proposed sample size was 20–30 patient–carer dyads, as per the rule of thumb for feasibility studies(192) and based on pragmatic findings from the preliminary study.

8.2.4 Intervention

The features of the CARENET intervention are described in Appendix 17 and represented in Figure 19. CARENET involved delivery of the CSNAT-I by OTs as an integrated part of usual discharge planning practices across hospital and home settings. During the hospital stay, carers completed two components: an assessment and prioritisation of their needs using the CSNAT-I tool (needs assessment), an action plan to meet their needs (responding to needs) via support from treating OTs or signposting other avenues of support for the carer to initiative themselves, and (within 72 hours after returning home from hospital) received a review of carers needs via telephone (review).

The assessment component of the CSNAT-I consisted of the carer choosing three priorities from 15 domains of support need. The domains related to the practical aspects of caring as well as their personal needs as a carer.(51) Before recruitment commenced, OTs completed training and participated in a planned implementation strategy to support the delivery of the intervention. This included a 90-minute individual online learning module on the CSNAT-I(64) and two one-hourly group education sessions on the CARENET intervention protocol and trial processes. During recruitment, occupational therapists were supported and their adherence monitored by clinical champions, an expert working group of OTs, researchers and consumers, and file audit and informal assessment of clinician compliance (conducted by research assistant MLT and primary investigator CM) (Appendix 20).

8.2.5 Outcomes

The primary outcomes were intervention and trial feasibility (recruitment and adherence). Secondary outcomes were eligibility/attrition (practicality) and intended effect of the intervention on patient and carer outcomes (limited efficacy). These outcomes are aligned with the study's research questions, areas of feasibility, measures and endpoints in Table 15.

8.2.6 Data collection

Measures used for data collection are presented in Table 15. Patient and carer-related data were collected as standardised measures. Service, process and costing data were collected from medical records and project-specific case report forms. Data collection at the three time points (T1, T2 and T3) for study measures occurred as follows: T1 1–3 days before intervention, T2 1–2 days before discharge, during intervention, and T3 1 week after discharge, discharge, post intervention. Patient and carer outcome measures were the only measures collected across all three time points. Patient-related measures were the Australian Karnofsky Performance Scale (AKPS),(140) Resource Utilisation Groups – Activities of Daily Living (RUG-ADL),(141) Symptom Assessment Scale (SAS),(193) and EuroQol 5-Dimensions-5-Levels (EQ-5D-5L).(194) Carer-related measures were the Preparedness for Caregiving Scale(195) and Carer Quality of Life (QOL) Instrument (CarerQOL-7D).(196) The features of these valid and reliable measures are summarised in Appendix 18. Demographic data were collected at baseline (T1); on-cost data, as well as adherence, process and service data, was collected at T3. On-cost survey was adapted from other local feasibility trials, and consisted of closed questions about healthcare, travel, and personal costs accumulated during caring (Appendix 19).

Table 15. Feasibility outcomes and alignment with research questions, areas of focus, measures and endpoints

Research questions	**Areas of focus for feasibility (Bowen et al 2009)**	**Outcomes**	**Endpoints/measures**
Primary outcomes			
Can participants be recruited to CARENET trial within the required timeframe?	Practicality	Recruitment	20 participants enrolled in study within 9 months
Can CARENET and its critical elements be delivered to intended carer participants in a controlled setting?	Implementation	Intervention adherence	At least 80% of enrolled carer participants would have had all three aspects of intervention delivered (needs assessment, responding to needs and after discharge review)
Secondary outcomes			
To what extent can CARENET be successfully carried out with intended carer participants using existing means and resources?	Practicality	Eligibility, attrition/dropouts	Recruitment rate and eligibility data (including reasons for non-recruitment and withdrawal) via screening log and project specific electronic Case Report Form (eCRF)
Does CARENET show promise of improving outcomes for carers in an acute oncology context?	Limited efficacy/practicality	Completion rates of measures Intended effects of intervention on outcomes	Service and process data via project specific eCRF Variances in patient and carer-related measures**(to power for larger study). Patient measures: AKPS, EQ-5D-5L, RUG-ADL, SAS, carer measures: Carer Preparedness Scale, CarerQoL-7D

*Secondary feasibility outcomes as evaluating using qualitative data derived from carer and clinician interviews. Reported elsewhere.
**Supplementary File 2 for measurement properties. electronic Case Report Form = eCRF; AKPS = Australian Karnofsky Performance Scale; EQ-5D-5L = EuroQol 5-Dimensions-5-Levels; ; RUG-ADL = Resource Utilisation Groups – Activities of Daily Living; SAS = Symptom Assessment Scale; CarerQoL-7D = Carer Quality of Life (QOL) Instrument

8.2.7 Data analysis

Analysis was conducted using Excel (Microsoft Office V23.08) and IBM SPSS v28 software. Means and standard deviations are reported for continuous normally distributed data, and interquartile ranges and medians for data deviating from the normal distribution. Results derived from categorical variables are presented as percentages and frequencies. All questionnaires were scored according to their respective scoring guidelines. To evaluate changes in patient and carer-related measures (i.e., functional performance, quality of life and carer preparedness) between T1 and T3, we calculated difference scores and 95% confidence intervals (CIs). Additionally, we conducted paired sample t-tests and Wilcoxon Signed-Rank Tests to assess the statistical significance of these changes.

8.3 Results

8.3.1 Participant recruitment and eligibility

Of 382 identified eligible participants, 336 (87%) were not invited to participate, mostly due to rapid and unpredicted hospital discharge. The consent rate for the remaining 46 (12%) dyads was 54%, meaning 25 dyads were recruited across the 8-month accrual period (Figure 20). Twenty-four (96%) consenting dyads participated in the study. Figure 20 shows lower completion rates of measures at T2 than at T1 and T3, for reasons including the research assistant being unable to contact the carer at time of discharge.

8.3.2 Clinician adherence

Partial adherence was reached, with 60% of enrolled participants completing all three intervention components (Figure 20). Adherence to components occurring before discharge was higher than in the review component occurring after discharge, with 84% of carer participants completing the needs assessment, and 68% completing the needs assessment and creating an action plan to respond to needs. Reasons for non-adherence included patient death prior to completing the intervention (n=5), patient discharge too early (n=1), transfer to palliative care ward (n=1), unable to contact carer (n=2), and unknown (n=1).

8.3.3 Participant characteristics

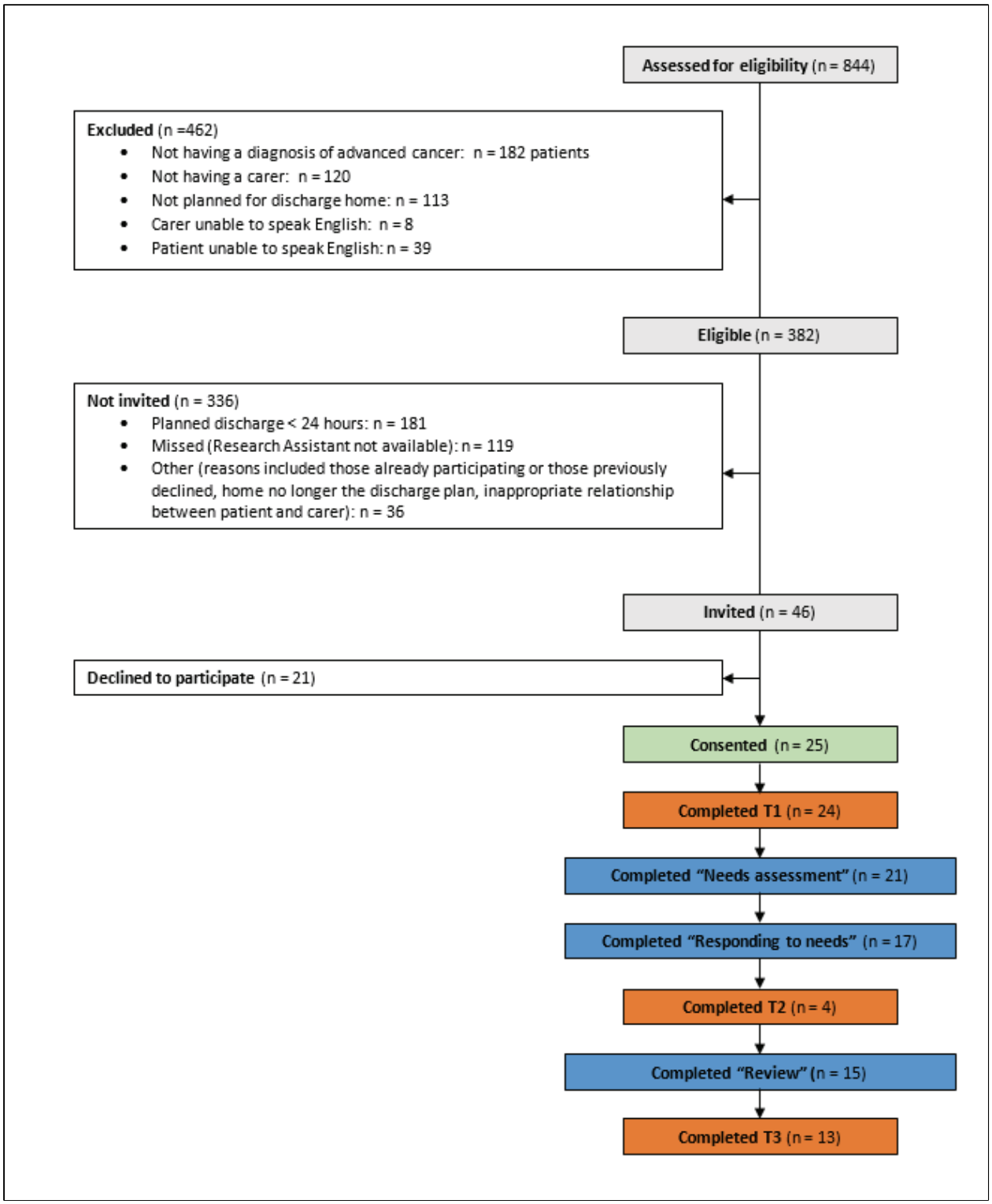
Key characteristics of patient–carer dyads are shown in Table 16. Carer participants had a mean age of 56.8 (SD=15.5), were more likely to be female (56%, n=14), born in Australia (76%, n=19), speak English at home (80%, n= 20), and be a spouse or partner to the person they were caring for (72%, n=18). Seventy-two per cent (n=18) lived with the person they cared for and 48% (n=12) were employed. Patient participants had a mean age of 59.7 (SD=15.9) and almost two thirds (64%, n=16) were female. Most patients spoke English at home (84%, n=21), more than half were born in Australia (64%, n=16), and 40% (n=10) were employed. There was high variance (heterogeneity) in the participant diagnosis, a median length of stay in hospital of 17.0 (IQR 14.5, 34.5) days, and home was the discharge destination for 76% of patient participants.

8.3.4 Limited Efficacy

Table 17 presents patient and carer measures (n=12) assessed before and after the CARENET intervention. Upon returning home (T3), patients reported higher care needs than during their hospital stay (T1), though they remained able to manage their own needs with moderate physical assistance. Symptom burden was also higher after returning home.

Carers exhibited mixed outcomes, reporting a decreased sense of preparedness for addressing patients' emotional needs but improved preparedness for practical caregiving tasks, including obtaining system support, managing emergencies, finding services, and providing physical care. The Preparedness for Caregiving Scale revealed increases in mean scores across practical domains, although these changes were not statistically significant.

Figure 20. Recruitment and participation, Project 3



T1 = Timepoint 1 – Before CARENET, T2 = Timepoint 2 – At discharge, T3 = Timepoint 3 – After CARENET

Table 16. Demographic characteristics of consented participant characteristics (N=25), Project 3

Carer participants

	n (%)
Gender	
Male	11 (44)
Female	14 (56)
Age (years)	
Mean (SD)	56.8 (15.5)
Median (IQR)	57 (53.0, 71.0)
Missing (n)	6
Relationship to the patient	
Spouse/partner	18 (72)
(Adult) child	4 (16)
Other (e.g., parent, sibling, friend) n	3 (12)
Level of education (completed?)	
Primary	0 (0)
Secondary	9 (36)
Tertiary	11 (44)
Missing	5 (20)
Employment status	
Employed	12 (48)
Unemployed	3 (12)
Retired	6 (24)
Missing	4 (16)
Primary language spoken at home	
English	20 (80)
Other	1 (4)
Missing	4 (16)
Country of birth	
Australia	19 (76)
Other	2 (8)
Missing	4 (16)
Length of time caring for the patient (months)	
Mean (SD)	14.5 (20.9)
Median (IQR)	5 (2.0, 16.0)
Missing (n)	4
	n (%)
Availability of carer	
Lives with patient	18 (72)
Lives with others	5 (20)
Missing	2 (8)
Other caregiving responsibilities	
Children n	4
Spouse/partner n	1
Other n	5
Patient participants	
	n(%)
Gender	

Male	9 (36)
Female	16 (64)
Age (years)	
Mean (SD)	59.7 (15.9)
Median (IQR)	63 (53.0, 72.5)
Level of education	
Primary	1 (4)
Secondary	10 (40)
Tertiary	8 (32)
Missing	6 (24)
Employment status	
Employed	10 (40)
Unemployed	3 (12)
Retired	8 (32)
Missing	4 (16)
Primary language spoken at home	
English	21 (84)
Other	3 (12)
Missing	1 (4)
Country of birth	
Australia	16 (64)
Other	9 (36)
Type of cancer	
Gynaecological	5 (20)
Lung	4 (16)
Haematological	3 (12)
Lower Gastro-intestinal	3 (12)
Skin & Melanoma	3 (12)
Upper Gastro-intestinal	2 (8)
Other*	5 (20)
Patient length of stay (days)	
Mean (SD)	23.8 (15.8)
Median (IQR)	17 (14.5, 34.5)
Number of readmissions within 30 days	
Mean (SD)	0.5 (0.6)
Median (IQR)	0 (0–2)
Missing (n)	6
	n (%)
Actual discharge destination	
Home	19 (76)
Died in hospital	5 (20)
Still in hospital at end of study	1 (4)

*Other = Breast, Head and Neck, Urological, Cancer of Unknown Primary, Neurological; IQR = Interquartile Range

Notably, carers' quality of life improved over T1–T3 (Table 18). While crude improvement was observed in several domains, including physical care, support from the health system, and overall preparedness, the only statistically significant changes occurred in carers' quality of life and overall preparedness. These findings suggest that the CARENET intervention enhanced carers' quality of life and preparedness for practical caregiving; and emotional support remains an area for improvement.

Table 17. Patient and carer outcome measures take before (T1) and after CARENET (T3) (n=12)

Outcome	T1 Mean (SD)	T3 Mean (SD)	Difference (T1–T3)^	95% CI
Preparedness for Caregiving Scale				
For physical care	2.50 (0.91)	2.83 (0.84)	-0.33	(-0.90, 0.23)
For emotional care	2.50 (1.01)	2.25 (0.87)	0.25	(-0.30, 0.80)
For service finding/set up	2.75 (0.87)	2.92 (0.79)	-0.17	(-0.70, 0.36)
For stress of caregiving	2.33 (1.07)	2.42 (0.10)	-0.08	(-0.82, 0.66)
To make caregiving pleasant	2.82 (0.75)	2.73 (0.79)	0.09	(-0.38, 0.56)
To handle emergencies	2.64 (1.03)	3.09 (0.83)	-0.46	(-1.27, 0.36)
To get support from the health system	2.75 (1.06)	3.17 (0.72)	-0.42	(-0.99, 0.16)
How prepared overall	2.75 (0.86)	3.25 (0.62)	-0.50	(-1.01, 0.01)
Total scores	21.09 (5.52)	22.36 (4.13)	-1.27	(-3.48, 0.94)
AKPS	68.89 (12.96)	61.11 (24.21)	7.78	(-5.41, 20.97)
RUG-ADL	4.44 (1.33)	7.33 (4.87)	-2.89	(-5.95, 0.17)
SAS	6.44 (4.56)	11.11 (12.23)	-4.67	(-12.15, 2.83)
Carer Quality of Life*	78.95 (14.09)	79.45 (12.45)	-10.47	(-17.10, -3.85)
EQ-5D-5L VAS Self - assessed health rating (0-100)	49.11 (31.17)	59 (35.92)	-0.51	(-9.46, 8.44)

* (0–4 scale, response options 0 = not at all to 4 = very well prepared), MCID = 0.25 point difference per item or more than 2-point difference overall

AKPS = Australian Karnofsky Performance Status, RUG-ADL = Resource Utilization Group – Activities of Daily Living, SAS = Symptom Assessment Scale, EQ-5D-5L = EuroQol 5-Level-5-Dimensions.

8.4 Discussion

This was the first phase 2 trial to test the feasibility of delivering the CSNAT-I to carers as an integrated part of planning for discharge of people with advanced cancer from hospital to home. While the recruitment target was reached, several challenges to the feasibility of the intervention and study conduct arose.

8.4.1 Implementation challenges

Firstly, a small minority of carers received the intervention; more than tenfold as many eligible carers were not invited to participate. This was due to a mismatch between the hospital discharge context and the trial's eligibility requirements. Rapid discharge for people with palliative care needs is commonplace in acute hospitals, and can occur within 24 hours (8, 174). Patients planning to return home in 24 hours had insufficient time to complete all aspects of the intervention and study measures. Another reason for the low recruitment rate may have been clinician "gatekeeping" by the occupational therapists that excluded patients and/or carers with perceived high levels of distress. (Such gatekeeping may be counterproductive: another CSNAT-I trial reported that clinicians who seek to avoid overwhelming carers may inadvertently limit support for those with greater needs (56).)

Secondly, in this trial, delivery of all intervention components as intended was difficult, particularly the review after discharge. Recorded reasons for not completing all components (i.e., availability of carers, patient death) were like those noted in other trials of adapted CSNAT-I models.(58, 62) However, it is possible that problems with delivering the CARENET as planned may have been due to shortfalls in the implementation process – specifically, training – that reduced occupational therapists' proficiency. The recommended implementation and training strategy was used for the CSNAT-I component,(64) but was hindered by high staff turnover, as well as occupational therapists' having reduced access to clinical champions and research staff for support and fidelity monitoring. Previous CSNAT-I studies highlighted the

importance of accessible and internally located clinical champions for successful implementation in both trial and usual practice settings.(63, 65) It is also possible that difficulty in delivering CARENET could be attributed to our use of a protocolised, multi-staged delivery model that is not congruent with the fast-paced and dynamic nature of the hospital discharge context. Discharge home from hospital can occur along pathways and timelines that differ from those for more stable and predictable community and home-based settings, in which most trials of the CSNAT-I have occurred.(54-56)

Thirdly, the study revealed difficulties with completion of the selected outcome measures. Obtaining data from patients and carers was more difficult to achieve at discharge (T2) than before and after intervention (T1 and T3). The positive trends observed for carer quality of life and overall levels of preparedness after intervention align with the findings of other CSNAT-I trials (55, 58) supporting the use of these outcome measures to test the impact of carer-targeted interventions. However, results must be interpreted with caution given the small sample size and the large proportion of eligible carers discharged prior to recruitment.

8.4.2 Implications and future directions

Our trial highlighted the opportunities and challenges of conducting carer-focused interventions in a high-pressure and unpredictable hospital discharge context. Future study designs must enable access to a larger and more diverse group of patient–carer dyads (e.g., with respect to age, ethnicity, and care needs) and ultimately improve the clinical translation of CARENET. This could include adopting a more flexible and multi-modal approach to eligibility, allowing for recruitment to occur at different times and settings that support carers' need and their patients' discharge pathways.(197) One such possibility is an opt-out approach, in which carers are automatically recruited to the study upon their patients' admission and given the choice to opt out.

A modifiable intervention model could improve access for carers who need support at discharge. This could entail intervening with carers at different levels with tailored delivery modes to accommodate their particular needs and circumstances. Research into carers of older hospitalised people supports flexible and adaptable models that

offer single and multistage approaches.(198) For carers of hospitalised people with advanced cancer, further research is required to understand the modifications that can occur without compromising the efficacy of the intervention itself.(198) This could include determining the core aspects of CARENET and those in which inclusion may be flexible. Tools to assist with adapting existing interventions could be used to systematise this process and achieve balance between carer access to the intervention and the impact on carer outcomes.(113)

Stepped-care intervention models offer a stratified approach in which level of care (or carer support) is matched to the level of complexity of the condition or individual need.(199) Stepped care models are well established in mental health care and are used to optimise access and efficiencies within given resources.(200, 201) Similarly, cancer prehabilitation models use a stepped care approach(202) in which all people having surgery are offered prehabilitation of varying scope and intensity. CARENET could be implemented in such a stepped-care approach, with intensity of support differing according to need. For example, carers of people experiencing escalating needs would need a greater intensity of intervention in discharge planning than carers of people whose needs are stable. If this approach was applied, additional feasibility studies would be needed to ensure intervention models are fit for purpose before proceeding to a larger-scale study.

It can also be argued that understanding the impact of a person-centred intervention like CARENET should be informed by the carers' engagement with the intervention, not just clinician adherence to protocol. Fidelity of enactment is a measure of engagement – specifically, whether the intervention leads to a change in behaviour that is enacted in daily life.(187) Even though the literature offers no consensus about the best way to measure enactment, there is shared opinion that high levels of enactment equate to good outcomes. Given that CARENET relies on carers responding to the needs assessment and the support offered for it to work, this aspect of fidelity should be considered in future feasibility study design alongside fidelity of delivery and receipt.(187)

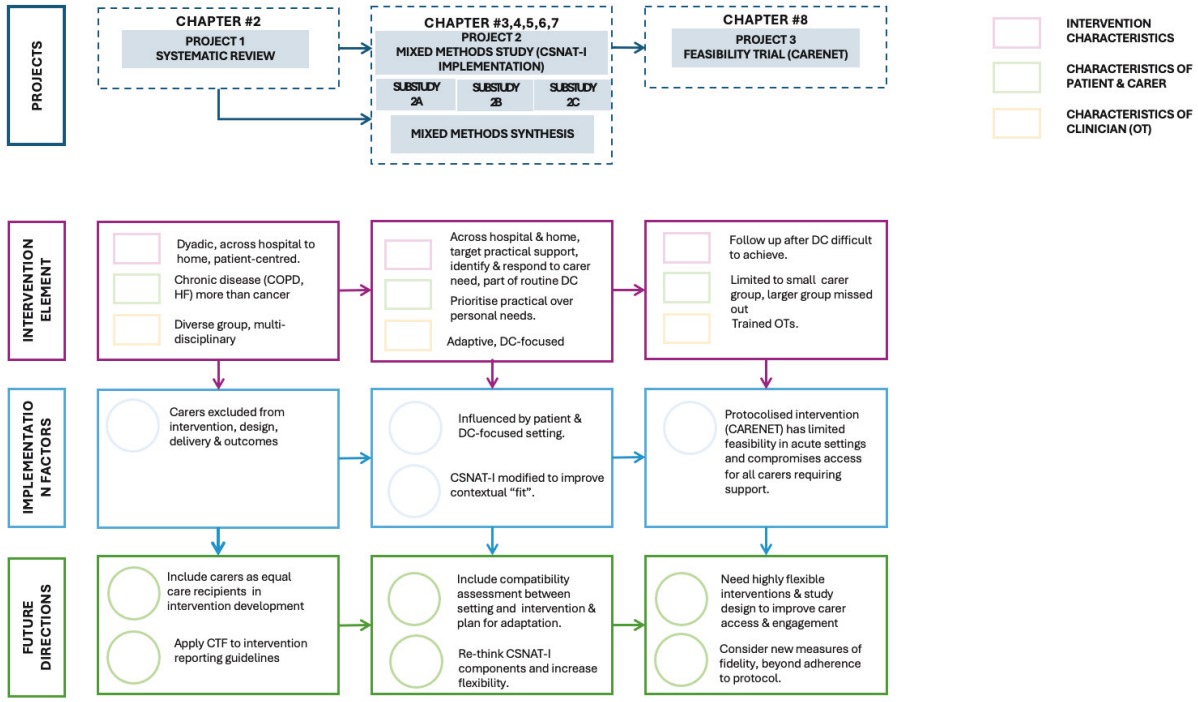
Several limitations of this study should be noted. Firstly, while the trial design was aligned with the MRC framework,(74) the single-arm design with no control group limited our scope to assess intervention effectiveness against usual care outcomes. Secondly, the small number of participants reduces the generalisability of the findings to other carer groups and hospital settings. Thirdly, the small sample size limits our ability to comment upon the efficacy of CARENET on patient–carer outcomes.

8.5 Conclusion

In conclusion, our trial supports the understanding that all carers of people with advanced cancer or palliative care needs will continue to need significant support during the transition from hospital to home. However, delivering a protocolised multi-staged intervention for some carers in this discharge setting may not be feasible and compromise access to support for other carers. Further exploration of the intervention content and delivery needed to benefit all carers and patients is required before proceeding to larger-scale trials.

As depicted in Figure 22, all three projects have now provided evidence of intervention elements, and implementation factors that can contribute the research aim of characterising a carer-focussed intervention to assist carers of people with advanced cancer at hospital discharge. A final synthesis that brings together all the projects' findings and future directions is the last remaining step required for this research. The final chapter (9) will report on this final synthesis, and important priorities for future research.

Figure 21. Research components, processes and findings: Projects 1, 2 & 3.



Chapter 9: Final discussion and conclusion

This chapter synthesises the empirical findings of Projects 1–3 and their interpretation. It reports on how the overarching aim of this body of work, namely to *characterise the core elements of a carer-focused intervention model that would facilitate successful hospital-to-home transitions for carers and people with palliative care needs*, was achieved. In addition, it provides answers to the overarching research questions:

- 1. What are the characteristics and mechanisms of carer-focused intervention models that target carers of people with palliative care needs to improve outcomes related to transitioning from hospital to home?
- 2. What are the key factors that influence implementation of a carer-focused intervention into usual practice in an oncology setting to assist with hospital discharge?

A synthesis of the mixed methods component of the program (studies 2a, 2b and 2c) was reported in chapter 7. This chapter presents a synthesis of the systematic review (Project 1), mixed methods research (Project 2) and the feasibility study (Project 3). These stages of synthesis, along with the sequence and context of each project and study, are represented in Figure 4.

9.1 Research question 1: what are the characteristics and mechanisms of carer-focused intervention models that target carers of people with palliative care needs to improve outcomes related to transitioning from hospital to home?

This doctoral research answered this question by identifying the elements of the CSNAT-I that can be readily implemented in an acute oncology setting to improve patient discharge. These elements and how they became evident across the study are presented in Figure 4.. Firstly, data from the mixed methods study showed the CSNAT-I was accepted by occupational therapists and carers as a **clinician-led dyadic intervention integrated into existing discharge planning processes, delivered across hospital and home**, and that **targeted the practical aspects of caring**. Similarly, the systematic review found that dyadic interventions before and after discharge were common in both cancer and non-cancer populations. Secondly,

themes arising from the qualitative work demonstrated how the CSNAT-I's principal features of **identification, actioning and follow-up of carer needs** were highly valued by all study participants and considered integral to delivering more support to carers. Even though this level of engagement was viewed as a core function of the proposed intervention, the quantitative data from the mixed methods and feasibility study showed that it was difficult to operationalise this in an acute clinical setting. In particular, findings showed that many carers required support for the adequate delivery of all stages of the CSNAT-I (and CARENET), and review of needs after discharge was not always achievable within or congruent with the acute context.

Thirdly, and importantly, findings from all three Projects show unequivocally that **intervention content and delivery need to be adaptable (or modifiable)** to improve contextual fit and accessibility for more carers. For example, the high variability in intervention designs reported in the systematic review suggest that a uniform approach to improving hospital-to-home transitions for carers is unrealistic. Also, qualitative themes arising from the mixed methods study showed that occupational therapists will modify a uniform intervention model (the CSNAT-I) to align with their current practice and the needs of individual carers. These qualitative findings informed the development of the CARENET intervention for the feasibility study, but its evaluation showed that the degree of adaptability applied within this study was still insufficient, resulting in eligible carers not receiving CARENET. Specifically, findings from the feasibility study affirmed the need for a **highly adaptable model** that can accommodate the different pathways patients can take across hospital and home and carers' preferences for support and engagement throughout this process.

The research also provided evidence of how the known mechanisms of the CSNAT-I operated in this new acute oncology setting. Mechanisms of complex interventions can be defined as the pathways through which an intervention leads to specific outcomes (110). The literature confirms that the CSNAT-I makes carer support needs visible, validating support for carers and enabling supportive conversations to occur (146). The mechanisms of the CSNAT-I that enable these outcomes include the creation of space to identify carers' needs separately from those of patients, and respond to the needs prioritised by the carer (146).

Qualitative themes derived from carer and occupational therapist experiences in the mixed methods study reflected these fundamental mechanisms (Chapter 4,5 and 7). For example, carers viewed the CSNAT-I as validating, increased an awareness of their needs, and elicited a sense of being "wrapped up in care".(138) The findings from the feasibility study and the process data collected in the mixed methods study built on this evidence, showing how these CSNAT-I mechanisms support carers in preparing for and facilitating patient discharge. Carers prioritised their practical needs over their emotional needs, and the CARENET trial showed positive changes in carers overall levels of preparedness after the intervention.

This new evidence about the mechanisms of the CSNAT-I is limited in its application beyond the carer population who participated in this research. Future researchers seeking to develop and test more flexible and modifiable CSNAT-I models must pay particular attention to how the original mechanisms might change with different carer groups and hospital settings, and the subsequent impact on carer outcomes.

9.2 Research question 2: what are the key factors that influence implementation of a carer-focused intervention into usual practice in an oncology setting to assist with hospital discharge?

This research question was answered by studying the implementation of the CSNAT-I in natural and controlled clinical environments in the Australian public health care system. The key influencing factors emerged from the research are presented in Figure 4 and explained below.

1. *Implementation was influenced by the **features of an acute oncology setting** and **adaptive response of** occupational therapists*

The **influence of the setting** on intervention delivery and peoples' experiences was a theme predominantly arising from the mixed methods research (Section 7.4) and strengthened by findings from the feasibility study (Section 8.4). Occupational therapists'' and carers' environment was almost exclusively centred around patient care, involved constant changes in care plans and pathways for discharge home, and

featured care delivered using palliative care principles. The uncertainties of their setting could explain clinicians' and carers' **adaptive responses** to delivering and receiving the CSNAT-I. Occupational therapists also modified elements of the CSNAT-I to improve its contextual fit into current practice and overcome barriers to practice change such as scarce time and resources.

2. ***A protocolised intervention*** *will not account for all carers' preferences and pathways home*.

The variation in carers' preferences and requirements when moving from hospital to home can also explain the difficulties encountered in delivering the CSNAT-I in a controlled and protocolised environment of feasibility testing, as in the CARENET trial. Recruitment and adherence data from the feasibility study showed that the modifications made to the CSNAT-I to develop CARENET were insufficient and limited access for more carers to receive support (Section 8.4). Data from this study also revealed multiple pathways home that had not been accounted for in intervention and study design, resulting in eligible participants missing out. The transition home from hospital for people with advanced cancer followed varied and flexible pathways, shaped by an individual's medical needs, the availability of support, and the capacity to manage care in a home setting. For patients in the trial who wanted to die at home, discharge planning occurred rapidly, sometimes within 24 hours of patients and carers making the decision to return home. In contrast, other patients required more time to optimise their functional performance before discharge, undergoing rehabilitation that extended their hospital stay. These different pathways undoubtedly placed different demands on carers and influenced their engagement with CARENET.

3. *CSNAT-I intervention and implementation assumed* ***carers were linked to patient care.***

A common thread across all the studies and this final synthesis was that intervention and implementation were **anchored to patient care.** Carers viewed themselves, and were viewed by others (occupational therapists and researchers), as inherently linked to caring for the patient. The goals of the CSNAT-I and later the CARENET were to improve the patient's transition from hospital to home and better support the carer for

their preparatory role with the patient. Intervening with the carer to improve care transitions was the underlying agenda of this doctoral research, and the intervention itself aligned with the best practice recommendations for including carer support in CTIs .(68)

However, findings across the studies suggest that focusing carer interventions solely on improving hospital-to-home transitions may offer a limited understanding of the broader carer population, including those who do not identify with the carer role. Data from the mixed methods and feasibility studies suggests that the CSNAT-I is well positioned to support carers who accept their preparatory role and are actively seeking support for the practical aspects of caring. This may explain the larger number of carers who are women who participated in the studies and used the CSNAT-I. However, this assumes that carers view themselves and the support they need as inherently linked to patient care.

Ewing et al demonstrated that carers can identify their own needs, separate to those associated with patient care.(51) Carers' needs span emotional, practical and relational domains, are often inter-related, and change across time and settings.(51) Personal support for carers could undoubtedly contribute to better hospital-to-home transitions for patients.(57) For example, a carer who can attend their own medical appointments and look after their emotional health in the home setting is likely to have greater capacity to cope with unexpected events, such as an unplanned hospital admission for the patient. This raises the question; how can carers emotional needs be addressed during the transition from hospital to home? The CSNAT-I could be delivered separately from the discharge planning processes, with clinicians not directly involved discharge interventions. Carer-centred navigator roles, which offer care coordination and emotional support, show promise. These roles could be filled by a clinician, including occupational therapists with appropriate competency-based training.

Quantitative findings from the mixed methods and feasibility studies have shown that there were carers who did not engage with the CSNAT-I or were not approached. Reasons for nor participating may have been because they: (1) did not identify as carers ("hidden" carers) (42, 203), (2) were unable to visit hospital because of cultural reasons

or stigma attached to caring, (3) were fulfilling cultural obligations, (4) identified stigma attached to caring role or (5) had simply chosen to not participate in the CSNAT-I. The importance of addressing this diversity of needs and preferences of carers is recognised in research and national strategy(42) where emphasis is placed upon the design of research and delivery of supportive interventions that are accessible and equitable for all carers.

9.3 Future directions

The key recommendation arising from this program of work is to develop a flexible carer support intervention model with a modular structure or a series of more diverse approaches. Such a model should focus on fostering accessibility and inclusion of carers who don't identify with their caring role. It should allow tailoring to individual needs and changes over time, thereby ensuring contextual fit. This work suggests that the model could be achieved by reconceptualising the core components of the CSNAT-I and ensuring the implementation strategy includes a systematic approach to assessing compatibility with new settings and considering intervention adaptations accordingly.

Operationalising the recommendation above requires a better understanding of the experiences and preferences of the carer groups that were not included in the research. Carers are a diverse group whose needs extend beyond the patient- and discharge-focused lens applied in this study. Therefore, the first step in producing a flexible carer support model, must be to return to the developmental stages of the MRC framework for complex interventions (Section 1.3.1) and undertake exploratory work to characterise carers. This could be achieved by employing a co-design approach, which would allow exploration of diverse carers' experiences and preferences for support and collaboration between researchers and stakeholders to develop a consumer-informed intervention. (204) This co-design research would need to include carer groups that were not represented in the current research and in research in the area more broadly. They include people from communities including culturally and linguistically diverse groups, older, younger adult and rural/remote groups, Aboriginal & Torres Strait Islander peoples, and "hidden" carers. Alongside carers, other stakeholders (clinicians, community members, service providers) should be included. It will be important to have strong carer representation but also gain perspectives at both clinician and policy

maker levels, given the influence of health system on carer support.(137) It is anticipated that a co-design approach would lead to:

- the development of more equitable and effective models through involvement of end-users;
- the minimisation of power imbalances between stakeholders (e.g., clinicians may design interventions *for* carers rather than *with* them; and
- the avoidance of research waste, in which studies proceed to testing stages and fail because they had inadequate consumer involvement in their development stages.

A co-design research program could involve a multi-phased approach with data collected through focus groups involving carers, clinicians, service providers and people receiving care. Phase 1 of the program would involve exploring the experience of caring and receiving support, Phase 2 would consist of studying carers' views on and preferences for support models (including adaptations of the CSNAT-I). Phase 3 would involve the development of adapted intervention models that consist of modules that align with specific carer groups but could evolve iteratively. These groups would include carers from diverse backgrounds who share a range of caring experiences (i.e., in terms of caring relationships, length of time caring, formal support systems). This iterative process would enable empirical findings from the research to be incorporated in the intervention development phases. For example, researchers could explore peoples' preference for flexible and individualised intervention models, and what constitutes fidelity of enactment (187) – that is, determine the core parts of intervention that carers will engage with and elicit meaningful change in their everyday life.

It is anticipated that this exploratory work with carers would generate bundles of carer support relevant for different groups or scenarios. Such bundles may include some or all elements of the CSNAT-I, depending on the preferences of the carer group.

Recommendations from a recent systematic review for co design in cancer research(204) could guide the co-design process. This would ensure that rigorous methodology, co-design principles and sound evaluation processes are enacted.

9.4 Conclusion

All carers need support at hospital discharge. Clinicians and health services must engage with carers as individuals with their own needs, not simply to support a hospital discharge. Doing so requires consideration of the experiences and preferences of all carers in the design of interventions and research. Intervention models need to be flexible and accessible, and model development must be driven by carers with diverse representation from across the community. In the short term, there is a need for co-design research that engages with all carer groups before proceeding to intervention testing and implementation.

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Appendix 1. Care Transition Framework: Example of domains, constructs and sub-constructs

Table 18. Care Transitions Framework—Intervention Characteristics

Construct	Description	Examples
A. Vision and change strategy (NEW)	The proposed changes envisioned by the intervention and the theory of change: how the intervention is supposed to work, what it is meant to achieve or do.[6] May be explicated in logic models, goals, outcomes, performance measures.	According to Complex Adaptive System (CAS) theory, a designated integrator can improve quality of communication among organizations, which will result in process improvement.[27]
B. Targeted groups	Staff and others (vendors, patients) who are the intended recipients or beneficiaries of the intervention.	—
C. Intervention source	Identifying who (which individuals or groups) originated the initiative and/or the source from which the components of the initiative were derived.	—
D. Evidence strength and quality	Target group and other stakeholders' perceptions of the quality and validity of evidence supporting the belief that the intervention will have the desired outcomes.[8]	Peer-reviewed published literature; consensus policy statements.
E. Relative advantage	Target group and other stakeholders' perceptions of the advantage of the selected intervention instead of other possible interventions or maintaining the status quo.[7]	—
F. Feasibility (NEW)	Target group and other stakeholders' perceptions of the extent to which the intervention can be successfully used or carried out within the organization(s).	—
G. Adaptability	Target group and other stakeholders' perceptions of the degree to which the intervention can be adapted to meet local needs.	—
H. Trialability	Target group and other stakeholders' perceptions of the ability to test components of the intervention on a small scale in the organization(s).	—
I. Complexity	Target group and stakeholders' perception of the duration, scope, centrality, and intricacy, and number of steps and organizations required to implement the intervention.	Packaged bundle of complementary activities vs. single activity (e.g., discharge planning).
J. Compatibility (NEW)	Target group and stakeholder perception of the alignment of the meaning, values, and norms attached to care transitions with those held by members of the organization(s).[21]	—
K. Radicalness (NEW)	Target group and other stakeholder perceptions of the degree of difference between the change envisioned and the current state of care transitions.[9]	—
L. User control (NEW)	The degree to which the intervention relies on the end-users' authority/skill to implement the intervention on their own vs. reliance on experts.	—
M Location of intervention activity (NEW)	Components of the intervention conducted outside the hospital/clinic/office setting using external service providers and organizations.	Case management, phone followup, home visits.
N. Design quality and packaging	Degree to which interventions within a bundle or program are well specified and well aligned with one another	A standardized intervention such as Project RED (Re-Engineered Discharge).
O. Workflows (NEW)	Tasks and workflows, including interdependencies between them that are the focus of the intervention or will be affected by it.[7]	Medication reconciliation, outreach to patients.
P. Task/process standardization (NEW)	Degree to which the intervention seeks to standardize tasks and processes that require iterative consultation.	—

Source: Rojas Smith L, Ashok M, Dy SM, Wines RC, Teixeira-Poit S. Contextual Frameworks for Research on the Implementation of Complex System Interventions. Methods Research Report. (Prepared by the RTI International– University of North Carolina at Chapel Hill Evidence-based Practice Center under Contract No. 290-2007-10056-I.) AHRQ Publication No. 14-EHC014-EF. Rockville, MD: Agency for Healthcare Research and Quality; March 2014. www.effectivehealthcare.ahrq.gov/reports/final.cfm.

Appendix 2. Supporting carers as patients move between hospital and home: A systematic review of interventions to support these transitions in care

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Supporting Carers as Patients Move between Hospital and Home: A Systematic Review of Interventions to Support These Transitions in Care

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Abstract

Background: Hospital-to-home transitions become more frequent and complex as people approach end of life. Although carers are critical to enabling these transitions, they report high levels of unmet need. A review of the interventions to assist these care transitions, along with understanding those intervention components and mechanisms that support carers of people with advanced illness, is required to inform an optimal care model for palliative care practice.
Aim: To describe the characteristics and reporting quality of intervention studies aimed at improving hospital-to-home transitions for carers of people with advanced illness.
Design: This is a systematic review with a narrative synthesis. (international prospective register of systematic reviews [PROSPERO] ID: CRD42020192088).
Data Sources: MEDLINE, EMCare, and PsychINFO databases were searched (2000–2021) for prospective studies reporting on interventions that (1) aimed to improve hospital-to-home transitions and (2) targeted carers of people with advanced illness. The Template for Intervention Description and Replication (TIDieR) checklist and constructs of the Care Transition Framework were used to assess the reporting quality of intervention design, delivery, and outcomes.
Results: In total, 37 articles were analyzed that included a range of study designs, interventions, and outcomes. Health care utilization ($n=29$) and clinical patient-related ($n=21$) measures were the most reported outcome. Theoretical discussion was minimal ($n=5$) with most studies using efficacy data from past research to justify intervention choice.
Conclusion: Carers are critical partners in hospital-to-home transitions at end of life; yet they are largely underrepresented in intervention design, delivery, and outcomes. Improving the reporting quality of carer-focused care transition interventions will inform future study design and support translation into practice and policy.

Keywords: carers; palliative care; patient transfer; systematic review

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Background

As disease progresses, it is common for persons to move through multiple different types of care (acute care, palliative care, and primary care) delivered at a range of sites including in their own home. The move between these types and sites of care is termed transitions.[1] People receiving palliative care in the last year of their life have increasingly complex needs, and more frequent transitions: commonly between hospital and home.[2–5] Transitions can be burdensome and result in increased anxiety for patients,[6] uncertainty for families or carers,[7,8] and may be accompanied by increased mortality.[9]

The carers of people with palliative care needs play a critical role in the transition from hospital to home. Carers provide most of the care at a personal cost to themselves.[10,11] Their capacity to care remains a key determinant of whether someone can be cared for at home and avoid readmission to hospital [9,12] They have a set of unique needs that remain largely unmet and unsupported.[11,13] According to one review, the most commonly reported unmet needs related to factors associated with transition between hospital and home.[11]

Interventions that aim to improve these transitions can be defined as ''a set of actions designed to ensure the coordination and continuity of health care, as patients transfer between different locations.''[14,15] These set of actions include communication, relationship, and process strategies that are specific to the context they are occurring in. These interventions are inherently complex and the way they are reported in studies varies considerably. They have proven effective in reducing disease burden, hospital readmissions, and health care costs in the older and chronic disease population.[16–18] The economic benefits of these interventions have also led to wide implementation into U.S. health care service delivery and policy.[17]

Interventions that target carers of people with palliative care needs during hospital-to-home transition are not thoroughly understood in palliative care research and practice. Specialist palliative care that explicitly prioritizes carers has been identified as one model of care that may facilitate discharge home. However, a recent review[19] examining the impact of inpatient specialist palliative care delivered before discharge excluded carers from their review.[19]

The complex nature of hospital-to-home transition interventions, the absence of evidence detailing the optimal intervention, and its components that target carers of people with advanced illness justifies the need for this review. According to the Medical Research Council (MRC) framework for developing and evaluating complex interventions,[20] before an intervention can be tested and implemented, preliminary work is needed to identify and characterize the interventions, its core elements, and mechanisms. No systematic reviews (SRs) to date have evaluated the reporting quality of carer-focused interventions that aim to improve hospital-to-home transitions, leaving a gap in empirical data to inform intervention design, evaluation, and translation.

Aims

This review aimed to:

1. Describe the characteristics and reporting quality of interventions, their core elements and mechanisms used in studies to improve the transition from hospital to home for carers of patients with advanced illness.
2. Examine their alignment with selected domains of Care Transitions Framework (CTF),[22] specifically intervention characteristics, implementation measures, and outcomes.

Review Questions

What are the characteristics and reporting quality of interventions and outcomes used in studies aimed at improving care transitions for carers for patients with advanced illness, and second, how well do they align with the CTF?

Methods

A SR was conducted using a narrative approach to synthesize and report according to the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) guidelines and was registered on the international prospective register of systematic reviews (PROSPERO; ID: CRD42020192088).[23]

Eligibility criteria

All prospective studies evaluating interventions related to improving transition of care across hospital and home for carers of patients with palliative care needs. For the purpose of this review, ''palliative care needs'' refers to people with advanced illness. A broader eligibility criterion was deemed necessary to capture all relevant studies because care transition interventions (CTIs) are multicomponent and interventions targeting carers can often be part of an ''intervention bundle.''

Defining transitions of care. For the purposes of this review, transitions of care were defined as the movement of the patient and family between health care settings, specifically across hospital/inpatient and community/home-based settings. Transitions of care occurring between clinicians or streams of care in the one physical setting (e.g., from intensive care to palliative care) were excluded.

Inclusion criteria

1. Prospective studies (quantitative, qualitative, or mixed-methods design).
2. Studies evaluating interventions related to improving transition from hospital to home.
3. Adult patients with chronic and/or advanced illness, can include carers.
4. Interventions that aim to improve the transitions of care across hospital/inpatient and home/community settings (home or residential care).
5. Interventions must include one or more of the key components recommended by World Health Organization (WHO):[1]
   a. Sharing and standardization of tools across settings (e.g., tracking systems).
   b. Systems approach (e.g., discharge planning, medication reconciliation, timely patient follow-up, timely clinical handovers, patient and carer support, and education).

c. Early assessment of those at risk, with complex transition needs.
d. Enhancing communication and relationships.

Exclusion criteria

1. Retrospective, case studies/series, and commentary pieces.
2. Studies evaluating interventions that aim to improve transitions of care between clinician or streams of care in one physical setting only (e.g., from intensive care unit [ICU] to palliative care).
3. Adult patients with asthma, diabetes, or curative cancer.

If SRs were identified in the abstract/title screening stage as meeting the inclusion criteria 2, 3, and 4, they were submitted to the full-text screening stage, so their included studies could be reviewed for inclusion/exclusion. The SR was not considered an included study.

The authors conducted the full-text screening in two parts: (Fig. 1) (1) Assessment against the mentioned inclusion/exclusion criteria and (2) a second screen looking for evidence in the intervention description of carers having received part or all the intervention. This was because it was not always evident in the titles or abstracts whether carers had been targeted in the study.

Information sources

A comprehensive search of three databases (MEDLINE, EMCare, and PsycINFO) was conducted. The search strategy (Box 1) was developed with assistance of the librarian and included (1) subject headings; MeSH terms; and keywords to search for palliative care, chronic and advanced illness, and care transition terms; (2) studies published from 2000 to current; and (3) adult population over 18 years. Must have citation of patient discharge or transition of care. Gray literature (including clinical practice guidelines) and unpublished studies were not included. Lateral searching was conducted for checking reference lists of 20 SRs. The search was run in February 2020 and repeated in August 2021. Search strategy is as per Box 1.

Study selection and data extraction

After removal of duplicates, a screening process was independently undertaken by four researchers with medical and allied health backgrounds (C.M., M.A., J.P., and D.D.M.). Screening criteria were tested by each researcher with 20 studies exported onto Excel from endnote before commencing formal title/abstract screen within Covidence. Title and abstracts were double screened—one researcher (C.M.) screened all the studies while three other researchers (M.A., J.P., D.D.M.) double screened one-third of studies each. Discrepancies regarding study selection were resolved by group consensus. Abstracts that met the eligibility criteria were reviewed as full-text articles by two researchers, by applying the same distribution method used for title/abstract screening.

Conflicts were managed through verbal discussion and revision of eligibility criteria between two researchers. Conflicts were resolved through discussion with a third reviewer. During full-text screening, we handpicked 89 studies from 20 SRs that met the criteria through abstract/title screen. A full-text screen was conducted on these 89 studies against criteria. An additional full-text screen was conducted to identify studies describing interventions that targeted carers either exclusively or in conjunction with patients.

Data were extracted by two reviewers (M.A. and C.M.) using a Microsoft Excel 2010 spreadsheet. Data were extracted under the following headings: author, year, title, study aim, population/setting, design, description of intervention and control intervention, outcome measures, and results.

Quality assessment

Quality assessment was conducted for selected studies that had reported on intervention components designed for carers—either for carers exclusively or a combined model for both patients and carers. The Template for Intervention Description and Replication (TIDieR) checkist and the CTF were the two approaches used for quality assessment.

The TIDieR checklist was used to review the reporting quality of the intervention and its key components.[21] The studies were assessed against all of the 11 items on the checklist and received 1 of 2 ratings: reported or not reported for each item.

The CTF[22] was used to determine study alignment with the different constructs within the following domains: (1) intervention characteristics, (2) measures of implementation, and (3) outcomes. The CTF is typically used to guide design and evaluation of CTIs. It was chosen for this review because it offers constructs that are particularly relevant to hospital-to-home transitions and identifies the range of contextual factors that can influence the success of implementation of these interventions. It also incorporates carer-specific constructs such as ''carer needs and resources'' and ''carer-centered outcomes.''

The selection of these domains and relevant constructs was determined by an expert working group of medical, nursing, and allied health clinicians, and considered important to care transitions from hospital to home for advanced illness. Data extracted from the study content were linked to a relevant CTF construct and rated according to the reporting quality of this construct. Star rating was applied—two stars meant the construct was well described, one star meant poorly described, and no star meant not described.

Each construct was rated according to criteria predetermined by the primary researcher (C.M.) and outlined in Supplementary File S1. The first nine items of the TIDieR and the ''intervention characteristics'' domain of the CTF both cover the features and rationale for the intervention. This close alignment meant that the results were presented in the TIDieR format only to avoid duplication.

Synthesis of results

A narrative synthesis approach was used to provide a coherent understanding across the expected heterogeneity of studies describing complex and variable interventions.[24] Synthesis was structured around descriptive summaries of the common intervention and outcome components, the quality of the reporting of these, and quality of alignment with the CTF

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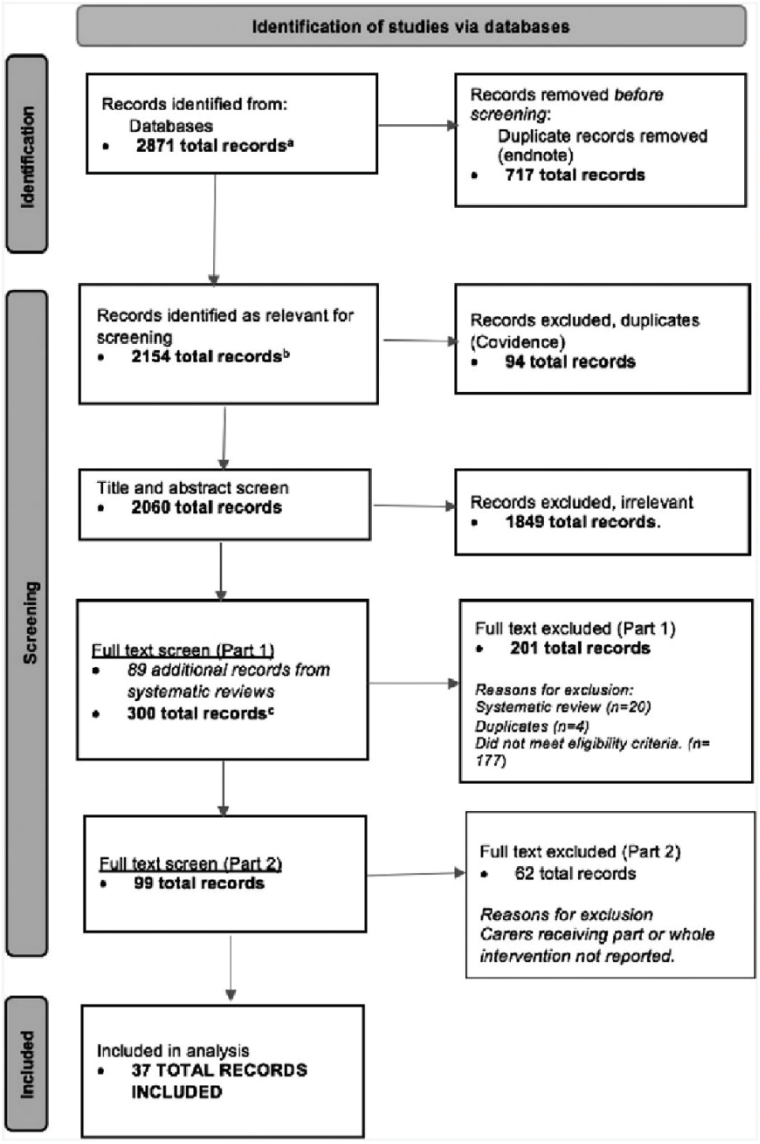

FIG. 1. PRISMA flow diagram of included and excluded studies. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta Analyses.

Box 1. Search Strategy

Database: Ovid MEDLINE(R) ALL <1946 to August 06, 2021> Search Strategy:
1 exp Palliative Care/ (53046) 2 exp Terminal Care/ (50519) 3 exp neoplasms/ (3295695) 4 exp Chronic Disease/ (260765) 5 (palliat* or terminal* or life limiting or chronic disease* or end stage or end of life or hospice or inoperable).mp. (970645) 6 (cancer* or carcinoma* or neoplas* or tumo?r* or malignan* or oncolog* or leuk?emia* or metasta* or adenoma* or adenocarcinoma* or adeno-carcinoma* or lymphoma* or melanoma* or sarcoma*).mp. (4363611) 7 (chronic adj4 (disease* or condition* or illness*)).mp. (552285) 8 (copd or cardiovascular disease* or cardiovascular disorder*).mp. (303406) 9 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 (5746094) 10 exp patient discharge/ or exp patient transfer/ or exp transitional care/ (36850) 11 (patient discharge or patient transfer or patient transition* or care transition* or transitional care or hospital discharge or hospital transition or discharge planning).mp. (62928) 12 10 or 11 (62928) 13 9 and 12 (9331) 14 palliative care transitions from acute care to community-based.m_titl. (2) 15 13 or 14 (9331) 16 1 or 2 or 5 (984269) 17 12 and 16 (3360) 18 exp Home Care Services/ or exp Community Health Services/ (299287) 19 (home care or community healthcare community health care or primary healthcare or primary health care or community based care or home healthcare or home health care or post hospital care).mp. (143897) 20 18 or 19 (391198) 21 13 and 20 (1096) 22 limit 21 to English language (963) 23 14 or 22 (963)

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domains. Included studies were reviewed iteratively exploring commonalities and differences and informed by the constructs of the CTF and TIDieR. Synthesis of efficacy was not planned because the focus was on understanding the nature of the intervention, and to include early intervention studies.

Risk of bias

The purpose of the review was to describe the components of the interventions, not their efficacy. As a result, risk of bias was not formally assessed.

Results

Study selection

Of the 2871 records found on the databases and additional 89 articles handpicked from 20 SRs, 2154 were identified for screening. Ninety-nine met Part 1 full-text screening process, and 37 met the Part 2 full-text screening process (i.e., evidence in the intervention description that carers received part or all the intervention). The PRISMA (Fig. 1) outlines the results of the first and second search.

Study characteristics

Table 1 outlines characteristics of the included studies. Twenty-eight of included studies were randomized controlled trials,[16,25–50] followed by experimental ($n=6$)[51–57] and observational ($n=3$) trials.[58–60] Studies were conducted in United States ($n=16$),[16,25,29,35,40,41,45,46,49,50,53,54,56,58–60] Europe ($n=9$),[28,30–34,36,48,51] United Kingdom ($n=2$),[42,47] Australia ($n=5$),[26,27,39,43,44] Asia ($n=4$),[37,52,55,61] and Iran ($n=1$).[57] Populations studied were patients with different diagnoses, primarily nonmalignant advanced illness: specifically, older population with chronic disease burden ($n=18$),[16,25,27,34,39,40,42–45,49,50,53–56,58,60] heart failure ($n=8$),[29,31,32,41,46,47,52,57] chronic obstructive pulmonary disease ($n=8$),[30,33,35–38,51,62] and followed by advanced cancer ($n=3$).[26,48,59]

Study participants were predominantly patients ($n=28$),[16,29–44,46,47,49–51,53–57,60] patient–carer dyads ($n=6$),[25–28,48,52] and carers ($n=3$).[45,58,59] Studies were mostly published after 2010 ($n=21$), half of these within the past five years ($n=10$) and the remainder between 2001 and 2010 ($n=16$).

Carers were included in the aim, intervention, and outcome descriptions of eight studies[26–28,45,52,58,59] and in the aim and intervention for three studies.[16,25,35] Four studies identified carers in the interventions and outcomes,[30,38,43,48] whereas 22 studies only mentioned carers in intervention section.[29,31–34,36,37,39–42,44,46,47,49–51] In the latter group of studies, carers were briefly described in the intervention section as recipients of different elements of the intervention such as phone-based education on symptom management.

Synthesis of results

Intervention characteristics through TIDieR. Table 2 presents the core elements of the intervention reported in the study using the TIDieR items. Studies described person-centered multicomponent interventions with variability in delivery mode, content, and timing.

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Table 1. Summary of Included Studies

Author and country	*Study design*	*Aim(s)*	*Participants*	*Outcome and measures*	*Findings*	*Carer elements*
Piette et al (2020),[25] United States	Randomized controlled trial, multisite	Evaluate CP intervention to improve postdischarge outcomes.	Patient–carer dyad: Inpatients with medical diagnosis (>50% COPD and HF). $N=283$; IG ($n=123$) and CG ($n=140$).	30 days readmission rates and readmission/ED visits. Rates of outpatient follow-up; characteristics of inpatient and outpatient episodes of care. Completion/success of call attempts.	No improvement in readmission rates. Pulmonary intervention patients had most clinical alerts ($p=0.004$) and reduced 30-day readmission risk (HR: 0.31; 95% CI: 0.11–0.87; $p=0.026$).	Aim, intervention.
Shaw et al (2016),[26] Australia	Randomized controlled trial, multisite	Test effectiveness of a phone-based carer intervention on improving patient and carer QOL, psychosocial outcomes and reducing hospitalizations.	Upper GI cancer, metastatic liver disease, stage 4 colorectal cancer adult inpatients. IG: patient ($n=64$); carer ($n=64$); CG: patient ($n=64$); carer ($n=64$).	Patient and carer-related measures related to QOL and psychosocial outcomes; service data and interviews to determine views on acceptability.	Carer QOL scores and other reported outcomes were similar. IG had increased sense of social support ($p=0.049$) and less worry about finances ($p=0.014$). Patients IG had less ED visits and readmissions. High fidelity and high carer acceptance.	Aim, intervention, and outcome.
Toye et al (2016),[27] Australia	Randomized controlled trial	Evaluates impact of Further Enabling Care at home on carers outcomes, then patients and the health care system when delivered after discharge.	Older medical inpatients. Patient–carer dyads. IG: ($n=62$); CG ($n=79$).	Primary: Preparedness for Caregiving Scale. Secondary: (1) Caregiver-rated Symptom Assessment Scale, (2) Barthel ADL Index, (3) Family Appraisal of Caregiving Questionnaire, (4) carer well-being rating (SF-12v2 Health Survey).	IG significantly improved preparedness to care from Time 1 to Time 3 (effect size = 0.52, $p=0.006$) and Time 1 to Time 3 (effect size = 0.43; $p=0.019$). Small significant differences in carer strain and other outcomes.	Aim, intervention, and outcome.
Coleman et al (2006),[16] United States	Randomized controlled trial	To test whether a CTI (for older people and their carers) can reduce hospitalizations.	Inpatients. IG: ($n=379$) and CG ($n=371$). Advanced age, advanced disease, high hospitalization, and ED use.	Primary: Rehospitalization rate at 30, 90, and 180 days after discharge. Secondary: Rehospitalization rate for the same condition. 180 Days.	IG had significantly lower rehospitalization rates at 30 days and at 90 days than CG and significantly lower rehospitalization rates for the same condition at 90 days and at 180 days than controls. IG had lower mean costs at 180 days than CG.	Aim, intervention.

(*continued*)

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Table 1. (Continued)

Author and country	*Study design*	*Aim(s)*	*Participants*	*Outcome and measures*	*Findings*	*Carer elements*
Utens et al (2014),[28] Netherlands	Substudy of randomized controlled trial. (nonblinded)	To evaluate impact of hospital at home on CSI, satisfaction, and preferences for venue of care compared with usual hospital care.	Inpatients with COPD exacerbation and their carers. CG: Patients ($N=69$), carers ($N=62$); IG: patients ($N=70$); carers ($N=62$).	Carer questionnaire at day 7 post-treatment and 90 days follow-up. Measures included CSI, satisfaction, and preference for venue of care.	No significant difference in carer strain; most carers preferred hospital at home and strongly associated with patient preference for hospital at home. Overall satisfaction with program.	Aim, intervention, and outcome.
Naylor et al (2004),[29] United States	Randomized controlled trial, multisite	To test effectiveness of transitional care intervention to elders hospitalized with HF.	Population: inpatients >65 years old from home, admitted with HF. $N=641$ eligible. Sample: IG $n=118$ and CG $n=121$.	Time to first rehospitalization or death; number of rehospitalizations, QOL, functional status, costs, and patient satisfaction.	Intervention significantly increased time between discharge and readmission or death; reduced readmissions and costs. Improvements in physical QOL ($p <$ –0.0.05) and patient satisfaction ($p<0.001$).	Intervention.
Aimonino et al (2008),[30] Italy	Randomized controlled trial	To evaluate the impact of physician-led hospital at home model for older people with COPD on hospital readmission rates and mortality.	Acute inpatients >75 years old, COPD exacerbation. IG $n=52$, CG $n=52$.	Primary: Readmission and mortality rates at six months. Secondary: Function (Katz ADL, Lawton IADL), depression (GDS), nutrition, cognition (MMSE), QOL (Nottingham Health Profile), carer stress (Relative Stress Scale), and satisfaction questionnaire, acute care costs, nutritional status at six months.	Intervention associated with reduced risk of readmission at six months, lower costs and better QOL. IG had lower readmission rate. IG had significantly better improvement in depression and QOL. No differences in function, cognition, or carer burden. High satisfaction across both groups. Lower cost per patient per day for IG.	Intervention, outcome.
Angermann et al (2012),[31] Bavaria	Randomized controlled trial, multisite	To evaluate mode of action and effects of a nurse-coordinated DMP (HeartNetCare-HF).	Patients discharged from hospital after cardiac decompensation. Intervention $n=352$, usual care $n=363$.	End point time to death or rehospitalization (and primary outcomes); secondary: HF symptoms and QOL (SF-36).	Primary end point was neutral; IG improved re-NYHA class ($p=0.05$), physical functioning ($p=0.03$), and physical health ($p=0.03$). High compliance.	Intervention.

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Table 1. (Continued)

Author and country	*Study design*	*Aim(s)*	*Participants*	*Outcome and measures*	*Findings*	*Carer elements*
Atienza et al (2004),[32] Spain	Randomized controlled trial, multisite	To assess effectiveness of discharge and outpatient program in patients admitted for HF.	Patients discharged with CHF. Sample: IG: $n=164$, CG: $n=174$.	Primary: Event-free survival at one year. Secondary: Readmission rates; QOL (Minnesota Living with HF) after one year and cost of management.	IG had significantly less events per year, longer time to first event, and lower readmission rates. QOL improved and cost of care reduced in IG.	Intervention.
Casas et al (2006),[33] Spain and Belgium	Randomized controlled trial, multisite	To evaluate impact of integrated care intervention can prevent readmission for COPD patients.	Patients admitted with COPD exacerbation. IG: $n=65$, CG $n=90$.	Health care utilization at 1,3,6, 9, and 12 months through phone interviews.	IG had significantly lower hospitalization rate than control and higher percentage without readmissions. No significant differences in mortality.	Intervention.
Hendrix et al (2011),[58] United States	Feasibility/pilot study	Examine feasibility of carer training program and impact on carer self-efficacy and preparedness for discharge.	Carers of older hospitalized veterans. $N=50$.	(1) Service and process data; (2) self-efficacy (Lorig's self-efficacy scale) and preparedness (family caregiving inventory) taken at pre- and postdischarge; (3) phone interviews at week 1 or 4 after discharge.	Feasible intervention, viewed positively by carers, and may improve self-efficacy and preparedness.	Aim, intervention, and outcome.
LeGrain et al (2011),[34] France	Randomized controlled trial, multisite	To determine if a new multimodal discharge-planning intervention would reduce readmissions or ED visits for older inpatients.	Patients >70 years old admitted to AGU. IG: $n=317$; CG: $n=348$.	Primary: Readmissions or ED visits three and six months after discharge. Secondary: Cost analysis of secondary health care costs per participant.	IG: At three months, significantly less readmissions to hospital or ED and higher survival rate. Lower secondary health care cost for IG at six months.	Intervention.
Hendrix and Ray (2006),[59] United States	Pilot study	To determine feasibility of carer training before discharge at bedside of older cancer patients.	Informal carers of older patients with cancer $n=7$ (female, mean age of 56 years), >50% African American.	Carer experience and views of intervention through interview data. Acceptance and completion rates of training.	High completion rate. Individual experiential training on symptom management and home care is a feasible model and received well by carers.	Aim, intervention, and outcome.

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Table 1. (Continued)

Author and country	*Study design*	*Aim(s)*	*Participants*	*Outcome and measures*	*Findings*	*Carer elements*
Abad-Corpa et al (2013),[51] Spain	Quasi-experimental	To evaluate the effectiveness of discharge planning intervention for patients with COPD.	Patients with COPD admitted to hospital. IG: $n=56$, CG: $n=87$.	Readmission rate, patient satisfaction (LOPSS12), QOL (St. George's Respiratory Questionnaire), and knowledge about COPD.	Discharge planning improves QOL at 12 and 24 weeks after discharge and knowledge of disease. Ineffective in reducing readmissions.	Intervention.
Aboumatar et al (2019),[35] United States	Randomized controlled trial	To evaluate outcomes of hospital-initiated transition program for COPD patients and their family carers.	Patients with COPD admitted to hospital. IG: $n=120$, CG: $n=120$.	Primary: Readmission and ED visit and patient HRQOL at six months after discharge. Secondary: Mortality rates, intervention implementation, and adverse events.	Significant higher readmissions and ED visits in IG. No significant improvement in QOL for both groups.	Aim, intervention.
Chiang et al (2012),[52] Taiwan	Quasi-experimental	Evaluate the effectiveness of nurse-led telehealth care on the outcomes of family carers of HF patients.	HF patient–primary family carer dyad. IG: $n=30$, CG $n=30$.	(1) CBI, (2) MMS, and (3) FFFS: at predischarge and at one month follow-up.	Carer burden, stress mastery, and family function significantly improved for IG. Telehealth plus discharge planning can benefit carer outcomes within 30 days postdischarge.	Aim, outcome, intervention.
Coleman et al (2004),[53] United States	Quasi-experimental	To test whether a CTI for older patients and carers can reduce readmission rates.	Older adults admitted to hospital. IG: $n=158$, CG: $n=1235$.	Hospitalizations at 30, 60, and 90 days postdischarge. Patient experience using care transition measure between 24 and 28 days postdischarge.	IG significantly less likely to readmit at 30, 90, and 180 days. They are more confident in disease management during transition.	Aim, intervention, outcome.
Lainscak et al (2013),[36] Slovenia	Randomized controlled trial	To test whether coordination of discharge from hospital reduces hospitalizations in patients with COPD.	Inpatients admitted with COPD, IG: $n=118$, CG: $n=135$.	Primary: Readmission rates Secondary: time to readmission, all-cause mortality, all-cause readmission, days alive out of hospital, and HRQOL. At 7 or 10 days, 30, 90, and 180 days.	Discharge coordinator intervention reduced both COPD hospitalizations ($p=0.002$) and all-cause hospitalizations ($p=0.33$).	Intervention.

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Table 1. (Continued)

Author and country	*Study design*	*Aim(s)*	*Participants*	*Outcome and measures*	*Findings*	*Carer elements*
Li et al (2014), [37] China	Randomized controlled trial	To observe the effects of transitional care on the QOL of COPD patients.	Inpatients with diagnosis of COPD. IG; $n=57$, CG $n=57$.	SGRQ, GHQ-12, and BMI. At predischarge and three months home visit.	Significant improvements in QOL including symptoms, activity, and mental status. No changes noted in BMI.	Intervention.
Jenq et al (2016),[54] United States	Quasi-experimental	To evaluate whether overall Medicare readmissions were reduced through an intervention applied to high-risk discharge patients.	Population: Hospital high-risk patients >64 Sample: Preintervention period: IG: $n=12,345$, CG: $n=11,775$; intervention period: IG: $n=18,223$, CG: $n=20,077$.	30-day unplanned same-hospital readmission rates in the baseline and intervention period.	Reduced readmissions by 9.3% among the full population targeted by the care model despite being delivered only to high-risk patients. But it did not achieve the goal reduction set by the CMS.	Intervention.
Kwok et al (2004),[38]Hong Kong	Randomized controlled trial	To evaluate the effectiveness of an intensive CN-supported discharge program in preventing hospital readmissions of older patients with CLD.	Population: Older hospital patients with diagnosis of CLD. Intervention: $n=77$, control: $n=80$.	Primary: Readmissions at six months. Secondary: Readmissions at four weeks; bed days, ED visits, 6MWT, psychosocial scores (LHS, GHQ and MHLC); and cost of care index; at baseline and six months. Carer burden through interviews.	No evidence that an intensive intervention can prevent hospital readmissions, or significantly change secondary measures except for social handicap score.	Intervention, outcome.
Preen et al (2005),[39] Australia	Randomized controlled trial	Evaluate impact of multi-disciplinary discharge care plan on hospital utilization, QOL and clinician satisfaction.	Older (mean age 75 years) inpatients with a primary diagnosis of chronic cardiorespiratory disease. IG: $n=91$, CG $n=98$.	(1) QOL before and seven days after discharge. (2) Satisfaction survey seven days postdischarge, (3) GP survey predischarge and seven days postdischarge, (4) hospital LOS.	For IG significant improvements in patient satisfaction, mental QOL. No difference in LOS between groups. Significant improvement in speed and GP communication.	Intervention.
Shu et al (2011),[55] Taiwan	Prospective experimental study.	To investigate the impact of an integrated PDTC program.	Older inpatients admitted with general medical disease. IG: $n=219$ (mean age: 69 years). CG: $n=94$ (mean age: 71 years).	Primary: Unplanned readmission or unexpected death within 30 days of discharge. Secondary: ED or unplanned clinic visits.	Integrated PDTC program can reduce rates of postdischarge readmission and death within 30 days of discharge (15% vs. 25%, $p=0.021$).	Intervention.

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Table 1. (Continued)

Author and country	*Study design*	*Aim(s)*	*Participants*	*Outcome and measures*	*Findings*	*Carer elements*
Watkins et al (2012),[60] United States	Descriptive single group nonexperimental study.	To evaluate effectiveness of a social-worker navigator transitional care model for at-risk older people being discharged from hospital.	Older inpatients (65 years or older) $N=292$, mean age 80 years.	Postdischarge ED visits, hospital readmissions, QOL through SF-36, and patient satisfaction (survey), service/activity data.	Reduced readmission rates by 61% and costs. Significant improvement in QOL for mental and physical aspects. High patient/family satisfaction (99%).	Intervention.
Zimmerman et al (2017),[56] United States	Experimental	Assess cost-effectiveness of four different doses of HBCTI compared with usual care at two and six months after discharge.	Inpatients with chronic disease. $N=126$.	Patient QOL (EQ-5D) between baseline, two, and six months follow-up, health service utilization (readmissions rates, ED visits) at two and six months. PAM and cognition (MoCA) baseline to two months.	Intervention most cost-effective for normal cognition/high activation patients; least cost effective for low cognition/low activation group.	Intervention.
Enguidanos et al (2012),[40] United States	Randomized controlled trial	To evaluate the impact of nurse practitioner intervention on CTs for older hospitalized patients discharged home.	At-risk older adults (>50 years) discharged home. IG $n=100$, CG $n=99$.	(1) Self-efficacy survey, (2) satisfaction with care, (3) service utilization (ED visits, hospital admissions, LOS).	Significantly improved patient satisfaction and self-efficacy and less primary care visits; no change in readmissions at six months.	Intervention.
Laramee et al (2003),[41] United States	Randomized controlled trial	Test effect of CHF CM on the 90-day readmission rate in a more heterogeneous setting.	Patients admitted with primary or secondary CHF, LVD <40%, or evidence of pulmonary edema. IG: $n=141$, CG: $n=146$.	Primary: All cause 90 days readmission. Secondary: Adherence to intervention, patient satisfaction, cost of medical care. Other: Readmission cause, LOS, CHF readmissions, hospital days, and days to first readmission.	90-day readmission rates were equal in IG and CG (37%). Reduced inpatient costs (14%) and readmission costs (26%) for IG. Significantly better adherence to intervention for IG. Patient subgroup had significant decrease in readmissions.	Intervention.

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Table 1. (Continued)

Author and country	*Study design*	*Aim(s)*	*Participants*	*Outcome and measures*	*Findings*	*Carer elements*
Nazareth et al (2001),[42] United Kingdom	Randomized controlled trial	To investigate the effectiveness of a pharmacy discharge plan in elderly hospitalized patients.	Inpatients >75 years and on four or more medications. IG: $n=181$, CG: $n=181$.	Primary: Readmission within six months. Secondary: mortality, clinic attendance, GP visits, hospital days, patients' well-being, satisfaction, and medication adherence.	No difference found in readmissions and secondary outcomes across both groups. Pharmacy discharge plan did not improve outcomes.	Intervention
Lim et al (2003),[43] Australia	Randomized controlled trial	To evaluate the benefits of coordinating community services through the PAC program in older patients after discharge from hospital.	Inpatients 65 years and over who met risk criteria and required community services after discharge. IG $n=311$; CG $n=287$.	Primary: Readmissions within six months. Secondary: QOL (through AQoL), carer stress at baseline and one month after discharge, mortality, hospital and community service utilization, and health-related service costs six months after discharge.	Significant improvements in QOL in one month; less hospital bed days in six months; and less hospitalization, community resource, and intervention costs in IG.	Intervention, outcome.
Naunton and Peterson (2003),[44] Australia	Randomized controlled trial	To evaluate pharmacist-conducted follow-up at home of high-risk elderly patients discharged from hospital.	High-risk medical inpatients (>60 years and prescribed four or more medications). IG $n=57$, CG: $n=64$.	Primary: Readmissions within 30 days, total days of readmission, and out-of-hospital deaths. Secondary: DRPs, number, and type of medications, compliance level, patient satisfaction questionnaire.	Significantly improved compliance in IG after 90 days. Less readmissions in 90 days for IG. Intervention well received by patients and GPs. GP implemented pharmacist recommendations in 79% cases.	Intervention.
Dellsega and Zerbe (2002),[45] United States	Randomized controlled trial	To investigate whether an APN intervention would benefit physical and emotional outcomes in carers of discharged older patients.	Carers of frail rural elderly patients (>65 years) currently in urban hospitals. Patient–carer dyad. IG: $n=16$, CG $n=16$).	Carer health and well-being (Health and Daily Living form) and stress and burden (CBI). Data on carer problems and APN visit time through Omaha Classification System. Taken through phone at 48 hours, 2, and 4 weeks after discharge.	Intervention had significantly better health outcomes—less emotional symptoms at week 4, less depressive symptoms at weeks 2 and 4 and lower thoughts and feelings stress at 48 hours than control.	Aim, intervention, outcome.

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Table 1. (Continued)

Author and country	*Study design*	*Aim(s)*	*Participants*	*Outcome and measures*	*Findings*	*Carer elements*
Pugh et al (2001),[46] United States	Randomized controlled trial	To test impact of PIC model on QOL and functional status; and determine its cost-effectiveness for older people.	Older HF patients >65 years who lived at home and admitted to acute hospital in 48 hours. IG: $n=27$, CG $n=31$.	QOL (SF-36), functional status—6MWT, costs (ED and hospital visits, readmissions, doctor, and nursing visits) taken at baseline and six months.	Positive effect of the intervention on functional status and QOL but no significant difference between groups. No significant difference in costs between groups.	Intervention.
Thompson et al (2005),[47] United Kingdom	Randomized controlled trial	To determine the effectiveness of a hybrid program of C+HBI in reducing recurrent hospitalization in CHF patients.	Inpatients with CHF discharged home. IG: $n=58$, CG: $n=48$.	Primary: death or unplanned readmissions, rate of recurrent all-cause readmission within six months of discharge. Secondary: QOL (SF-36) at one and six months.	Benefits of C+HBI program on recurrent hospitalization are consistent with home or clinic-based CHF programs; but not statistically significant.	Intervention.
Halling et al (2020),[48] Denmark	Randomized controlled trial (with economic evaluation)	To evaluate the cost-effectiveness of a fast-track transition process from oncological treatment to SPC enriched with a psychological intervention at home, for patients with incurable cancer and their carers.	Inpatients with incurable cancer and carers: Patient IG: $n=162$, CG: $n=159$, carers IG: $n=126$, CG: $n=109$.	ICER, including health care costs, intervention cost, and informal care from carers. QALYs through EORTC QLQ-C30 for patients, SF-36 for carers.	This model of fast-track SPC enriched with a psychological intervention yields better QALYs than usual care ($p=0.026$) with a large increase in costs.	Intervention, outcome.
Hastings et al (2020),[49] United States	Randomized controlled trial	To examine the effectiveness of a primary care-based nurse telephone support intervention for veterans treated and released from the ED.	Older patients discharged home from ED. IG: $n=257$; CG: $n=257$.	Primary: Repeat ED use within 30 days. Secondary: engagement with primary care, mental health, and chronic DMPs; total health care costs. HRQOL used at baseline, 30, and 180 days.	A brief primary care-based nurse telephone support program after an ED visit did not reduce repeat ED visits within 30 days, despite intervention participants' increased engagement with primary care and some chronic disease management services.	Intervention.

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Table 1. (Continued)

Author and country	*Study design*	*Aim(s)*	*Participants*	*Outcome and measures*	*Findings*	*Carer elements*
Schumacher et al (2021),[50] United States	Mixed-methods, RCT, multisite	To determine whether an ED-to-home transitional care intervention reduces hospital-based acute care in chronically ill older ED visitors.	Older chronically ill ED patients. IG: $n=406$, CG: $n=544$.	Primary—Hospital admission rate within 60 days. Secondary—clinic visits within 60 days.	Did not significantly reduce rehospitalizations or increase clinic visits. If returned to ED, IG less likely to be hospitalized than CG. Coaching intervention did not reduce hospital use due to systemic factors.	Intervention.
Rezapour-Nasrabad (2018)[57] Iran	Experimental (case-controlled intervention)	To investigate the effect of transitional care on QOL in patients with CHF in physical, emotional–spiritual, and socioeconomic dimensions.	Patients between 20 and 76 years, admitted with HF. IG: $n=84$, CG $n=84$.	QOL—MLHFQ, participation rates, intervention elements (visits, phone calls).	Patient QOL in the IG is significantly higher than the CG in physical, emotional–spiritual, and socioeconomic dimensions ($p<0.05$).	Intervention.

6MWT, 6 minute walk test; ADL, activities of daily living; AGU, acute geriatric unit; APN, advanced practice nurse; AQoL, Assessment of Quality of life; BMI, body mass index; C+HBI, clinic plus home-based intervention; CBI, Caregiver Burden Inventory; CG, control group; CHF, congestive heart failure; CI, confidence interval; CLD, chronic lung disease; CM, case management; CN, community nurse; COPD, chronic obstructive pulmonary disease; CP, care partner; CSI, carer strain index; CT, care transition; DMP, disease management program; DRPs, drug-related problems; ED, emergency department; EORTC QLQ-C30, European Organisation for Research and Treatment of Cancer Quality-of-life Questionnaire Core 30; EQ-5D, European Quality of Life Five Dimension; FFFS, Feetham Family Functioning Survey; GDS, geriatric depression scale; GHQ-12, Short General Health Questionnaire; GI, gastrointestinal; GP, General Practitioner; HBCTI, home-based care transition intervention; HF, heart failure; HR, hazard ratio; HRQOL, health-related quality of life; IADL, Instrumental Activities of Daily Living; ICER, incremental cost-effectiveness ratio; IG, Intervention Group; LHS, London Handicap Scale; LOPSS12, La Monica-Oberst Patient Satisfaction Scale; LOS, length of stay; LVD, Left ventricular dysfunction; MHLC, Multidimensional Health Locus of Control scales, MLHFQ, Minnesota Living with Heart Failure Questionnaire; MMS, Master of Stress Scale; MMSE, Mini mental state examination; MoCA, Montreal Cognitive Assessment; NYHA, New York Heart Association; PAC, postacute care; PAM, patient activation measure; PDTC, postdischarge transitional care; PIC, partners in care; QALYs, quality-adjusted life years; QOL, quality of life; SF-12v2, Short Form 12 Health Survey Version 2; SF-36, Short Form 36 Health Survey Questionnaire; SGRQ, St George's Respiratory Questionnaire; SPC, Specialised Palliative Care,

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Table 2. Template for Intervention Description and Replication Table for Included Studies

Author	*What*	*Rationale and/or theory*	*Who provided*	*How*	*Where*	*When and how much*	*Adherence*	*Tailoring and modifications*
Piette et al (2020)[25]	Accessible health technology and carer support posthospitalization. IVR phone calls to patients, automated alerts to clinicians, and structured e-mail feedback to carers.	IVR-supported interventions can improve self-management of chronic illness and providing EB behavior change education. Used with carers can decrease their distress.	Staff provided with detailed protocol.	E-mail; automated phone responses, fax alerts. Individual.	Three hospitals; home setting.	IVR calls—First two weeks daily calls, three attempts per day. Then three times per week for two weeks, then weekly for nine weeks. Clinical alerts—individualized for each patient; CP communication—after each IVR call, CP received e-mail, feedback, and alerts.	76% of attempted IVR calls were completed. Clinical alerts generated for 18% of completed calls.	Individualized alerts and actions dependent on patient response to automated questions on IVR calls, and feedback from CP.
Shaw et al (2016)[26]	The family connect telephone intervention. Carer needs assessment and education on supportive care strategies delivered after discharge.	Carer interventions can improve cancer patient and carer well-being. Family connect trialed in other studies. Qualitative pilot work revealed carers indicate time after discharge can be most stressful time.	Experienced psychologist trained in oncology and communication skills.	Phone based.	Four hospitals, home.	10-week period, 4 phone calls at 14 days, 4, 6, and 10 weeks. Patient could reschedule if required. Required length of time per call NR on.	High withdrawal rates prerandomization. High fidelity maintained through use of intervention recordings in training. High participation. Interviews at three months indicated carer acceptance—satisfied with timing, content, and mode of delivery.	Carers could reschedule phone calls. Strategies to address needs were tailored to individual participants needs.
Toye et al (2016)[27]	Usual care+further enabling care at home program—phone-based interventions between nurse and carer to review discharge information, needs assessment, and postdischarge follow-up.	Based on U.K. care-led tool known to improve carer outcomes. Hospital discharge needs of carers poorly met. Telephone based intervention considered most effective.	Dedicated nurse trained in needs assessment tool and overall intervention.	Phone-based.	600-Bed hospital, home.	Across three phone calls—Contact 1: within one week postdischarge; Contact 2: 7–10 days postdischarge; Contact 3: within 14 days of discharge.	56% consented to study. 13.5% Attrition for both groups.	Change to timing of nurse contacts due to limited availability of carers.
Coleman et al (2006)[16]	CTI—Coaching and self-management model using hospital and home visits and phone calls.	Based on evidenced-based conceptual domains developed through qualitative data from patients and carers in previous studies.	Trained transition coaches (nurse practitioners).	Face to face and phone.	Hospital, home.	Hospital visit predischarge, one home visit within 48–72 postdischarge, then three follow-up phone calls within 28 days of discharge.	67% IG received all components, 0.8% received none. 86% received at least home visit and phone call.	Individualized through person-centered record.
Utens et al (2014)[28]	Community-based hospital at home scheme. Early discharge and nursing support for patient and carer.	Based on GO AHEAD intervention. Carers important part of hospital at home scheme.	Nursing.	Face to face, phone.	Six hospitals, home.	First seven days: 4×home visits, 1×hospital visit, then 90 days follow-up. Access to 24-hour support. Education, counseling provided to patient and carer.	NR.	NR.

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Table 2. (Continued)

Author	*What*	*Rationale and/or theory*	*Who provided*	*How*	*Where*	*When and how much*	*Adherence*	*Tailoring and modifications*
Naylor et al (2004)[29]	Transitional care management model—three-month APN-directed discharge planning and home follow-up through visits and phone support for patient and carer.	Evidence supports multidimensional person-centered approach that occurs across hospital and postdischarge period.	Led by APN. Trained and HF experience. Physician joined APN in predischarge and initial follow-up visit.	Face to face, phone.	Six hospitals, home	Predischarge: daily visits; postdischarge: at least 8× visits; 1× within 24 hours, then weekly, to bimonthly across three-month period in total.	NR.	Intervention content adapted to individual (through goal setting and care plans).
Aimonino et al (2008)[30]	Physician-led hospital treatments at home. Medical and rehabilitation services. Patient and carer education on disease and symptom management.	Physician-led substitutive clinical unit hospital at home model will reduce readmissions, mortality, and other medical outcomes.	Established multidisciplinary team and service, no additional training reported.	Face to face, phone based.	Geriatric hospital, home.	Daily nurse and physician visits, then daily nurse, and every two to three days intervals for physician. Additional urgent home visits available. Dosages of OT and PT NR.	Both groups received similar rates of COPD treatments. IG received 14.1 nursing visits and 9.9 physician visits. NR.	Number of visits dependent on patient's medical needs.
Angermann et al (2012)[31]	Nurse-coordinated DMP for patients and carers—through hospital visit, weekly phone follow-up, medication adjustment, and specialist care.	DMP can reduce hospitalization and mortality rates. Intervention elements developed by MDT and current evidence.	Led by trained nurses, supported by cardiologist and psychologist.	Face to face in hospital, phone based at home, with patient, carer, and clinician.	Six hospitals, home.	Predischarge—hospital visit after discharge: weekly contacts in first month, individualized frequency. Contacts 10–15 minutes. Emergency contacts available.	High compliance with self-monitoring and drug adherence training and supervision model applied for fidelity.	Adapted to meet patient unmet need. Receipt of intervention modules and frequencies varied.
Atienza et al (2004)[32]	Comprehensive hospital discharge planning and outpatient HF management program for patients and families. Physician led.	Evidenced-based physician-led clinical model used. Education predischarge and early after discharge important element for successful transition from inpatient to outpatient care.	Treating physician. Training not described.	Face to face in hospital and clinic, telemonitoring through phone.	Three hospitals, home, clinic.	(1) Patient and family interview and self-management education predischarge, (2) physician home visits two weeks postdischarge, and (3) follow-up clinic visits every three months; (4) 24-hour phone support line from discharge to end of study.	NR.	NR.

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Table 2. (Continued)

Author	*What*	*Rationale and/or theory*	*Who provided*	*How*	*Where*	*When and how much*	*Adherence*	*Tailoring and modifications*
Casas et al (2006)[33]	Standardized integrated care intervention: Includes hospital visit, patient/carer access to postdischarge support through home visits, web-based call center.	Integrated/shared care may prevent readmissions by improving coordination among different settings/ levels.	Delivered by specialist nurse and GP. Training not described.	Face to face in hospital, initial period home, then phone based.	Two hospitals, home.	At discharge: (1) Initial assessment, (2) patient/carer education, (3) individual care plan. Postdischarge: (1) access to nurse through web-based call center (2) Spain—home visit within 72 hours and respiratory nurse support (3) Belgium GP CM. (4) Weekly phone call in first month (5) Visits as required.	Barcelona had 448 calls through call center—194 scheduled, and 254 (43%) scheduled. Leuven had 201 calls, 128 (63%; nurse triggered). The mean duration of phone calls was 20 minutes for both sites. Leuven, no home visits were planned after discharge.	Adapted to different health systems. GPs key role in one site, while nursing in other. Individualized care plans generated for each patient.
Hendrix et al (2011)[58]	Individualized experiential carer training and phone follow-up after discharge. Based on Coleman's transition model.	Based on theory of problem-based adult learning and designed to enhance self-efficacy. Self-efficacy can improve patient and carer outcomes.	Nurse trained in protocol and supported with mock training, feedback, and weekly consultation.	Face to face, phone.	Four medical units at VA hospital, home.	Before discharge: one or two interactive sessions at least two hours long. Follow-up phone call 24–72 hours after discharge for mediation reconciliation.	High completion rate (80%), actual dosage range: three to six hours in one day; except one carer across two days.	Training individualized to patient and carer needs.
LeGrain et al (2011)[34]	OMAGE discharge planning intervention using chronic treatment review, self-management education (patient and carer), and communication.	Intervention used EB self-management education approach; and targeted three risk factors of preventable readmissions: DRPs.	Trained geriatricians.	Face to face and phone.	Six AGUs.	4× Education sessions, mean duration: 98.7 minutes education, 70.7 minutes treatment review, and 44.2 transition of care communication.	Acceptance and fidelity reported. 92.7% participants eligible for education, 41.2 and delivered to patient, 24.5% to patient and carer; and 34.2% to carer.	Individualized education session modified based on patient and carer needs.
Hendrix and Ray (2006)[59]	Individualized experiential carer training at bedside before discharge on symptom management. And home care skills. Carer led.	Self-efficacy theory applied to carer training model. Self-efficacy (confidence) contextual factor to be able to provide care.	Trained nursing specialists.	Face to face.	Extended rehabilitation center, home.	One or two training sessions, minimum of two hours long; duration and frequency led by carer and their needs. Before discharge.	Carers viewed training as effective. 22 patients referred; 15 had carers at home but half patients refused for carers to participate. Seven or eight carers agreed to participate. Actual range: three to six hours in one day; except one carer across two days.	Individualized based on patient and carer needs.

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Table 2. (Continued)

Author	*What*	*Rationale and/or theory*	*Who provided*	*How*	*Where*	*When and how much*	*Adherence*	*Tailoring and modifications*
Abad-Corpa et al (2013)[51]	Multicomponent nurse-led intervention. Includes patient/carer education and care coordination predischarge; home visit and phone follow-up.	Discharge planning and multidisciplinary interventions reduce hospital utilizations, improve care coordination, and HRQOL.	Trained nursing.	Face to face and phone.	Two acute hospitals, home.	Predischarge (1) Patient/carer education on disease (2) Needs identification (3) Referral to other HCP. Across five days. After discharge: Care plan, follow-up home visit <72 hours and contact with primary care team. Phone follow-up at 2, 6, 12, and 24 weeks.	26% eligible participants recruited. Higher satisfaction with nursing care in IG.	Individualized person-centered model.
Aboumatar et al (2019)[35]	BREATHE program transition and self-management through hospital, home, and face to face predischarge and three months after. Patients and carers.	Transitional care interventions can reduce ED visits and readmissions and need to focus on long-term outcomes. Codeveloped with patients, carers, and stakeholders.	COPD trained nurses.	Face to face, home visits, phone.	447-Bed acute hospital, home.	(1) Patient and family support for discharge (2) COPD self-management support (3) Behavior change education (4) community supports. Mean no. 6.1 sessions Mean duration of 23.8 minutes; > half sessions with carer present.	85% had at least one hospital visit, completed the intervention.	Individualized person-centered model.
Chiang et al (2012)[52]	Telehealth care model through hospital and home. Nurse-led discharge planning, phone support, and patient–carer use of devices to monitor symptoms after discharge.	Advanced disease management models prevent readmissions. Guided by Meleis's transition theory. Transitions can impact on patient's well-being, their relationships, and their family carers.	Telehealth nursing specialist and referred to physician as required.	Face to face, telehealth device, and phone.	Acute medical center, home.	Contact made within 48–72 hours, then daily contact and monitoring of symptoms. Duration and dosage individualized for patient's needs.	No participants lost to follow-up.	Individualized for patient and carer need and respond to change in condition.
Coleman et al (2004)[53]	Multicomponent coaching model across hospital and home. Phone support for 24 days postdischarge: (1) medication self-management, (2) patient-centered and owned record, (3) postdischarge follow-up, and (4) identify red flags.	Applied evidence-based CTI—constructs based on qualitative data from patients and carers. Self-management improves transitions.	Trained nurse practitioner.	Face to face, phone.	Hospital, home.	(1) Hospital visit, (2) home visit within 24–72 hours postdischarge, at least 3×phone calls across 24 days.	High adoption and acceptance. 91% received home visits, 72% received >3 phone calls. Reported improved confidence and skills in self-management.	Individualized according to patient and carer needs, details on health care record.

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Table 2. (Continued)

Author	*What*	*Rationale and/or theory*	*Who provided*	*How*	*Where*	*When and how much*	*Adherence*	*Tailoring and modifications*
Lainscak et al (2013)[36]	Multicomponent discharge coordination model across hospital and home. Discharge planning with patient and carer, follow-up phone support, and home visit after discharge.	Little evidence supporting discharge coordinators for COPD patients. Transition programs targeting discharge critical to reducing health care costs.	Discharge co-ordinator.	Face to face, phone.	Specialized pulmonary hospital, home.	(1) Needs assessment (2) Communicated plan to other providers (3) Phone contact 48 hours after discharge (4) Ongoing review through phone by discharge coordinator (5) Home visit 7–10 days after discharge.	High acceptance; only 18/118 did not receive follow-up visits.	Number of phone calls tailored according to patient need.
Li et al (2014)[37]	Two-stage self-management program across hospital and home. Included patient–carer psychoeducation in hospital, home, and over the phone for three-month period.	Transitional care interventions can enable continuity of care and has shown positive results in Western countries in discharge planning.	COPD-trained nurses.	Face to face, phone, home visits.	Hospital, home.	1×Hospital visit, phone calls 3,5,7, and 9 weeks after discharge; and home visits 72 hours and 3 months after discharge.	Low dropout ad withdrawals.	Individualized assessment.
Jenq et al (2016)[54]	Individualized transitional care, including patient–carer education, medication reconciliation, follow-up telephone calls, home visits, and linkage to community. Across hospital and home.	Evidence supports transitional care programs in reducing readmissions. Based intervention on proven models.	Transition care coaches trained social workers delivered intervention.	Face to face, phone.	Hospitals, home.	Predischarge: Patient–carer needs assessment; postdischarge: (1) Minimum 1× follow-up phone call per week for medication/support review. (2) Home visits if functional assessment needed. Plus, usual practice of written discharge instructions.	NR.	NR.
Kwok et al (2004)[38]	Intensive community nursing (CN) supported discharge program. Predischarge assessment, home visits for disease management, and psychoeducation for patient–carer. Access to support hotline.	Evidence suggests CNs improve discharge and reduce readmission for older people. Informed design for CLD participants.	Community nurses with greater than two years' experience. Trained in care of CLD patients.	Face to face, phone.	Hospital, home.	Predischarge initial visit. Home visits: 1×within seven days of discharge, then weekly for four weeks and monthly until six months. Access to phone line as needed.	High adoption (87%) of home visits. Average number of home visits per subject was 11.8±3.9 (range 2–24), the average number of telephone calls per subject was 10.3±6.1 (1–24), and total time spent by CN per subject was 9.9±3.3 (2.3–17.1) hours.	Phone hotline based on need and self-directed by patient/carer.
Preen et al (2005)[39]	Evidence-based multidisciplinary discharge care plan given to patient/carer before discharge and sent to GP and community providers. GP follow-up seven days postdischarge.	Evidence gap in efficacy of multidisciplinary discharge care plan. Inadequate communication to GP can increase LOS, cause breakdown of care.	NR.	Face to face, phone.	Two hospitals, home.	Care plan provided 24–48 hours before discharge, GP follow-up 7 days postdischarge.	GPs 90.1% compliance with discharge care plan return, 47.2% returned before discharge. Average (mean±SD) care plan return time was 3.0±3.2 days postdischarge.	Care plan included patient/carers' goals, individual needs. If GP had not followed up, research nurse would contact them.

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Table 2. (Continued)

Author	*What*	*Rationale and/or theory*	*Who provided*	*How*	*Where*	*When and how much*	*Adherence*	*Tailoring and modifications*
Shu et al (2011)[55]	Integrated PDTC program. Predischarge care plan, follow-up phone call, access to hotline, and referral to clinic. Patient–carer education.	Based on Coleman's CTI, expected to reduce adverse events and readmission rates.	Study nurse and treating physicians.	Face to face, phone.	Hospital, home.	(1) Provision of care plan predischarge; (2) 5×follow-up phone calls at days 1, 3, 7, 14, and 30 postdischarge. Hotline counseling and support as required.	62% Patients received all follow-up phone calls;. 20% of IG used hotline. 14% IG attended scheduled clinic visits, 2% unplanned clinic visits.	Individualized interventions provided based on care plan.
Watkins et al (2012)[60]	Individualized hospital-to-home transition program using social worker navigator. Home care services setup predischarge, patient and family support for after discharge through home visits.	Model adopted from pre-established CTI. Targeting psychosocial needs of patients to improve IADL performance and ability to stay home.	Social workers.	Face to face, phone.	961-Bed hospital, home.	At least 30 days after discharge or up to 4 months. 1×hospital visits, 1×home visit within 72 hours after discharge; then visits and phone calls on need basis.	Average of 63 days per patient in the program. Average of 2.7 visits, 3.5 phone calls, and 16 hr of in-home assistance. Average of 12 days between discharge and their first primary care physician visit.	Individualized home care service provision and follow-up.
Zimmerman et al (2017)[56]	HBTCI for multimorbid patients. Multicomponent self-management model across hospital and home using coaching and teach back method.	Patients need different dosages of CTI to enable change. Cognition and patient activation inform intervention design. CTI models and activation science as theoretical base.	Nursing and nursing assistant trained in intervention.	Face to face, phone.	Acute hospital, home.	Dosage and frequency varied by group. Included medication management, personal health care record development, red flag identification, and action planning.	Drop-out rates recorded across four groups.	Individualized to patient need.
Enguidanos et al (2012)[40]	Nurse practitioner and physician-led intervention discharge planning and postdischarge follow-up through home visits and phone calls for patient–carer education, medication review.	Hospital utilization can be reduced if older people properly followed up after discharge. Based on preexisting CT model by Coleman and adapted for high-risk population.	Nursing and physician.	Face to face, phone.	Hospital, home.	3×home visits, 2×phone calls. Duration NR. First visit within 72 hours of discharge.	High adoption and fidelity reported across all intervention elements. Average time 75 minutes spent with patients.	Individualized care plan.
Laramee et al (2003)[41]	CHF Hospital-based CM program. Early discharge planning, patient and family education, phone follow-up, and medication education.	CHF CM linked to better health utilization and patient outcomes core components based on EB guidelines.	Nursing CHF CM, trained in cardiology and critical care.	Face to face, phone.	Hospital, home.	Patient/family received phone calls 1–3 days after discharge and at weeks 1, 2, 3, 4, 6, 8, 10, and 12. Duration from 5–45 minutes. CM also on call during Monday to Friday.	70% acceptance rate, 86% completed intervention. Greater adherence to treatment plan and higher satisfaction with care for IG. Higher doses and use of medication for IG.	Individualized care plan.

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Table 2. (Continued)

Author	*What*	*Rationale and/or theory*	*Who provided*	*How*	*Where*	*When and how much*	*Adherence*	*Tailoring and modifications*
Nazareth et al (2001)[42]	Pharmacy discharge care plan. Medication education before and after discharge to patient–carer and follow-up with GP, community pharmacist.	Coordinated care between hospital and community pharmacists, patient and family can improve medication adherence for older people.	Hospital and community pharmacists.	Face to face.	Three acute hospitals and one long-stay hospital, home.	(1) Predischarge: Medication management, information, and discharge plan. (2): 7–14 days after discharge home visit follow-up by community pharmacist.	Hospital: 81% received discharge plan. Community:7 1% patients received home visit. Mean of 1.9 interventions per visit, and 2.8 per patient. Mean duration of first home visit was 38 minutes, second visit was mean time 27 minutes. 32 minutes of extra clinician admin time.	Individualized-based inpatient/ carer and community care provider's needs.
Lim et al (2003)[43]	A PAC program for older people after discharge. Short-term CM and care coordination pre- and postdischarge.	High readmission risk immediately after discharge. PAC program provides coordinated care and short-term community follow-up to minimize risk.	PAC coordinators (nursing or allied health).	Face to face, phone.	Four acute hospitals, home.	(1) Needs assessment; (2) As needed: follow-up phone call, available for crisis management, liaison with service providers, coordination of, and access to extra service provision.	311 Received intervention, (293 followed up; 5 withdrew, 13 lost to follow-up).	Individualized "as required" or "as appropriate."
Naunton and Peterson (2003)[44]	Home-based follow-up of high-risk older patients after discharge. Patient care education, compliance medication review, liaise with community.	Readmissions related to DRPs can be avoided through system-based interventions involving patient and clinicians.	Pharmacists.	Face to face.	400-Bed acute hospital, home.	Planned: 2×home visit. First home visit (five days) mean duration 50 minutes (range 25–120). Second Home visit (90 days) mean duration 30 minutes (range: 15–60).	57 Received intervention, 8 withdrew or lost to follow-up. High acceptance of recommendations (76%), information (84%), and contact (94%) with pharmacist.	Medication review required categorization of DRP to develop individualized plan and education.
Dellsega and Zerbe (2002)[45]	APN intervention through hospital and home visits, phone calls. Psychoeducation model.	Rural carers at higher risk of readmissions and adverse outcomes. APN models improve patient, carer, and service outcomes. Based on Brooten's transitional care model.	APN (postgraduate training).	Face to face, phone.	Rural hospital, home.	Standard care+APN intervention: 1×hospital visit, two home visits at 48 hours and one to two weeks post discharge. Phone call between two home visits. Based on Brootens' transitional care model.	71% of carers completed interviews (not intervention) due to feeling overwhelmed.	NR.
Pugh et al (2001)[46]	PIC model—long-term patient CM. Enhanced discharge planning, self-management education for HF through workbook, nursing assessment, and six-month follow-up by case manager.	Nonpharmacological longitudinal CM can improve outcomes for HF patients—including goal attainment, reduced LOS, better resource utilization, carer coordination.	Nursing.	Face to face, phone.	Two acute care hospitals, home.	NR.	NR.	NR.

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Table 2. (Continued)

Author	*What*	*Rationale and/or theory*	*Who provided*	*How*	*Where*	*When and how much*	*Adherence*	*Tailoring and modifications*
Thompson et al (2005)[47]	Nurse led, C+HBI. Across hospital, home and clinic. Patient-family education on disease management, referrals to support services.	Hybrid program of nurse-led, clinic plus home-based follow-up most beneficial for CHF patients based on other intervention studies.	Two nurses skilled in HF management and postgraduate qualifications, using strict protocols.	Face to face.	Two acute care hospitals, home, clinic.	1×Ward visit, 1×visit within 10 days of discharge, attend monthly regular clinic visits for six months.	High acceptance. 98% receive home visit within 10 days, 79% attended all their clinic sessions.	NR.
Halling et al (2020)[48]	Fast-tracked specialist palliative CT model with enriched psychological intervention. (across hospital and home for patient and carer/ family).	Earlier trialls shown intervention improves patient QOL and carer outcomes (anxiety and depression). Fast-track nature likely to show economic benefits.	NR (in protocol paper).	Face to face.	Hospital, home, clinic.	Hospital sessions NR; team conference at home +2×psychology settings in first month then as needed. Carers received three additional sessions postbereavement.	NR.	NR.
Hastings et al (2020)[49]	DISPO ED. Nurse phone support after discharge for disease management and counseling.	Evidence shows phone support improves continuity of care. Not tested in ED. Should improve transition through disease management and patient and family education.	Nursing.	Phone.	Veteran medical center, home.	Call 1: needs assessment; Call 2: referral for chronic disease management and counseling. Optional call 3: during week 2 for additional needs. Can initiate additional calls for 30 days.	High adherence: 92% completed Call 1, 98% completed both calls; half completed optional and 3% initiated one call within 30 days. Low uptake from carers. 33% acceptance of recommendations.	Support based on individual need.
Schumacher et al (2021)[50]	Colemans CTI—modified for ED. With added supports for meals and transport. Coaching model through phone and home four weeks after discharge.	Self-management approach of intervention will address factors that lead to patients seeking ED over primary care. Colemans' CTI proven effective for older inpatients.	Coaches have bachelor's degree or completion of CTI. Not limited to nursing.	Phone, face to face.	Two ED's, home.	1×Home visit. Within 30 days coach called patient weeks 1, 2, and 4; lasting 60 minutes. Extra calls and visits based on need.	37% did not receive intervention due to coach unable to schedule home visit, 8% received transportation, 26% received meals. None lost to follow-up.	Additional phone calls and visits based on need. Individualized program.
Rezapour-Nazrabad (2018)[57]	Nursing liaison TCM CHF patients. Psychoeducation for patient and family across hospital and home. Phone call and visits tailored to individual need.	Based on Naylor's TCM—improves patient outcomes through nursing support.	Nursing.	Phone, face to face.	Hospital, home.	Nursing liaison support provided during admission and after discharge up to six months through phone or visit. Duration and number of times NR.	100% Response rate. Nil other data reported.	Dosage of phone and visits based on individualized need.

Some TIDieR items have been combined in the table for ease of reading: What = items 1, 3, and 4; adherence = items 11 and 12; tailoring and modifications = items 9 and 10. Comparator item has been removed and is given in Supplementary File S1.

APN, advanced practice nurse; CTs, care transitions; CTIs, care transition interventions; DISPO ED, discharge information and support for patients receiving care in the ED; EB, evidence based; HBTCI, home-based transition care intervention; HCP, Health Care Professional; IVR, interactive voice response; MDT, Multi-disciplinary team; NR, not reported; OMAGE, Optimization of Medication in AGEd; OT, Occupational Therapy; SD, standard deviation; TCM, transition care model; TIDieR, Template for Intervention Description and Replication; VA, veteran affairs.

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Intervention materials and procedures. Most of the studies described interventions ($n=33$) that aimed to target both patients and carers. Four studies reported interventions that targeted carers exclusively. These included practical carer training at bedside,[58,59] individualized education, and support before and after discharge.[26,27] Interventions were primarily delivered across both hospital and home settings ($n=35$). Three studies described interventions occurring in one setting—hospital for practical carer skills training[59] and home-based setting for community pharmacy follow-up program and carer phone support.[26]

Most studies adopted a combination of delivery modes—face to face and phone ($n=31$). Smaller numbers used phone,[26, 27] face to face,[42,47,59] and automated response devices.[25] The time points at which these types of contacts occurred varied greatly and were dependent on the design of the intervention bundle. Persons responsible for delivery of the interventions sat primarily with nursing staff ($n=17$),[27–29,31,35,37,38,41,45–47,49–51,56,58,59] followed by other disciplines such as treating physicians,[32,34] social work,[60] psychologists,[26] and pharmacists.[42,44] Some interventions ($n=8$) were delivered by more than one discipline.[29,30,33,36,40,43,52,55] Two studies did not explicitly report on who was delivering the intervention.[39,48]

All studies described self-management as the core intervention approach used to improve care transitions for patients and carers. This was enacted using various techniques and combinations: (1) patient and carer education targeting disease and symptom management,[16,25,26,28–38,40,41,43,45–48,50–57] practical caring skills,[27,58,59] and psychosocial support; (2) standardized needs assessments[27,36,43,51]; (3) standardized discharge planning such as medication reviews[16,39,40,42,44,53–55] and carer training; and (4) referrals to other health care providers.[43,47] Interventions occurring after discharge continued to include education and support and for some studies extended into rehabilitation[30] for patients, counseling,[28,29] and postbereavement support for carers.[48]

Intervention frequency, duration and dosage. Most studies ($n=36$) reported on the number and frequency of clinician contacts across hospital and home settings. Eighteen studies involved contact within 72 hours of discharge[16,28,30,33,36,37,39–41,43,45,51–53,55,56,58,60] and 14 studies involved contacts made more than a week after discharge.[25–27,31,32,35,38,42,44,47–50,54] There was limited or no reporting of intervention frequency for three studies.[43,46,63] The final contact in the intervention commonly was at three months,[28,29,32,37,41,44,51] but ranged from seven days[36,39,42] to six months after discharge.[38,47,51,57] Eight studies reported that the final contact was determined by individual need.[35,43,48,50,52,54,56,60] The planned duration of intervention sessions was reported by 20% of studies ($n=8$).

Adherence. Adherence to intervention was commonly described as participant completion rates, including participation in different components of the intervention,[16,25,26,30,33–36,38,40–42,44,47,50,52,53,55,58–60] recruitment and retention rates,[27,37,42–45,50–52,56,57] and acceptance and compliance with recommendations made.[31,34,40,44,49,53] Seven studies (19%) did not report on adherence. Clinician adherence to the proposed intervention delivery (fidelity) was reported as audio recording of intervention, and supervision/training models.[26,31] Actual clinician adherence was described as rate of intervention delivery.[34,39,40]

Tailoring modifications. Reporting of specific modifications to core components of the intervention was limited to two studies. This involved altering intervention timing according to carers' availability and adaptations to ensure applicability across different hospital settings.[27,33] Most studies described interventions as tailored to meet the needs of the individual ($n=30$) through individualized care plans,[16,25,29,31,33–36,39–44,49–51,53,55,59,60] needs assessments,[26,30,31,34,36,37,38,52,56–59] and goal setting.[29]

Rationale. Rationale for the choice of intervention was reported as quantitative data from earlier controlled studies ($n=30$).[25–54,58,60] Adoption of established care models including Colemans CTI ($n=10$)[16,26,40,50,53–57,60] and Naylor's transition care model,[57] alongside qualitative data from preliminary work and earlier studies ($n=6$),[16,26,31,35,48,53] was also presented as rationales for intervention choice. Well-described rationales relied upon a combination of these aspects. Only five studies referred to specific theoretical models to explain how their intervention worked and achieved proposed outcomes. These include self-efficacy theory,[59] problem-based adult learning,[58] Meleis's transitions theory,[52] Brooten's transitional care model,[45] and activation science.[56]

Alignment to the CTF

Implementation measures. Table 3 illustrates how well the studies align with the CTF domain ''implementation measures.'' These measures were derived when studies had reported on adherence data in the TiDIER checklist. All constructs except for penetration were reported on to varying extents: acceptability ($n=31$),[16,25–31,34–42,44,47–60] adoption ($n=31$),[16,25,26,29,34–45,47–60] appropriateness ($n=27$),[16,25–31,34,35,37,39–45,50–55,58–60] intervention cost ($n=13$),[16,29,30,34,38,43,45,47,48,54,56,60] fidelity ($n=24$),[16,25–27,29–31,33,34,39–42,44,45,47–50,53,55,56,58–60] reach ($n=3$),[26,30,54] replicability ($n=9$),[25,29–34,37,48,49] and sustainability ($n=3$).[31,32,58]

Studies had alignment with an average of four constructs. Most studies reported data on the three constructs of acceptability, adoption, and appropriateness. Alignment to the most common constructs of acceptability, adoption, appropriateness, and fidelity was evidenced in two ways: by (1) descriptions of quantitative data related to participation rates, initial uptake, withdrawals, and satisfaction with the intervention and (2) describing data collected from earlier feasibility or exploratory studies that aligned with these constructs. Studies reporting both quantitative and qualitative data for these measures were given higher ratings (as per Table 3) than studies reporting on only one.

Outcomes

Outcomes were described at the individual level and service level in various combinations across the different studies. These are outlined in Table 4. The strongest alignment was with clinical outcomes construct ($n=31$). These included patient-specific ($n=21$),[25,29,31–33,35–40,42,44,46,47,49,51,55–57,60] carer-specific ($n=3$),[52,58,59] and patient–carer combined ($n=7$).[26–28,30,43,45,48] Common patient-related outcome measures included health-related quality of

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Table 3. Alignment to Care Transitions Framework Implementation Measure Constructs

Citation	*Acceptability*	*Adoption*	*Appropriateness*	*Intervention cost*	*Fidelity*	*Reach*	*Penetration*	*Replicability*	*Sustainability*
Piette et al (2020)[25]	*	*	*		*			*	
Shaw et al (2016)[26]	**	*	**		**	**			
Toye et al (2016)[27]	*		*		*				
Coleman et al (2006)[16]	**	**	*	**	**				
Utens et al (2014)[28]	**		**						
Naylor et al (2004)[29]	*	*	*	**	*			*	
Aimonino et al (2008)[30]	**		**	**	*	**		**	
Angermann et al (2012)[31]	**		**		**			**	*
Atienza et al (2004)[32]				**				*	
Casas et al (2006)[33]					*			*	
Hendrix et al (2011)[58]	**	**	**		*				**
LeGrain et al (2011)[34]	**	*	**	**	**			*	
Hendrix and Ray (2006)[59]	**	**	**		*				
Abad-Corpa et al (2013)[51]	*	*	**						
Aboumatar et al (2019)[35]	**	*	*						
Chiang et al (2012)[52]	**	*	**						
Coleman et al (2004)[53]	**	**	**		**				
Lainscak et al (2013)[36]	*	*							
Li et al (2014)[37]	*	*	*					*	
Jenq et al (2016)[54]	*	*	*	**		**			**
Kwok et al (2004)[38]	*	*		*					
Preen et al (2005)[39]	**	*	**		**				
Shu et al (2011)[55]	*	*	*		*				
Watkins et al (2012)[60]	*	*	**	**	*				
Zimmerman et al (2017)[56]	*	*		**	*				
Enguidanos et al (2012)[40]	**	**	**		**				
Laramee et al (2003)[41]	**	**	**		*				
Nazareth et al (2001)[42]	**	**	*		*				
Lim et al (2003)[43]		*	*	*					
Naunton and Peterson (2003)[44]	**	**	**		**				
Dellsega and Zerbe (2002)[45]		*	*	*	*				
Pugh et al (2001)[46]									
Thompson et al (2005)[47]	*	*		*	*				
Halling et al (2020)[48]	**	*		**	*			*	
Hastings et al (2020)[49]	**	**			**			*	
Schumacher et al (2021)[50]	**	**	*		**				
Rezapour-Nasrabad (2018)[57]	*	*							

No star = not described; * = poorly described; ** = well described.

Table 4. Alignment with Care Transitions Framework Individual and Service Level Constructs

	Patient- and carer-reported outcomes (PROMS)			*Health service-related outcomes*		
	Patient/ carer-centered outcomes	*Patient/ carer experience*	*Clinical outcomes*	*Provider experience*	*HC utilization*	*Cost*
Piette et al (2020)[25]			*P	*	**	
Shaw et al (2016)[26]	*	**C	**		*	
Toye et al (2016)[27]	*	**C	**			
Coleman et al (2006)[16]		*P			**	**
Utens et al (2014)[28]	*	**C	**			
Naylor et al (2004)[29]			*P		**	**
Aimonino et al (2008)[30]		**	**			
Angermann et al (2012)[31]			*P		**	
Atienza et al (2004)[32]			*P		**	**
Casas et al (2006)[33]			*P		**	
Hendrix et al (2011)[58]	*	**C	*C			
LeGrain et al (2011)[34]					**	**
Hendrix and Ray (2006)[59]	**	**C	*C			
Abad-Corpa et al (2013)[51]		*P	*P		**	
Aboumatar et al (2019)[35]			*P		**	
Chiang et al (2012)[52]	**	**C	*C			
Coleman et al (2004)[53]	*	**		*	**	
Lainscak et al (2013)[36]			*P		**	*
Li et al (2014)[37]			*P			
Jenq et al (2016)[54]					**	*
Kwok et al (2004)[38]		*C	*P			
Preen et al (2005)[39]		**P	*P	**	**	
Shu et al (2011)[55]			*P		**	
Watkins et al (2012)[60]		**P	*P		**	
Zimmerman et al (2017)[56]			**P**		**	**
Enguidanos et al (2012)[40]		*P	*P		**	
Laramee et al (2003)[41]		*P			**	**
Nazareth et al (2001)[42]		*P	*P	**	**	
Lim et al (2003)[43]			**		**	**
Naunton and Peterson (2003)[44]		*P	*P		**	
Dellsega and Zerbe (2002)[45]			**	*	**	*
Pugh et al (2001)[46]			*P		**	**
Thompson et al (2005)[47]			*P		**	**
Halling et al (2020)[48]			**		**	**
Hastings et al (2020)[49]			*P		**	**
Schumacher et al (2021)[50]				*	**	
Rezapour-Nasrabad (2018)[57]			*P			

No star = not described; * = poorly described; ** = well described.
C = carer measures only; P = patient measures only; ** = well described patient and carer measures.

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life ($n = 15$),[26,29,30,32,36,39,43,46–49,51,56,57,60] mortality ($n = 8$),[29,30,32,33,35,36,42,43] and physical and psychological function ($n = 7$).[26,27,29,30,38,46,56] Carer-related outcomes were mostly self-reported appraisals of caregiving preparedness and well-being ($n = 4$),[27,45,52,58] followed by burden or distress levels ($n = 8$).[26–28,30,38,43,45,52]

The second strongest alignment was with health care utilization outcomes construct ($n = 29$), specifically readmission rates ($n = 25$),[16,25,29–33,35,36,38,40–42,44,46,47,49–51,54–56,60] emergency department presentations ($n = 10$),[25,34,35,38,40,41,46,55,56,60] hospital days ($n = 3$),[39–42] and clinic visits ($n = 3$).[25,50,55] Fourteen studies aligned with the cost construct—describing measures of direct and indirect health care costs.[16,29,32,34,36,41,43,45–49,54,56]

Data on individual experience were reported for 15 studies—6 studies measured carer experience,[26–28,38,52,58,59] 7 studies measured patient experience,[16,39–42,44,51,60] whereas 2 studies measured patient and carer experience.[30,53] Measurement tools used included satisfaction surveys ($n = 9$),[28,30,39–42,44,51,60] rating scales ($n = 2$),[27,53] and individual interviews ($n = 4$).[38,58,59] Less experience data reported on for clinicians and service providers ($n = 6$).[25,39,42,45,50,53] A small number of studies ($n = 7$)[26–28,52,53,58,59] demonstrated alignment with the CTF construct "patient/carer-centered outcomes," evidenced by links made between what patients/carers have voiced are their goals/needs and the chosen measures.

Most studies ($n = 24$) used health service utilization as the primary outcome, including two studies with patient–carer dyads. Clinical outcomes were used as the primary measure for 12 studies, and individual experience for 1 study.

Discussion

This is the first review to examine the reporting and methodological quality of CTIs for carers of patients

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with advanced illness and their alignment to a theoretical framework.

This review has shown that carers are under-represented in transition interventions as evident by the intervention content, delivery, and selection of outcomes. Just one-third of the studies that met the original inclusion criteria included carers, with most of these providing brief descriptions of carers only as they were considered as a component of patient-directed interventions. Carers appeared to be considered as ''resources'' rather than recipients of care in many of these studies—something that has been identified in other literature[64] and consistent with clinical practice.

Studies predominantly reported on clinical patient-related and health utilization outcomes. Although these can be considered objective easy to measure and well accepted as drivers for policy change, the dominance of these measures implies that carers are less visible and their needs less influential upon clinical translation and policy change. The costs of caring—the individual and societal costs that are generated when a person takes on the caring role—are significant, yet measuring cost-effectiveness and equity remains difficult.[60,65,66]

These could be important elements to consider integrating into an optimal research and policy frameworks for CTIs. However, operationalizing this is likely to pose many challenges, and more research is needed to understand the extent to which this is already happening. Equally researchers should be more cognisant of the policy context in which their research is positioned, and consider moving carers' outcomes to greater prominence to drive change.

The United Kingdom has faced challenges in the implementation of the Care Act 2014 that highlights the needs of the carer.[67] This legislation stipulates that all carers should have access to assessment and support that is on par with the person they care for in health service design and delivery. How this is enacted and interpreted is up to individual health services and authorities. Although this legislation is an important step in recognizing the needs of carers, Carer UK found a national hospital discharge model fell short in supporting carers of people with palliative care needs, with carers reporting up to a six-month wait for a carer assessment.[68]

This review has also shown there is an absence of theoretical discussion to inform transition intervention selection, with most studies relying on previous studies to justify their choice. The theoretical underpinnings of an intervention should form part of the preliminary development of a complex intervention, such as is required to support transitions, to ensure it effectively addresses the problem at hand.[20] The effectiveness of one study in one context does not guarantee it will work in another context. Recent study by Thompson et al highlights the importance of the need to better understand and report both theory and the mechanisms that underpin heart failure CTIs.[69]

Practical advice that can help researchers ''identify, disentangle, and verify'' mechanisms in complex intervention research was a suggested way to achieve this.[71] Unfortunately, there is little evidence that this advice has been adopted for heart failure transition interventions, and even less evidence evaluating carer needs. Applying the CTF in the design phase could improve the reporting quality at the evaluation stage and assist in addressing this issue.

Findings of this review demonstrate the broader application of the CTF to the examination of the reporting quality-of-intervention studies, and its alignment with the TiDIER. It has highlighted specific constructs that may be common to interventions for hospital-to-home transitions in palliative care, and can be used by researchers in developing and evaluating studies in these contexts. It supports the inclusion of carers when reporting intervention content, delivery, and outcomes measures—equivalent to patients. It also offers the opportunity to position the carer as the primary recipient of an intervention that aims to improve the transition to home for end-of-life care.

The CTF could also inform standardized reporting guidelines. Standardized reporting guidelines are available for an increasing number of methodologies and play an important role in facilitating study replication and translation into practice.[25,70] It is important to note that not all CTF constructs will be relevant for each study, nor should they be applied or necessarily be reported in one article. This challenge has been addressed in the Standards for Reporting Implementation Studies (StaRI) reporting guidelines for implementation studies that follow dual strands—one for reporting of implementation strategy and the other for the clinical or health intervention being implemented.[53] Future study on the development of a reporting guideline for CTIs could adopt this approach and use established methodologies for this process.[25]

Limitations

This review has some limitations that require mention. There was an over-representation of chronic disease populations in the final sample compared with advanced cancer. This influenced the nature and timing of the interventions, lending themselves toward disease and case management models. This is most likely due to the well-established care transition models[16,17] for this population that have core principles and components that can be readily applied to intervention design and development, allowing researchers to test them in controlled studies. Although the number of intervention studies targeting carers of people with advanced cancer has increased in recent years,[13] these have been primarily in home-based settings rather than hospital discharge settings.

Mapping to a single set of constructs within the CTF was difficult; instead, content was mapped to all relevant subdomains. Published articles that detailed the development of relevant interventions such as protocols and qualitative feasibility studies were excluded from this study. They may have offered additional information detailing the theory and mechanisms underpinning intervention design and choice of outcomes. Nevertheless, reference to this preliminary study in intervention articles is needed so that the research can be replicated.

The authors of this review also acknowledge that there are other transitions of interest including discharge from subacute settings such as skilled nursing or rehabilitation facilities to home. A review of these intervention models could also inform future intervention design and delivery.

Conclusion

There was considerable variation in the characteristics of CTIs due to their multicomponent nature and the influence of contextual factors. This review has shown that carers are under-represented in CTI content, delivery, and selection of outcomes. Health services, researchers, and governments are faced with the challenge of how carers should be positioned in both the research and policy agenda.

A standardized reporting tool that integrates the relevant constructs of the CTF could help address this challenge by offering the opportunity to include the carers in the intervention design and evaluation. Establishing a standardized reporting tool would also improve the reporting quality and clinical translation of these complex interventions, especially for carers of people with palliative care needs, wherein an optimal care model is yet to be established.

Data Management and Sharing

All relevant data are included in the article and Supplementary File S1. Any other data are available by request from the corresponding author.

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Authors' Contributions

C.M. and M.A. were responsible for study concept and design and the drafting of the article. C.M. was responsible for the acquisition of the data. All authors contributed to the analysis and interpretation of the data and the critical revision of the article. All authors approved the final version of the article to be published.

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Supplementary Material

Supplementary File S1

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Appendix 3. Rating criteria for mapping studies against Care Transition Framework (CTF) constructs.

Overall ratings applied:
No star = not described
*=partially described
**well described.

Additional detail on rating criteria only applied to constructs that required more explicit explanations (based on consultation amongst researchers CM and MA)

Implementation Measures

Acceptability:
*= satisfaction/ qualitative measures OR completion/withdrawal rates
**= satisfaction/qualitative data AND completion/withdrawal rates

Appropriateness:
*= Only describing quantitative measures, no qualitative data
** = qualitative and quantitative work used to describe whether intervention did what it intended to do (e.g. improve transition).

Adoption:
*= Brief description of participation and drop-out rates/attrition rates
** = More detail re participation rates and droup-out rates *(e.g. specifying reasons and timeframes.)

Fidelity:
*=completion rates of intervention elements
** = completion rates of intervention elements plus other components measures (e.g. adherence to protocol, staff training, clinician/views re adherence)

Replicability:
*= described views on how replicable the intervention would be and considerations.
** = detailed description of considerations, process and outcomes related to replication.

Outcomes

Patient/carer-centred outcomes
*= limited description of how the selection of person-centred outcomes was consistent with individual preference (eg. preferred venue of care).
** = more detailed description (qualitative data) of how the selection of person-centred outcomes was consistent with individual preference
No star if only reporting measures that are used to demonstrate change in health status (e.g. QOL, stress, function, symptoms.

Patient/carer experience

*=describes questionnaire or short structured interviews
**= multiple questionnaire or in=depth interviews exploring aspects beyond satisfaction.

Appendix 4. Summary of Implementation process and behaviour change strategies used

The implementation process occurred across three stages – before, during and after implementation; and was based on the evidence-based implementation and training program developed by the CSNAT-I research group (University of Manchester 2022). A broad range of behaviour change strategies were applied across these stages targeting individual clinician behaviour based on Michie and colleagues Behaviour Change Wheel (2011). These strategies are listed in table below and the timeline they occurred across is illustrated in Figure 6.1. It can be noted that there is overlap in the how these strategies were operationalised and is typical of how behaviour change techniques work in healthcare (Michie et al 2011).

Education took on various forms across the stages to increase understanding, motivation, and beliefs in their capability of adopting the CSNAT-I into practice. Initially, this was in the form of tailored training sessions, process, and intervention mapping to compare current practices to anticipated practice change, followed by ongoing reflective practice sessions that occurred formally through focus groups, working group meetings and weekly case reviews, and informally between local clinicians on the ward and during caseload reviews. These sessions were facilitated by clinical champions and influenced by feedback, data from audits, clinical supervision, and modelling with senior occupational therapists.

Clinical champions played a central role to the implementation process. Clinical champions were clinical leads from each team, and facilitated the adoption of the CSNAT-I through coordinating reflective practice sessions, attending project working groups, overseeing local audits and adherence to CSNAT-I protocol. At mid-way, feedback from **reflective practice** sessions led to a reallocation of clinical champion roles at each site to optimise impact on the team and manage change in individual workloads and capacity to carry out the role as originally intended.

Strategies to **enable practice change i**ncluded development of local CSNAT-I protocols informed by clinicians participating in focus groups and working groups, and consumer input across these forums. Eligibility to receive the CSNAT-I was reviewed during implementation in regard to what constitutes a complex discharge and to assist clinicians in managing workload. Other persuasive strategies were used including sharing of consumer and carer stories across the team; including consumers in process development and evaluation, and feedback loops to convey success and learnings from using the CSNAT-I within the teams.

The adaptive design of the process enabled **modifications** to occur across the implementation period including changes to eligibility criteria, re-allocation of clinical champion roles, changes to audit processes; and introducing additional strategies to encourage uptake e.g. additional case reviews, incentives, training videos; and new features to the electronic medical record template.

After implementation, **an online training program** was developed based on data collected across the project; that could be applied to implementation initiatives across other disciplines in the same setting. This program consisted of the established implementation program for the CSNAT-I developers with additional strategies related to reflective practice sessions, expectations, and management of clinical champions specific to the setting.

References:

Michie, S., Van Stralen, M. M., & West, R. (2011). The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science, 6*, 42. https://doi.org/10.1186/1748-5908-6-42

University of Manchester & University of Cambridge. (2022). *Carer Support Needs Assessment Tool – Intervention*. Retrieved April 1, 2025, from https://csnat.org/

Table 5.1. Behaviour change strategies used for CSNAT-I implementation

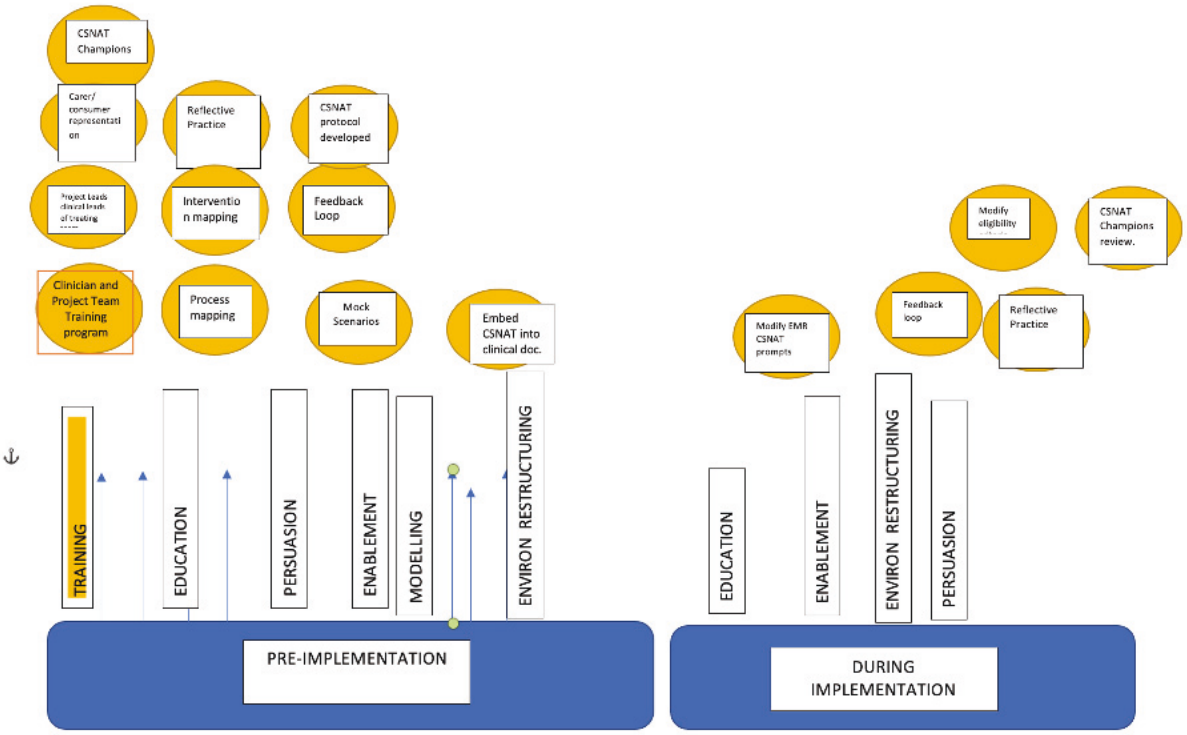
Behaviour Change Strategy	**Description**
Education (increasing understanding)	• Process and output mapping • Intervention mapping • Reflective practice sessions (case scenario, identifying barriers, ward audits) • Engagement in focus groups
Training	• Delivered CSNAT-I specific training modules across different levels (on-line, face to face).
Environmental restructuring	• Providing CSNAT-I tool, online templates for reporting in record. • Prompts on Electronic Medical Record (EMR) to remind people to complete CSNAT-I when documenting.
Modelling	• Mock scenarios of peer OTs providing CSNAT-I • Reflective practice opportunities in local teams • Use of clinical champions • Audio recording of intervention delivery. Eg. how it is introduced.
Enablement	• CSNAT-I process/pathway developed

	• CSNAT- process/pathway reviewed mid-way e.g. eligibility criteria. • Clinical champions – self-evaluation and reallocation of roles at mid-way. • Change in role allocation of CSNAT-I champion roles. • CSNAT -I champions within team • Project working group. • Project leads clinical leads of team. • Continual refining of data collecting processes to engage clinical champions and manage time demands of staff. • Increasing work capacity • Providing protocol, short cuts on EMR, supervision support via clinical champions • Altering eligibility criteria • Changing or adding clinical champion roles.
Incentivisation	• Incentives for clinicians to complete CSNAT-I • Ringing the "CSNAT-I" bell.
Persuasion	• Process and output mapping • Intervention mapping • Mid-way ward audits of eligible patients – led by clinical champions. • Carer and clinician stories • Use of consumer reps in working and focus groups • Reminders via Workplace and Teams • Feedback regarding outcomes of using the CSNAT-I, for team and carer at key points. • CSNAT-I Corner – snapshot of results, FAQs

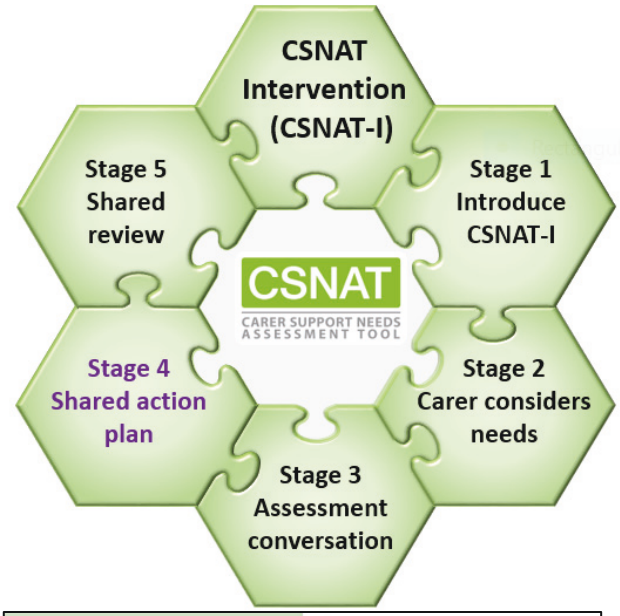
Intervention/strategy	Description
Reflective Practice	• CSNAT-I Project Working Groups

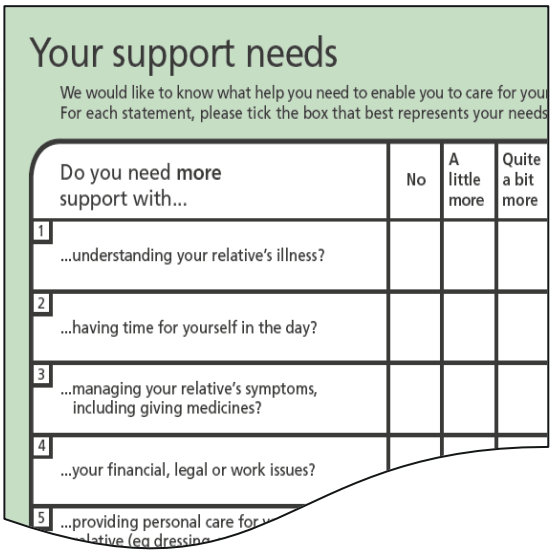
	• Focus groups at pre, mid and late implementation. Identifying current practices; potential and actual enablers/barriers to behaviour change. • Completing mid-way and late case scenarios and evaluation in team huddles; start general then targeting specific areas of concern e.g. identifying potential • Informal reflections with project lead in workspace • Add CSNAT-I to discuss in clinical supervision sessions.
Feedback loops	• Clinical **log** of CSNATs completed – clinician and champions responsibility. • Mid-way eligibility ward a**udits**. • Focus Group data informs change in process and implementation. • **Self-rating** of CSNAT Champions alignment with role. • Collation of service and process data at mid and late implementation – fed back – to stakeholders. • Sharing data on carer interviews
Iterative and adaptive project design	• Feedback from audit and reflections used to modify project design and processes.
Leadership	• Team Leaders as Clinical Champions • Team leaders as Project Leads
Carer stories	• Carer consumer reps • Sharing stories •

Figure 5.1 Timeline for CSNAT-I implementation strategies.



Appendix 5. CSNAT-I stages and paper-based tool example

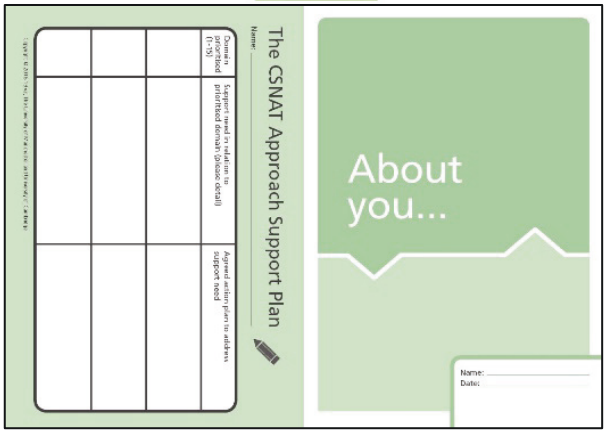




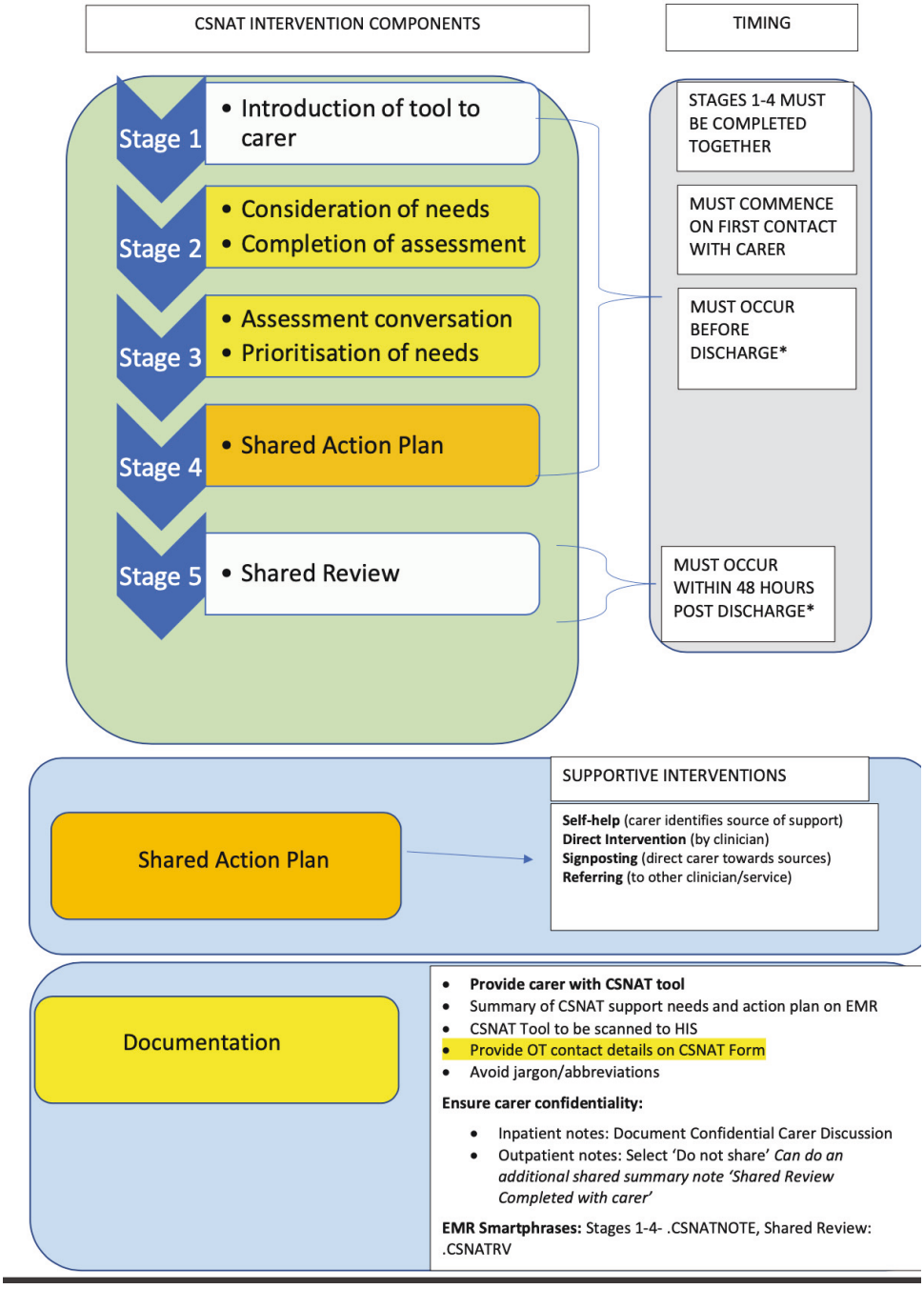
Your support needs

We would like to know what help you need to enable you to care for you
For each statement, please tick the box that best represents your needs

Do you need more support with...	No	A little more	Quite a bit more
1 ...understanding your relative's illness?			
2 ...having time for yourself in the day?			
3 ...managing your relative's symptoms, including giving medicines?			
4 ...your financial, legal or work issues?			
5 ...providing personal care for y... (eg dressing			



Appendix 6: CSNAT-I Clinical protocol for Project 2



Appendix 7. Ethics approval letters

Peter MacCallum Cancer Centre
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PETER MACCALLUM CANCER CENTRE HUMAN RESEARCH ETHICS COMMITTEE [EC00235]
ETHICAL APPROVAL

HREC Project ID: HREC/66596/PMCC
Peter Mac No: 20/132L
HREC Approval Date: 18 August 2020

Project Title: Implementation and evaluation of the CSNAT Approach: An early intervention to assist carers of advanced cancer patients in hospital discharge and the transition home

Coordinating Principal Investigator: Ms Celia Marston

I am pleased to advise that the above project has **received ethical approval** from the Peter MacCallum Cancer Centre Human Research Ethics Committee (HREC). The HREC confirms that your proposal meets the requirements of the National Statement on Ethical Conduct in Human Research (2018). This HREC is organised and operates in accordance with the National Health and Medical Research Council's (NHRMC) National Statement on Ethical Conduct in Human Research (2018), and all subsequent updates, and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95), the Health Privacy Principles described in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

Ethical approval for this project applies at the following sites:

Site
Peter MacCallum Cancer Centre
Royal Melbourne Hospital
Royal Women's Hospital

Approved Documents
The following documents have been reviewed and approved:

Document	Version	Date
Protocol	2	14 August 2020
Appendix 10.4 PICF- Clinician	2	12 August 2020
Appendix 10.5 PICF- Patient	2	12 August 2020
Appendix 10.6 PICF- Carer	2	12 August 2020
Appendix 10.1 Clinician Focus Group Question Guide	2	12 August 2020
Appendix 10.2 Clinician Interview Schedule	2	12 August 2020
Appendix 10.3 Patient Carer Interview Schedule	2	12 August 2020
Appendix 10.8 Patient Carer Invitation Script CSNAT	1	12 August 2020
Appendix 10.7 CSNAT Schematic	1	09 July 2020

Governance Authorisation
Governance Authorisation is required at each site participating in the study before the research project can commence at that site. You are required to provide a copy of this HREC approval letter to the principal investigator for each site covered by this ethics approval for inclusion in the site specific assessment application.

Conditions of Ethical Approval

- You are required to submit to the HREC:
  - An Annual Progress Report (that covers all sites listed on the approval) for the duration of the project. This report is due on the anniversary of HREC approval. Continuation of ethics approval is contingent on submission of an annual report, due within one month of the approval anniversary. Failure to comply with this requirement may result in suspension of the project by the HREC.
  - A comprehensive Final Report upon completion of the project.
- Submit to the reviewing HREC for approval any proposed amendments to the project including any proposed changes to the Protocol, Participant Information and Consent Form/s and the Investigator Brochure.
- Notify the reviewing HREC of any adverse events that have a material impact on the conduct of the research in accordance with the NHMRC Position Statement: *Safety monitoring and reporting in clinical trials involving therapeutic products November 2016*.
- Notify the reviewing HREC of your inability to continue as Coordinating Principal Investigator.
- Notify the reviewing HREC of the failure to commence the study within 12 months of the HREC approval date or if a decision is taken to end the study at any of the sites prior to the expected date of completion.
- Notify the reviewing HREC of any matters which may impact the conduct of the project.
- If your project involves radiation, you are legally obliged to conduct your research in accordance with the Australian Radiation Protection and Nuclear Safety Agency Code of Practice 'Exposure of Humans to Ionizing Radiation for Research Purposes' Radiation Protection series Publication No.8 (May 2005) (ARPANSA Code).

Please note: Template forms for reporting Amendments, Adverse events, Annual/Final reports, etc. can be accessed from: www.petermac.org/research/doing-research-us/ethics-governance.

The HREC may conduct an audit of the project at any time.

Yours sincerely,

Dianne Snowden

Digitally signed by Dianne Snowden
DN: cn=Dianne Snowden, o=Peter MacCallum Cancer Centre, ou=Human Research Ethics & Governance, email=dianne.snowden@petermac.org, c=AU
Date: 2020.08.18 15:36:56 +10'00'

Dr Dianne Snowden
Manager Human Research Ethics & Governance
Ethics Committee Secretariat
T: 8559 7540
E: ethics@petermac.org

HREC Approval Granted - ETH20-5452

Research.Ethics@uts.edu.au <Research.Ethics@uts.edu.au>
Tue 08/12/2020 16:28
To:Research Ethics <research.ethics@uts.edu.au>;Meera Agar <Meera.Agar@uts.edu.au>;Celia Marston <Celia.K.Marston@student.uts.edu.au>;anthea.udovicich@petermac.org <anthea.udovicich@petermac.org>

1 attachments (211 KB)
Ethics Application.pdf;

Dear Applicant

Re: ETH20-5452 -
"Implementation and evaluation of the CSNAT Approach: An early intervention to assist carers of advanced cancer patients in hospital discharge and the transition home"

[External Ratification: Peter MacCallum Cancer Centre, HREC approval HREC/66596/PMCC Local No. 20/132L -
18/8/2020 to 18/8/2021]

The UTS Human Research Ethics Executive Review Committee has reviewed your application 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.

Your approval number is UTS HREC REF NO. ETH20-5452.

Approval will be for the period specified above and subject to the provision of annual reports and 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). The Ethics Secretariat will contact you when it is time to complete your first report.

This research must be undertaken in compliance with the Australian Code for the Responsible Conduct of Research and National Statement on Ethical Conduct in Human Research.

You should consider this your official letter of approval. If you require a hardcopy please contact the Ethics Secretariat.

To access this application, please click here, a copy of your application has also been attached to this email.

We value your feedback on the online ethics process. If you would like to provide feedback please do so here.

If you have any queries about your ethics approval, or require any amendments to your research in the future, please don't hesitate to contact the Ethics Secretariat and quote the ethics application number (e.g. ETH20-xxxx) in all correspondence.

Yours sincerely,

The Research Ethics Secretariat

on behalf of UTS Human Research Ethics Expedited Review Committees
C/- Research Office
University of Technology Sydney
Research.Ethics@uts.edu.au | Website
PO Box 123 Broadway NSW 2007

Ref: E39

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Bendigo
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Moorabbin
Sunshine

Peter Mac
Peter MacCallum Cancer Centre
Victoria Australia

GOVERNANCE AUTHORISATION

SITE SPECIFIC ASSESSMENT (SSA) APPROVAL TO CONDUCT A RESEARCH PROJECT PETER MACCALLUM CANCER CENTRE

EPIC Study Code: PMC83438

Peter Mac No: 22/43L
Title: Caring for carers of people with advaNced cancer at hospiTal discharge (CareNET): A single-arm open label feasibility study
Principal Investigator: Ms Celia Marston

Reviewing HREC: Peter MacCallum Cancer Centre Ethics Committee (EC00235)
HREC Reference: HREC/83438/PMCC
HREC Approval Date: 01 August 2022

SSA Project ID: SSA/83438/PMCC
SSA Authorisation Date: 01 August 2022

I am pleased to advise that the above project is authorised to be conducted at the **Peter MacCallum Cancer Centre**. This approval is subject to compliance with the conditions set out below and any conditions specified by the reviewing HREC.

Approved Documents:

Document	Version	Date
Protocol	7	15 July 2022
Appendix 2 Cost questionnaire	2	05 May 2022
Appendix 3 Qualitative Participant Interview Schedule	1	09 February 2022
Appendix 4 Clinician Interview Schedule	1	25 August 2021
Appendix 5 CSNAT-I	2	05 May 2022
Appendix 6 CSNAT-I Staff Protocol	1	09 March 2022
Appendix 7 Patient Carer Invitation script	2	05 May 2022
Appendix 8 PMCC Participant Information Sheet and Consent Form Carer	2	05 May 2022
Appendix 9 PMCC Participant Information Sheet and Consent Form Patient	2	05 May 2022
Appendix 10 PMCC Participant Information Sheet and Consent Form Clinician	1	09 March 2022
Appendix 15 PMCC Participant Information Sheet and Consent Form Person Responsible	4	15 July 2022
Appendix 11 Email invitation for staff	1	09 March 2022
Appendix 12 EQ-5D-5L	1	09 March 2022
Appendix 13 Carer Qol English	2	05 May 2022
Appendix 14 Preparedness for Caregiving Scale	--	09 March 2022

Noted Document	Version	Date
Appendix 1 Summary of CSNAT Trials	1	09 March 2022

Use of the Electronic Medical Record for Research
Accessing identified patient information from health services other than your own for research purposes is NOT permitted. Precinct polices regarding appropriate access MUST be followed. Identified patient information must ONLY EVER be accessed after governance authorisation or quality assurance (QA) approval from the appropriate health service.

Research Governance
As Principal Investigator, you are required to:

1. Comply with the Investigator's responsibilities as outlined in the *Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95).*
2. Submit a copy of this letter to the person responsible for radiation safety at Peter MacCallum Cancer Centre. **This condition only applies if** the project involves exposure to ionising radiation that exceeds dose constraints, and the Medical Physicist's report has advised that the project needs to be added to the site's *Licence for Research Involving Human Volunteers* issued by the Department of Health Radiation Safety Section (for more information, visit www.health.vic.gov.au/radiation/). *Note: If the Medical Physicist's report has advised that the project needs to be added to the site's licence, the project cannot commence at site until you have confirmed that the project has been added to the site's licence.*
3. Notify the Peter MacCallum Cancer Centre Research Governance Office (RGO) of:
    - The actual start date of the project at Peter MacCallum Cancer Centre.
    - Any amendments to the project after these have been approved by the reviewing HREC.
    - Any adverse events involving patients of Peter MacCallum Cancer Centre, in accordance Peter MacCallum Cancer Centre Governance Guideline001 www.petermac.org/research/doing-research-us/ethics-governance .
    - Any changes to the indemnity, insurance arrangements or Clinical Trial Research Agreement for this project. This includes changes to the project budget or other changes which may have financial or other resource implications at Peter MacCallum Cancer Centre.
    - Your inability to continue as Principal Investigator or any other change in research personnel involved in this project.
    - Failure to commence the study within 12 months of the Governance authorisation date or if a decision is taken to end the study at this site.
    - Any other unforeseen events.
    - Any other matters which may impact the conduct of the project at Peter MacCallum Cancer Centre.
4. Ensure that HREC approval remains current for the entire duration of the project. Investigators undertaking projects without current Reviewing HREC approval risk their indemnity, funding and publication rights.

5. Submit an annual progress report every 12 months for the duration of the project. Continued SSA approval is contingent on receipt of an annual report by the RGO. In addition, a comprehensive final report should be submitted to the RGO upon completion of the project.

You must also abide by the following requirements:

6. Where applicable, ensure that the CTN has been electronically lodged to the TGA by the sponsor.

7. For clinical trials where Peter MacCallum Cancer Centre is the Sponsor, you are required to contact the Office for Cancer Research [ocr@petermac.org] to organise submission of the electronic Clinical Trial Notification (e-CTN) to the TGA. This must be completed before commencement of your project.
8. It is the Principal Investigator's responsibility to ensure that copies of the complete submitted e-CTN and TGA issued acknowledgement are included in the study Site File for the project at this site.
9. Ensure that the Clinical Trial Research Agreement (CTRA) and Indemnities (or other research agreements as applicable) are fully executed, i.e. signed by all parties; and an original version (or copy) placed in the study file.

Please note: Template forms for reporting Amendments, Adverse events, Annual/Final reports, etc. can be accessed from: www.petermac.org/research/doing-research-us/ethics-governance

---

The RGO may conduct an audit of the project at any time.

Yours sincerely,

Dianne Biermann Digitally signed by Dianne Biermann
Date: 2022.08.01 12:49:32 +10'00'

Dianne Biermann
Human Research Ethics & Governance
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Appendix 8. Experience and acceptability of a carer‐focussed intervention in acute oncology settings: A qualitative study of people with advanced cancer and their carers.

Check for updates

Received: 25 February 2023 | Accepted: 13 May 2023

DOI: 10.1111/1440-1630.12887

FEATURE ARTICLE

Australian Occupational Therapy Journal | WILEY

Experience and acceptability of a carer-focussed intervention in acute oncology settings: A qualitative study of people with advanced cancer and their carers

Celia Marston[1,2,3,4] | **Deidre D. Morgan**[5,6] | **Jennifer Philip**[7,8,9,10] | **Meera R. Agar**[4]

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[8]Palliative Care Service, St. Vincent's Hospital, Melbourne, Victoria, Australia

[9]Department of Medicine, University of Melbourne, Melbourne, Victoria, Australia

[10]Palliative Care Service, Royal Melbourne Hospital, Melbourne, Victoria, Australia

Correspondence
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Email: celia.marston@petermac.org

Funding information
Western and Central Melbourne Integrated Cancer Services (WCMICS) Funding Program

Abstract

Objectives: Providing optimal support for carers of people with advanced cancer is critical to facilitating discharge home from hospital. Carer Support Needs Assessment Tool–Intervention (CSNAT-I) has shown promise in supporting carers' needs in this context. This study aimed to explore patient and carers experiences with and views on the acceptability of the CSNAT-I delivered by occupational therapists in an acute oncology setting.

Methods: People with advanced cancer and their carers who had previously received the CSNAT-I as part of usual care while admitted to an Australian specialist cancer centre or acute hospital were invited to participate in interviews exploring their perceptions of the intervention. Data were analysed thematically.

Results: Two patients and 10 carers participated in semi-structured interviews. Three themes were constructed from the data: Carers viewed the CSNAT-I as comprehensive process that (1) 'covered everything' related to discharge planning; (2) generated an 'increased awareness of needs' for themselves, patients, and clinicians; and (3) triggered an emotional response of

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feeling 'wrapped up in care' that was maintained as they moved from hospital to home.

Conclusion: This study has demonstrated that the CSNAT-I was highly acceptable to carers as part of existing discharge processes supporting them through the transition from hospital to home and can be delivered by occupational therapists and other clinicians with a natural synergy to discharge planning. These findings will inform further development and testing of the delivery model of the CSNAT-I in future trials.

KEYWORDS
cancer, caregivers, occupational therapy, transitional care

1 | INTRODUCTION

Carers of people with advanced cancer are critical to supporting the frequent moves from hospital to home (Lawson et al., 2006; Rosenwax et al., 2011). International policy recommends support for cancer carers throughout the discharge planning process (Carers UK, 2021; Victorian Government, 2018, 2020). However, carers describe being largely unsupported, navigating distress and uncertainty (Guo et al., 2022; Isenberg et al., 2021; Marston et al., 2015; Miller & Porter, 2021; Plank et al., 2012; Wang et al., 2018). Carers report inadequate access to information and support related to the illness, treatment, discharge planning, and practical aspects of caring (Wang et al., 2018). Current research and state government policy such as the Victorian Cancer Plan is limited in their focus on effective discharge interventions in an advanced cancer setting that targets carers (Harding et al., 2012; Rocío et al., 2017; Victorian Government, 2020). In most studies, the carer is positioned as a patient resource during discharge rather than a recipient of care and support (Marston et al., 2023; Saunders et al., 2021).

The Carer Support Needs Assessment Tool Intervention (CSNAT-I) has proven effective in improving carer outcomes in palliative care (Aoun et al., 2015; Grande et al., 2017; Lund et al., 2020; Toye et al., 2016). The CSNAT-I creates opportunity for carers to communicate and prioritise their needs and to develop action plans with clinicians. The CSNAT-I has been evaluated primarily in the community palliative care setting, with limited evaluation in the hospital context (Aoun et al., 2018, Ewing et al., 2018; Toye et al., 2016). It has been found to support carers through the discharge process with carers, suggesting it could help with hospital to home transition if introduced early and if their needs are reviewed soon after the patient returns home (Ewing et al., 2018).

Key Points for Occupational Therapy

- Carers are recipients of care rather than resources or witnesses.
- Integrating the CSNAT-I into existing occupational therapy discharge planning models may enhance its adaptability of working across different contexts.
- Occupational therapists are well positioned to deliver a carer-focussed intervention as part of usual discharge planning models of care.

To our knowledge, no studies have evaluated the lived experience of carers receiving the CSNAT-I in an acute oncology setting. Understanding lived experience from the lens of intervention acceptability, in this case a carer discharge intervention, is an important phase of complex intervention development (Craig et al., 2008; Sekhon et al., 2017).

This study sought to understand advanced cancer patient and carers' experiences with the CSNAT-I and views on acceptability in the hospital discharge context when delivered by occupational therapists. Acceptability was defined as the 'extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experiential cognitive and emotional responses to the intervention' (Sekhon et al., 2017 p.4). This study is part of an evaluation of a program of work whereby the CSNAT-I was implemented using the evidence-based toolkit (1) with other components of the evaluation occurring at health professional and service levels (implementation strategy: Box 1).

14480630, 2023, 5, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/1440-1630.12887 by Celia Marston - Royal Melbourne Hospital , Wiley Online Library on [01/04/2025]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

BOX 1 Intervention model and implementation process

What: The CSNAT-I is a five-stage person-centred model led by carers and facilitated by clinicians to identify, prioritise and address needs related to their role of caring for the advanced cancer patient. Details on the different elements of this intervention can be found at www.csnat.org. The five stages were:

1. Introduction of CSNAT-I (OT introduces the CSNAT-I to the carer during admission)
2. Carer consideration of needs (Carer completes self-assessment and prioritises needs)
3. Assessment conversation (Carer and OT discuss prioritised needs)
4. Shared action plan (Carer and OT identify and follow up actions to address needs)
5. Shared review – (OT and carer schedule and complete shared review).

When and how: The timing, outputs and delivery of these stages were determined via clinician feedback provided within training and discussion groups (as Training and Implementation Toolkit). [1] This feedback informed the development of a clinical guideline for each site. The CSNAT-I was delivered by the treating occupational therapist and modified iteratively based on findings from the data collected during the study. There was also a primary focus on commencing the CSNAT-I early in the admission and providing a second review post discharge as per recommended in a recent feasibility study for its use in acute discharge planning. [2]

Who: All carers who care for someone with advanced cancer, and an occupational therapy referral and complex discharge needs were able to receive the CSNAT_I. Given the adaptive design of this project, who was suitable to receive the CSNAT-I evolved further to enhance acceptance.

2 | STUDY DESIGN

This study employed a pragmatic qualitative approach. Pragmatism informs qualitative inquiry by enabling researchers to seek answers to practical questions that can inform actions (Patton, 2015). This study sought to understand carers' experiences of receiving an intervention in usual everyday practice: specifically, how they thought it worked and how it made them feel. A pragmatic approach also enabled decisions to be made during the research process within real world constraints (Patton, 2015). Real world constraints can be defined as time and resource limitations related to conducting research in a natural clinical environment. Findings were mapped against the Theoretical Framework of Acceptability (TFA) (Sekhon et al., 2017). Consolidated criteria for reporting qualitative research (COREQ) guidelines guided reporting (Tong et al., 2007).

2.1 | Setting

The setting was a 140-bed specialist cancer centre and a 571-bed acute hospital in metropolitan Melbourne. Medical, surgical, haematology, and palliative care wards at both sites were included. Occupational therapists within the interdisciplinary team provided complex discharge planning for patients wanting to receive care at home.

2.2 | Participants

Potential participants were patients with advanced cancer and their carers (patient–carer dyad) who received the CSNAT-I during their admission. Carers were defined as 'Lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management' (NICE, 2004 p.155). Patient-carer dyads were eligible for the CSNAT-I if they were planning to return home and had complex discharge needs (as per Supporting Information S1). This aligned with embedding the intervention within a natural clinical environment. In some instances, the CSNAT-I was partially delivered, and a person's discharge destination changed from home to residential care or rehabilitation. Both members of the dyad did not have to agree to participate in the interview to be deemed eligible in the overarching study. Of the 50 patient–carer dyads who consented for the main study, 10 carers and 2 patients agreed to participate in interviews.

2.3 | Sampling and recruitment

Patient–carer dyads were approached within the overarching study after being identified by treating occupational therapists. A researcher (AU) obtained consent via face to face or phone from eligible participants during hospital admission. Participation in the study involved the following: (1) researcher access to medical records for patients; (2) access to information recorded on the

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CSNAT-I and demographic details for carers; and (3) and an optional interview for both patient and carers. Both members of the dyad did not have to agree to participate in the interview to be deemed eligible in the overarching study. Participants able to provide informed consent and participate in a phone-based interview 2 weeks after discharge were recruited (as per Supporting Information S2). Researchers (AU or CM) repeated verbal consent via phone prior to scheduled interview. Participants were purposively selected to obtain a broad representation of different diagnoses and social situations and until data saturation was reached. For this pragmatic study, data saturation was limited to the level of analysis needed to answer the overarching research questions. This was reached for the main themes when new codes or themes informed the study (Saunders et al., 2018; Thorne, 2020).

2.4 | Data collection

Data collection occurred between November 2020 and June 2021. Patient and carer interviews were conducted via phone by CM within 2 weeks post-hospital discharge. Interviews explored participant experiences and views on the purpose, benefits, and drawbacks of the CSNAT-I. The interview schedule was based on past CSNAT-I qualitative studies and piloted with carer consumers (Supporting Information S3). Interviews were audio-recorded and transcribed verbatim. Transcription summaries were given to participants for review. Interviews lasted between 12 and 43 minutes. Field notes were also recorded by CM.

2.5 | Data analysis

Data were managed using NVivo software. Inductive thematic analysis was used to examine participants' experiences, thoughts, and behaviours arising from the interviews and recorded field notes. Data analysis was informed by Braun and Clarke's (2006) six step process:

1. Interviews (transcript and fieldnotes) were read and re-read individually and then as a whole to ensure familiarisation with data.
2. Initial codes were identified and defined from three interviews and used to develop a coding manual. These were then applied to the entire data set. Additional notes were made regarding any potential patterns that may inform future theme generation. These two steps were conducted by two experienced qualitative researchers (CM and AU).
3. Codes were analysed and organised into themes and an audit trail of theme development was maintained.
4. Researcher triangulation with another two other researchers (MA and JP) ensured that themes reflected the data and focus of study.
5. Final theme and subthemes were constructed and interrelationships between themes articulated by CM and DM. (Supporting Information S4). TFA constructs and qualitative data from other CSNAT-I studies were used to inform coding and early theme development. This was to align with timeline for project and responsiveness needed to identify and address problems along the way.

3 | FINDINGS

Demographic and clinical characteristics of interviewed participants are outlined in Table 1 and Supporting Information S5. Most carer participants were female, and ages ranged from 27 to 69 years. Partners and adult children made up most of the cohort. Time spent in caring role for eight carers ranged from 3 months to 10 years, with two carers reporting 'a few months' and 'since diagnosis'.

Carers described their experience with the CSNAT-I in the context of preparing for the person they are caring for to return home. The following themes were constructed from the data: (1) covered everything, (2) increased awareness of needs, and (3) wrapped in care. Themes and subthemes are described below.

3.1 | Theme 1: Covered everything

3.1.1 | It centralised everything

Patients and carers described the CSNAT-I as a coordinated process that enabled identification of carer needs relating to discharge home and practical ways to

TABLE 1 Participant demographics

Carer ($n = 10$)	
Gender	Female: 7; male 3
Age	Range: 27–69
Relationship with patient	Spouse: 4; adult child: 4; parent: 1; friend: 1
Patient ($n = 2$)	
Gender	Female: 1, male: 1
Age	42; 69
Diagnosis	Glioblastoma, metastatic melanoma

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address them. For most carers, the process of identifying their needs using the 'About Me' booklet was central to their experience. Carers often referred to the booklet as the 'green form' [CP35] and viewed it as a valuable resource that assisted them in navigating the hospital discharge process. This carer appreciated how the booklet offered a starting point to accessing what was needed for discharge for his mother and was also something he and other family members could refer back to:

> ... it was good that [name] provided that 'cause at least I'm able to centralize and go back and forth, OK this is how we're supposed to start .... [CP8]

Another carer described how the booklet was instrumental in navigating their new role as a carer and how to prepare for the future:

> It helped me to understand what kind of thing I need 'cause this is the first situation we met and I've got no idea what kind of thing I need maybe in the future and the green form let us know everything we may need in the future. [CP35]

One carer found it difficult to recall the 'green form'; however, the process of needs assessment and support was still a central focus of their experience:

> Yeah, no I did understand the form. To be honest I can't remember exactly what it said .... So I ... went home with the confidence that everything was gonna be good and we'll do as much as we can and, yeah, it was all available, oxygen, anything, any questions that we've had were answered. [CP21]

3.1.2 | Comprehensive way of working through needs

Most carer participants valued the structured approach around pre-determined domains to work through their specific needs, offering a smooth coordinated approach to an overwhelming situation described as a comprehensive process that 'covered a lot' [CP21]. The pre-determined domains included in the 'About Me' booklet were considered thorough and relevant, except for one carer [CP35] who suggested an additional section was needed to record support with ambulance insurance.

> I can't really think of anything else that you could put on there that's going to ... 'cause it's really got everything, it did have, you know, whatever you needed. [CP33]

> ... it was very thorough like to the point so I was happy with that ... I was happy with the sentences because I've usually found the ones what was important to us. [CP8]

The checklist format was described by one carer as a key feature that made the CSNAT process easy to understand and respond to

> ... I think the tool is very good, I think anyone would probably like it as well 'cause it helps a lot. You know, you just tick what you know already or if you need anything else you just mark it down, it's pretty straightforward so it's really helpful ... I have an admin job so I'm pretty into ticking boxes .... [CPRMH8]

One carer found the comprehensive nature of the CSNAT-I initially overwhelming but useful over time:

> Overwhelmed—with everything that is happening so it was good to have time to reflect on I I sat down with coffee and breakfast next day to complete; then went through again with (AD)—and realised that some things had been addressed or changed. [CP20]

In contrast, the process of how these steps were enacted was not always clear to the patients and carers, particularly the process after discharge. Carers recalled this process in different ways, ranging from not knowing who should contact who to having contact with various different health professionals involved in their care. This carer had pre-established relationships with the lung cancer nurse:

> About two weeks ago he was struggling big time and I rang Mary, although I didn't speak to her I spoke to another person there and they were able to fix my problem actually which was good and Mary sent me a message saying, you know, what she thought I needed to do as well. So I feel very supported. [CP21]

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3.2 | Theme 2: Increased awareness of care needs

3.2.1 | Self-awareness

The CSNAT-I facilitated an increased self-awareness of carers' own current and future care needs and priorities but also improved clinician awareness of carer needs. This was mostly centred around the practical needs of caring, such as 'what I need to be able to care' [CP11] and 'making sure you're doing things the right way' [CP11] to support both the carer and the patient after hospital discharge. Needs included help with fast tracking funding applications for additional care, obtaining equipment and knowing who to contact for assistance in the future. One carer, new to the role, explained how the CSNAT-I provided them with the information and knowledge needed to navigate what was to come:

> I think it just highlights, you know, to people what's available and what's possible and, you know, I think it's a knowledge thing, just to know what's there and what could help you and things like that. [CP8]

The CSNAT-I also alerted two carers to consider and attend to their own personal needs, at a time when these were often not prioritised:

> Make me stop and think—how I am going to manage myself .... Thinking of her needs not mine; financial, own needs. [CP20]

This awareness could also be overwhelming. The CSNAT-I confronted one carer, whose husband was rapidly deteriorating, with the reality of the situation 'It just makes everything real' [CP11]. Another carer new to caring for her adult daughter needed time to adjust and understand what was needed and valued the support of the occupational therapist during this adjustment.

> Sitting down with occupational therapy was better than doing it on your own—to help you navigate. [CP20]

3.2.2 | Validation

Working through the care needs was validating for most participants. This occurred by confirming that there was help available that they would not otherwise know about and a way to acquire knowledge or information.

> But ... it had sections on there that made you think about other options that we may not have known of because ... we've never been in that situation. So ... you can actually get someone to help you at home or help you, [with] ... the garden or whatever it may be like, you know, extra help, ... that sort of thing, ... and assistance ... some of the things [I] probably wouldn't have known of, so that would be a big benefit .... [CP2]

> Oh no it's always useful to know what's available too to help you should you need. I mean you can't ask for help if you don't know what's available. [CP11]

In other cases, becoming aware of their own capability in responding to needs was affirming. For some carers, using the CSNAT-I verified that they were managing aspects of their caring role more proficiently than they thought.

> Validating things I thought I wasn't sure of; that I actually was. [CP20]

3.2.3 | Needs don't stop

Several carers spoke of their awareness of their changing needs, mostly once they returned home. One carer realised that the hospital bed that she did not think was necessary was actually 'really beneficial' [CP11]. Another carer witnessed her father become more dependent once he was home and felt the CSNAT-I was needed beyond hospital discharge, stating 'Needs don't stop after going home ...' [CP21].

One carer participant spoke of how some needs became less important over time:

> There was problems—... on the form that were relevant and that became irrelevant within a day or two. [CP11]

3.2.4 | Helping others understand what we need

Carers reported that working through the CSNAT-I with clinicians, enabled clinicians to gain immediate insights into what was needed, and carers to better understood what areas the clinicians were likely to be able to help them with.

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> I think it is beneficial to them so they understand, you know, where we come from as well and they can see what we need and what they can assist on too, so I think it helps? .... [CP8RMH]

One patient recognised the benefit of the CSNAT-I for the OT and their work structure: 'I guess it's to help the OT staff learning ahead and give them an idea about what to do next day' [PP5].

3.3 | Theme 3: Wrapped up in care

3.3.1 | Feeling cared for

Increased awareness of care needs triggered emotional responses for all carers. They described feeling more supported, cared for, and reassured that they will be able to cope. Some participants reported a noticeable shift from feeling 'panic' [CP33] to feeling more prepared for caring for their loved one at home. Knowing there was someone to contact was reassuring.

> We were very nervous bringing him home. It ... was comforting to know that they were there and ringing and making sure that everything is going well ... I was very pleased. [CP33]

One carer described how the CSNAT-I may have also elicited a sense of reassurance and comfort for the patient—knowing that the carer was being cared for:

> Yeah I think it would definitely benefit the patient as well 'cause, you know, they're rest assured that the carer is getting that backup ..., so they don't get stressed like everything's on that carer obviously, and they're making sure that the carer gets assistance at the same time as well as they're getting assistance too, so kind of like a balance .... [CP8RMH]

3.3.2 | Receiving support from all sides

Carers described feeling surrounded in this extra care that extended across hospital and home. Care ranged from systematically working through the 'green form', access to required equipment they needed so 'they wouldn't injure themselves' [CP11], to the support from the community-based palliative care nurses provided once they got home:

> ... It's been really quite good because we had the [home nurses] ... that brought all the tools that we need for [unclear] ... the chair, the bed, and they were ... excellent. So we didn't really need to panic on how are we going to, ... move him around the house and take him to the toilet .... It was really quite easy because ... they came, set it all up for me .... [CP33]

Carers described a sense of relief in knowing that there were people they could contact if they had questions and could help them with the unexpected. This support contributed to a sense that they were not alone in preparing for the return home of their loved one.

> It's a good thing to happen because it's two things for us, it's like firstly the empathy and communication that you're following something through to making sure that everything's OK in one end, and then from our perspective it's an opportunity also to ask questions that we forgot to ask the hospital, or maybe if my mum is a bit unwell maybe they can provide us with other guidelines. So it works both ways. [CP8]

3.3.3 | Care coordination

Carers described the experiences of support from a coordinated team across hospital and community rather than a specific person. Most carers could specify the nature of the support—'bringing all the tools—the chair, the bed ...' [CP33], but only a few accurately identified the specific discipline of the person providing care. Although individual disciplines of team members were rarely identified, there was a shared sense of appreciation and comfort in knowing that the support was available and accessible.

> I wouldn't put that down as a negative that you had multiple calls because at least you know that's checking in, at least if there was an issue then you've got these people calling and they can be like OK, that's OK, we'll help you or we'll do this or whatever, you know. But if no one calls then you'd be like oh my gosh, we've just left and they've just left us with nothing sort of thing. [CP33]

However, one carer preferred to have one key contact person:

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> Cause one of the things I said it's too much information overload. You nearly need one person, again too many people. [CP33]

4 | DISCUSSION

This is the first study to examine carers' experiences of using the CSNAT-I delivered by occupational therapists in an acute oncology setting. Overall carers described the CSNAT-I positively, as a comprehensive process that increased awareness of care needs and generated responses to practical aspects of caring, resulting in them feeling more supported and surrounded in care as they moved from hospital and home.

4.1 | Working through the practical needs

Our findings provide new evidence highlighting how carers address their needs in the hospital discharge context. A prominent benefit was the process of working through needs related to practical aspects of caring. The function of the CSNAT-I in systematically identifying and addressing carers' needs has also been reported when evaluated in other clinical settings, including home-based community palliative care settings (Aoun et al., 2015; Ewing et al., 2015) and carers of people with motor neurone disease (Ewing et al., 2020). Like this study, other carers have recalled this needs assessment process as making them feel listened to, validated, and more confident in the caring role (Aoun et al., 2015; Ewing et al., 2020).

A changing and uncertain environment demands that carers adapt quickly to new or higher caring responsibilities when their loved one goes home (Marston et al., 2015; Plank et al., 2012). Carers spoke of the CSNAT-I primarily addressing their practical needs with less reference to their emotional needs. This is not surprising in the context of discharge where obtaining information and practical resources to carry out the caring role is at the forefront of carers' minds and recognised as key domain of unmet need (Toye et al., 2016; Wang et al., 2018). Carer prioritisation of practical over emotional needs has also been reported in a trial testing of an outreach model that used the CSNAT-I to support carers of older people following discharge from a short stay medical unit (Toye et al., 2016). Carers most prioritised knowing who to contact, what to expect in the future, and how access to practical help in the home. The practice scope of the occupational therapist may have also influenced carers' focus on the practical aspects of caring. Facilitating discharge is core practice of occupational therapists working in oncology and palliative care (Eva & Morgan, 2018), and carers have viewed occupational therapists as providers of practical solutions in other palliative care research (Marston et al., 2015). That said, carers still acknowledged how the CSNAT-I created opportunities to address emotional needs, for example, asking carers if they needed support with their own feelings, worries, or spiritual concerns. This suggests that even in a discharge focussed context, the comprehensive nature of the CSNAT-I and its ability to reach across a broad range of needs is still favoured by carers.

4.2 | Embedded within the discharge process

Our study has provided insights into positioning this intervention in interdisciplinary care. Carers viewed the CSNAT-I as part of the usual discharge process rather than a separate, exclusive model of care. This was evident in two ways. First, participants perceived the CSNAT-I as part of a bundle of care that was not specific to one discipline. It was a supportive model where they could determine what was needed, what options they had for support in the future, obtain support from 'all sides', and across hospital and home. Carers did not link their experience exclusively to the occupational therapist. Instead, they perceived their experience involving different people and across various time points.

Second, carers viewed themselves as active recipients of care within the discharge planning model. Carer descriptions of feeling surrounded by car, and actively addressing their own needs as well as the patients suggest that they were engaging as care recipients. Other qualitative studies have suggested inclusion of the CSNAT-I in the discharge planning process is likely to be well received (Ewing et al., 2018; Toye et al., 2016), but our study shows this to be the case.

Carers have expressed a need to be included and positioned as partners in the discharge planning process (Allen et al., 2014)—often feeling unrecognised and excluded (Miller & Porter, 2021; Wang et al., 2018). For carers to fulfil their caring role and prevent breakdown of care once their loved one returns home, they need to be engaged with multi-disciplinary, multi-component interventions that reach across hospital and home and facilitate optimal information provision, care coordination, and communication (Miller & Porter, 2021). Carers' experiences reported in our study align with these characteristics and build on the existing evidence that the CSNAT-I can contribute to better hospital to home transitions for carers and the people they care for.

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Our study also builds on the notion that carers wish to receive further support beyond discharge. Carers' appreciation and positive response to follow up after discharge supports the evidence that the final review stage of the CSNAT-I is best completed once the patient has returned home to ensure needs have been addressed (Ewing et al., 2018). Some needs may not be identified by carers prior to the patient's discharge home, especially if the caring role is new or the nature and complexity of care have changed. Findings demonstrated that carers were looking beyond that initial transition period and sought follow up of new and outstanding needs via the CSNAT-I—aware that needs would continue to arise, and more support may be needed. This could also include more support for their emotional needs once the person is home from hospital. These findings echo other studies, which demonstrate that access to ongoing support and a review of their needs as carers is important to carers and often remains unclear or unaddressed at both patient and service levels (Ewing et al., 2018). The CSNAT-I developers recommend that the CSNAT-I should be repeated at key points in the care trajectory such as following discharge. However, these key points are dependent on the context in which the CSNAT-I is delivered in and the preference of the carer (Diffin et al., 2018; Ewing et al., 2015; Lund et al., 2022). For example, there may be key points after discharge where carers' emotional needs become more of a focus.

4.3 | Strengths and limitations

The primary investigator had a dual role as the clinical lead for the service and interviewer with the potential to influence the collection and interpretation of the data. This was managed by rigorous discussion with experienced qualitative researchers outside the clinical service to assist overall analysis and confirm themes. This dual role also served to benefit the analysis by offering a real life understanding of meanings and patterns generated from the data, that is, how the intervention worked in this context and potential clinical implications. The sample may have not included carers who were experiencing more complex situations, as discharge planning can be a distressing and overwhelming time for carers. The lack of critical or negative feedback also potentially is a limitation, as carers may have felt less able to express these views during care transition, particularly as this was conducted during the COVID 19 pandemic. Nevertheless, how to capture data from this specific group of carers is still an important consideration for future research.

4.4 | Implications for clinical practice and research

This study has highlighted the adaptability of the CSNAT-I and its capacity for implementation in different contexts with similar outcomes, that is, to generate more support for carers as they navigated the hospital discharge process.

The CSNAT-I can be integrated into existing discharge models and delivered by several clinicians in the multi-disciplinary team. Its natural synergy with discharge planning helps to address known implementation challenges by providing support to carers within their existing scope of practice and offer efficiencies by embedding it into existing models and supporting more economical adoption into practice. At a practice and policy level, carers need to be considered 'receivers' of care and support not just providers of care for someone else.

Further research is needed to further examine the drivers for carers to accept and engage with interventions. Acceptability relies on the cognitive and emotional response of people receiving and delivering the intervention (Sekhon et al., 2017)—that is, 'if it feels good, I will use it'.

5 | CONCLUSIONS

The CSNAT-I was accepted by carers as a way of systematically considering their needs and generating more support during the hospital-to-home transition. The CSNAT-I can be integrated into existing discharge planning models and practice scope of members of the multidisciplinary team, including occupational therapists. The mode of delivery of the CSNAT-I can be adaptable to different hospital contexts and could play an important role in transforming care at discharge to include and better support carers of people with advanced cancer.

AUTHOR CONTRIBUTIONS

All authors meet the criteria for authorship as defined by the International Committee of Medical Journal Editors (ICMJE). Celia Marston and Meera R. Agar were responsible for study concept and design and drafting of article. Celia Marston was responsible for the acquisition of the data. All authors contributed to the analysis and interpretation of the data and critical revision of the article. All authors approved the final version of this article to be published.

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CONFLICT OF INTEREST STATEMENT

The authors declared no conflict of interests related to the research, authorship, and/or publication of this article.

DATA AVAILABILITY STATEMENT

Research data are not shared.

ETHICS STATEMENT

Approval was obtained from the ethics committee of Peter MacCallum Cancer Centre, Royal Melbourne Hospital (HREC No. 66596) and University of Technology Sydney (ETH20-5542). The procedures used in this study adhere to the tenets of the Declaration of Helsinki. Informed written consent was obtained from all patient and carer participants included in the study. Verbal consent was reported immediately prior to the interview. In the case of the patient being unable to consent, consent was obtained from the authorised representative.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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Appendix 9. Interview guide for qualitative study 2a (patients and carers)

Interview Schedule* (Patient/carer)

Thank you for agreeing to talk to us around your experience with the CSNAT. The CSNAT or Carer Support Needs Assessment Tool was:

> *(Carer Script)…* a form that you completed with the assistance of an occupational therapist whilst the person you care for was in hospital. This form enabled you to select the different things you thought you needed the most help with planning for discharge home. The therapist helped you get the support that you needed and also gave you a call at home afterward to see if you needed anymore support.
>
> *(Patient script)*…a form that the person who cares for you completed with the assistance of an occupational therapist while you were in hospital. This form helped your carer work out what support they would need upon your return home and the therapist helped them get access to this support.

As part of this study we have been collecting information from patient/carer relating to your experience of using the CSNAT. But we are also interested in your perception/thoughts of the strengths and limitations of the CSNAT more broadly and its potential applications/use in the future. We value your insights and thoughts around this issue.

We will be recording this discussion, just so that we can carefully think through and understand the things you bring up. Once recorded, your name will not be associated with the things you say, and all these details will be confidential. What you say will not have any bearing on your relationships with the hospital or health care providers. Your participation in the interview implies that you have consented to be part of this study. Participation is voluntary and you may ask for the recording to be stopped at any time.

Do you have any questions before we begin?
……

I have just pressed record. I'll just ask if you could indicate that you're aware this is being recorded and that you are okay with that.

1. Before I start asking you specific questions about the CSNAT I am interested in knowing about what your overall experience was like preparing for you loved one's return home as well what it was once they were home? Learning about what this was like to you will also help the heath service improve how they support carers in your situation.

2. **Tell me what you understand to be the main purpose of the CSNAT and how it is meant to work?**
    - *What do you perceive to be the benefit?*
    - *Were their elements that were difficult to understand? What things improved your understanding?*

3. **Tell me about your overall experience with the CSNAT.**
    - *When did you use it? In hospital/home, tell me what this was like for you? What happened?*
    - *Did you complete all of the steps before and after discharge (e.g. prioritise needs, develop and action a plan, follow up suggestions or referrals?). If not, why not?*
    - *Tell me what worked well, not so well? Were you satisfied with the experience?*
    - *How did it compare to past experiences you have had with planning for discharge home or seeking support?*

4. **Tell me about how you feel about using the CSNAT?**
    - *Do you think this is something you/ your carer could continue using?*
    - *If not, tell me why this is the case? What factors are preventing you from using it in the future?*

5. **Tell me your thoughts on what you think the benefits and drawbacks are of the CSNAT?**
    - *Tell me about what you think the benefits and drawbacks of the CSNAT are:*
        - *For you?*
        - *For your family member?*
        - *For the hospital?*
        - *For preparing for discharge home?*
    - *Can you tell me how you think some of the drawbacks/issues you mentioned could be addressed?*

Appendix 10. Raw data of participant characteristics for study 2a (patients and carers)

Supplementary File: Participant characteristics

Carer Participant*	Gender	Age	RS with patient	Time in caring role
CP3"Alice"	F	65	Wife	9 months
CP5 "Fred"	M	52	Husband	10 years
CP8 "Eric"	M	48	Son	8 years
CP11 "Lynne"	F	69	Wife	12 months
CP21 "Jan"	F	63	Daughter	3 months
CP20 "Lucy"	F	46	Mother	"a few days"
CP33 "Maria"	F	67	Wife	6 months
CP35 "Paul"	M	33	Son	"new to caring"
RMHCP5 "Cherie"	F	66	Friend	8 months
RMHCP8 "Jasmin"	**F**	**27**	Daughter	"Since diagnosis"
Patient Participant	**Gender**	**Age**	**Diagnosis**	
PP5	F	42	Glioblastoma	
PP30 "Pete"	M	69	Metastatic Melanoma	

*Names have been changed to maintain participant confidentiality.

Appendix 11. Focus group guide

Clinician Focus Group Question Guide

Focus Group 1: Current practices and perceived fit of the CSNAT (embedded within training sessions)

During this training session, you will be asked a series of questions to understand your views on how carers are currently supported in your hospital setting and how the CSNAT could fit into your everyday practice to assist with this. We value your insights and thoughts around this issue.

We will be recording this discussion, just so that we can carefully think through and understand the things you bring up. Once recorded, your name will not be associated with the things you say, and all these will be confidential. What you say will not have any bearing on your relationships with the hospital or the care you provide. Your participation is voluntary and you may ask for the recording to be stopped at any time.

Discussion point 1:
As an organisation, why do you believe is it important that we identify and address carers' support needs?
(Prompts: What role do carers play in patient care/discharge planning?)

As you are going to use the CSNAT approach in your practice, it will help to put this into context if you first consider the following questions:

Discussion point 2:
How do you currently become aware of/identify carer support needs in your everyday practice (eg. picking up on cues, speaking with the carer when making a patient assessment)?

- ***Where*** *do you tend to speak with a carer? e.g. at the end of a patient visit on the 'door-step' of the home, in the 'corridor' of a ward, alongside the patient, over the telephone.*
- ***Who*** *initiates this process? (e.g. you, the patient, the carer)*
- ***How*** *do you start a conversation with the carer about their support needs? e.g. pick up on their 'cues', asking 'how are you?'*
- ***What*** *type of support needs do you routinely discuss with carers?*
- *Do you consider your existing practice to be a* ***comprehensive*** *assessment?*
- *Is the* ***carer aware*** *that you are discussing their support needs as* ***part of an assessment****?*
- *Does your current approach* ***distinguish the carer's needs as separate*** *from the patient's needs?*
- ***What*** *support needs do you usually address? e.g. practical, emotional*

Discussion point 3:

3a - What are the positives of your existing approach to identifying carer needs?

3b - What are the limitations of your existing approach to identifying carer needs

Discussion point 4:

Now that you are aware of what the different stages of the CSNAT entail; how could you follow each stage within your practice?

- *Stage 1 – How would you introduce it to the carer?*
- *Stage 2*
    - *How would I give the carer time to consider their support needs for each domains?*
    - *How will I know what are the most important support needs for the carer?*
- *Stage 3 –*
    - *How will I unpick the type of support the carer requires for each domain they have prioritised?*
- *Stage 4 – How ill I find out what the carer feels will help them before highlighting what is available*
- *Stage 5 – How can I help facilitate a shared review with the carer?*

Discussion point 5:

In what ways does the… The CSNAT Approach differs from your existing practice?

- *Do carers currently know they are being assessed?*
- *Are they able to reflect on what their needs are at that particular moment in time?*
- *Do you create a shared action plan of how to address their support needs?*
- *Do you review how their support needs change over time?*

Discussion point 6:

Can you talk about what you feel the benefits of The CSNAT Approach are for patients/carers/clinicians/organisations?

Focus Group 2 & 3 (Embedded within feedback sessions)

We would like to get some feedback about how you have used The CSNAT Approach within your practice. This will help us with our evaluation. We value your insights and thoughts around this issue.

We will be recording this discussion, just so that we can carefully think through and understand the things you bring up. Once recorded, your name will not be associated with the things you say, and all these will be confidential. What you say will not have any bearing on your relationships with the hospital or the care you provide. Your participation is voluntary and you may ask for the recording to be stopped at any time.

Reviewing your use of the CSNAT

As part of the pilot of The CSNAT Approach, we recommend that you review how you used it within your practice. This will serve as a basis for the evaluation of the pilot and for future planning on how The CSNAT Approach can be incorporated into routine practice within your site.

Area for review	Comments

Approximately how many carers have you assessed using The CSNAT Approach?	
Which of the CSNAT domains have been identified as priorities most often? *Can you explain why?*	
What are the most common individual support needs of carers in relation to each of the CSNAT domains identified as a priority? *Can you describe any identified carer needs that are different to those identified in your previous screening?*	
What actions have you taken to address the individual support needs of carers? *Can you explain why you have chosen this approach? /What influenced you to make these changes*	
Can you describe scenarios where **made a shared review with any carers or made plans for one?** *What was this like for you/the carer?*	

I would like to hear from people about any situations when the CSNAT was introduced but the carer did not feel they wanted to complete it. *Can you talk about why you think the carer chose not to do this?*	

Your CSNAT case example

We asked you to write up an example of when you have used The CSNAT Approach and you feel it has been beneficial for a carer. We will share this with your colleagues today and in general discussion outside of this group. Let's work through each stage together…

Discussion point 1:

Stage 1.

How and when did you introduce the CSNAT to the carer?

Stage 2:

Carers consideration of needs. How did you enable the carer to consider and prioritise their support needs?

Stage 3:

Assessment Conversation: Describe the assessment conversation you had with the carer. What domains did the carer feel they needed support with? What were their individual support needs in relation the domains prioritised?

Stage 4: Shared action plan: Describe how you made the shared action plan with the carer. What actions were taken to address their support needs?

Stage 5: Did you complete or make plans for a shared review?

Discussion Point 2:

Describe what you feel were the benefits of using the CSNAT Approach in this example?

<u>Evaluating your use of The CSNAT Approach</u>

We would like to get some feedback on those things that have gone well, any issues you have encountered, and what you feel may help to overcome such issues in the future.

1. What has gone well for you?
2. What are the main issues you experienced?
3. What do you feel could help overcome these issues?

(*Prompts for researcher):*

- *How did it impact on your workload? Time? Cost? Skill set?*
- *How well did the CSNAT align with your skill set? Or was it outside of your usual scope?*
- *Can you identify what areas you did/didn't feel comfortable with? Different steps of the CSNAT?*
- *How well did the shared review work post discharge?*

Thank you for your time today.

Appendix 12. Interview guide

Thank you for agreeing to talk to us around your experience with the CSNAT. As part of this study we have been collecting information from clinicians relating to their experience of using the CSNAT; and the process they have been involved in . But we are also interested in your perception of the strengths and limitations of the CSNAT more broadly and its potential applications in the future. We value your insights and thoughts around this issue.

We will be recording this discussion, just so that we can carefully think through and understand the things you bring up. Once recorded, your name will not be associated with the things you say, and all these will be confidential. What you say will not have any bearing on your relationships with the hospital or health care providers. Your participation is voluntary and you may ask for the recording to be stopped at any time.

Do you have any questions before we begin?

.....

I have just pressed record. I'll just ask if you could indicate that you're aware this is being recorded and that you are okay with that

1. **Tell me what your understanding the main purpose is of the CSNAT and how it works?**

- *What do you perceive to be the benefit?*
- *Were their elements that were difficult to understand?*
  What things improved your understanding?
- *What worked well, not so well with the training and support provided?*

2. **Tell me about what your general impressions or reflections of your overall experience with the CSNAT.**

- *What was your role/experience?*
- *What went well or not so well?*
    - *Can you explain why?*

    - *How did you feel about that?*
- *How did it compare to how you used to address the needs of carers related to discharge planning?*
    - *Can you unpack that some more?*
- *How much effort was it for you to incorporate the CSNAT in to your everyday clinical practice (and using the CSNAT if relevant)?*
    - *If effortful, was worth it worth the effort? Why/why not?*
- *The implementation process involved a number of different training and education strategies. What worked well, not so well?*

I'd like to talk with you now about how …

3. …you feel about the CSNAT and its use in clinical practice?

- *Do you think this fits into your usual practice?*
- *How has this changed compared to when you first started using it?*
- *What do you think was responsible for/influenced this change?*
- *Do you think CSNAT is something you could continue using?*
    - *If not, tell me why this is the case? What factors are preventing you from using it in the future?*
    - *If yes, can tell me why this is the case? What would enable you to continue to use it in the future?*
- *If this is to be adopted by the organisation, what do you think would help this occur? What do you think would prevent this?*

4. ..how well you do think the CSNAT has achieved what it intended?

- *How well do you think the CSNAT addressed carers needs related to hospital discharge? What else did it achieve?*
- *Did it pick up carers needs you might not have picked up on before? If it did, how did you manage these?*
- *Did the CSNAT bring up issues that you may have glossed over in the past/ or thought it was not your role? Did the CSNAT help you attend to these?*
- *If it wasn't effective, why do you think this is the case? How can this be addressed?*

5. I am interested to know your thoughts and reflections on how well the CSNAT was implemented into usual practice over the last few months?

- *What strategies worked well for you, not so well?*

- *Eg. training, feedback sessions , project working groups etc*
- *Were there any specific things related to these strategies that really helped or hindered rolling out the CSNAT into usual practice?*
- *What was challenging for you and others?*
- *Do you have any thoughts on how to address some of these challenges?*

Is there anything we haven't discussed today that we should have?

In closing/my last question for you is what is the most important thing to you that we have discussed today?

Appendix 13. Coding guide using the Theoretical Domains Framework

TDF DOMAIN	CONSTRUCTS	CODING STRATEGY	EXAMPLES
1. Knowledge ***An awareness of the existence of something.***	- Knowledge (of condition/scientific rationale) - Procedural knowledge - Knowledge of task environment	- OT explains what they know about x (eg. how to address carer needs). - OT explains what they don't know about x - OT explains mindset/how or why they work in a particular way,	- Explanation on how something is done, how they know what to do etc. fx based assessments, carer training, - Or what they don't know what to do
2. Skills ***An ability or proficiency acquired through practice***	- Skills/skill development - Competence/ability - Interpersonal skills - Practice/ Skill assessment	OT explains what they can/can't do; what they have learnt to do/become more confident in eg. carer training, end of life care discharges. Skills and abilities related to clinical and communication skills with carers	- Carer training, emotional support for carers. - Self appraisal of how well they address carers needs.
3. Social/professional role and identity ***(A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting)***	- Professional identity - Professional role - Social identity - Identity - Professional boundaries - Professional confidence - Group identity - Leadership - Organisational commitment	Their views on their professional role eg. holistic/comprehensive. OT describes how compatible X is to professional role/identity i.e. is the CSNAT something they are supposed to do or is it someone else's role.	- Holistic, comprehensive in assessment. - Inclusive of carer in assessment – but focussed on their capacity to care based on patient's fx needs.
4. Beliefs about capabilities ***(Acceptance of the truth, reality, or validity about***	- Self-confidence - Perceived competence – - Self-efficacy	OT describes how easy/difficult it is to do X OT referred to confidence levels – professional and	- You can't do it too early. Need to look for entry points,

an ability, talent, or facility that a person can put to constructive use)	- Perceived behavioural control - Beliefs - Self-esteem - Empowerment - Professional confidence	personal confidence in what they do; views on their capabilities.	build rapport, guided by carer (past experience) Professional confidence, self efficacy in OT role and discharge planning - If I know what the patient needs fx I know what the carer needs.
5. Optimism ***(The confidence that things will happen for the best or that desired goals will be attained)***	- Optimism - Pessimism - Unrealistic optimism - Identity -	- Look for OT's general disposition - OTs explain how their optimism and pessism influences what they do	- Eg. I feel bad that I am not talking to the carers about what they want.
6. Beliefs about Consequences ***(Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation)***	- Beliefs - Outcome expectancies - Characteristics of outcome expectancies - Anticipated regret - Consequents	- OT states that if x is done x will occur. - If a behaviour/action is carried out then this will behaviour/outcome will occur - OTs explain views on outcomes, the pros and cons of doing/performing X	If we don't address carers needs we don't address patient. (Attitude) - Positive and negative consequence of addressing carers needs. -Personal statements re if you do x x will happen…. Eg. impact of time, carer-centred approach, carers needs on patient needs. "opening the can of worms"
7. Reinforcement ***(Increasing the probability of a response by arranging a dependent relationship,***		- OT describes experiences that have influenced whether or not X is	-

or contingency, between the response and a given stimulus)		performed (CSNAT, follow up post dc)	
8. Intentions ***(A conscious decision to perform a behaviour or a resolve to act in a certain way)***	- Stability of intentions - Stages of change model - Transtheoretical model and stages of change	OT describes conscious decision to do X or perform in a certain way	?Avoid approaching carer too early; avoid making them feel overwhelmed.
9. (Goals) ***(Mental representations of outcomes or end states that an individual wants to achieve)***			
10. Memory, attention and decision processes ***(The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives)***			
11. Environmental context and resources. ***(Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour)***	- Environmental stressors - Resources / material resources - Organisational culture /climate - Salient events / critical incidents - Person x environment interaction - Barriers and facilitators	OT identifies factors related to the setting (people, hospital, physical, financial) that help or hinder ability to support ability to do x (CSNAT/carer support) and also adapt to the new intervention/change.	Time restraints and role restraints Organisational expectations, pressure Limited by x, helped by x - different environmental factors influencing their support if carers

12. Social influences ***(Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours)***	- Social pressures - Social norms - Group conformity - Social comparisons - Group norms - Social support - Power Intergroup conflict - Alienation - Group identity - Modelling	OT identified social factors (groups/teams/norms/feedback) that help or hinder them doing x OT refers to interpersonal situations (communication, observing others) that alter their thoughts or behaviours towards x. eg. how views of others influence their behaviour	Views on pall care team, organisational commitment Interaction, support, seeing others do x (interact with carers) eg, spiritual care addressing emotional needs.
13. Emotion ***(A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event)***	- Fear - Anxiety - Affect - Stress - Depression - Positive / negative affect - Burn-out	OT has emotional response to X.	Feel x way because of current practice. "feel horrible" that I don't ask carers.
14. (Behavioural regulation) ***(Anything aimed at managing or changing objectively observed or measured actions)***	- Self-monitoring - Breaking habit - Action planning	OTs describe ways they doing thing to achieve desired outcomes/performance eg. I use x to achieve x OT identified strategies you us eot help them do x OT identifies strategies that woud like.	(feedback, what steps are need to do the CSNAT? What might hinder it?) eg. mock scenarios, practice, feeeback, pathways
Nature of behaviours		OT drawing on past experiences; routine practice or habits related to doing X.	You can't do it to early. Need to look for entry points, build rapport, guided by carer (past experience)

Appendix 14. Table of measures and outcomes for study 2c (process)

Type of data	Prior to using the CSNAT	Whilst using the CSNAT	After using the CSNAT	Source of data
Patient/carer demographic and clinical characteristics: *(intervention receipt)*		X		Patient - Electronic Medical Record (EMR) Carer – phone interview
Clinician training and participation rates *(intervention training + monitoring of intervention delivery)*	X	X	X	Project specific Case Record Form
CSNAT-I domains of need identified by carers *(intervention receipt)*	X	X	X	
CSNAT-I referral and completion rates *(intervention receipt)*		X		
Clinical activity (time/no. of contacts) *(intervention delivery)*		X		
Other clinical activity and outputs		X		
Readmission rates (30 day)			X	

Appendix 15. Proof manuscript and correspondence for Project 3: Caring for carers of people with advanced cancer at hospital discharge (CARENET): A single-arm open label feasibility trial

PALLIATIVE & SUPPORTIVE CARE

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Caring for carers of people with advanced cancer at hospital discharge (CARENET): A single-arm open label feasibility trial

Journal:	*Palliative & Supportive Care*
Manuscript ID	Draft
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Keywords:	advanced cancer, carers, discharge planning, palliative care
Abstract:	Objectives: Carers are critical to support discharge home from hospital at end of life yet remain under-represented in health service initiatives to assist this transition. A carer-focussed intervention embedded into practice may facilitate hospital discharge. This open-labelled, single-arm phase 2 study aimed to determine the feasibility of (1) delivering a multi-staged intervention (CARENET) to carers of advanced cancer patients in a hospital setting and (2) the study design to inform a phase 3 trial. Methods: CARENET, delivered before and after discharge to address carer support needs was tested in an Australian specialist cancer hospital. Eligible participants included carers of advanced cancer inpatients with planned discharge home. The primary outcome was intervention and trial feasibility (recruitment and adherence). Secondary outcomes were

	eligibility and effects of intervention on outcomes including carer preparedness. Results: Of the 382 potential patient-carer dyads, twenty-five were recruited within required time frames. The intervention adherence outcome feasibility threshold of 80% of carer participants completing all three core components of CARENET was not achieved (60% completion). Trends in improvement in overall carer levels of preparedness were observed from baseline to discharge home (n=12 mean (95% CI)) 0.5 [-0.0007, 1.007]). However, a downward trend in preparedness to provide emotional care after discharge was observed (n=12 mean (95% CI)) 0.25[-0.30, 0.80]). Significance of results: Delivering all elements of the CARENET intervention to address carers' needs in the discharge planning context was not feasible. However, some elements were feasible, including identifying and responding to carer need, whilst completing elements after discharge were less feasible. Findings can be explained by problems with adherence, eligibility, and clinician barriers to fitting a multi-staged carer intervention into an acute healthcare setting. Future research should test a more adaptable intervention and delivery model that is accessible for all carers across and compatible with acute care settings.

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Short title: Supporting carers at discharge: A feasibility trial.

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Objectives:

Carers are critical to support discharge home from hospital at end of life yet remain under-represented in health service initiatives to assist this transition. A carer-focussed intervention embedded into practice may facilitate hospital discharge. This open-labelled, single-arm phase 2 study aimed to determine the feasibility of (1) delivering a multi-staged intervention (CARENET) to carers of advanced cancer patients in a hospital setting and (2) the study design to inform a phase 3 trial.

Methods:

CARENET, delivered before and after discharge to address carer support needs was tested in an Australian specialist cancer hospital. Eligible participants included carers of advanced cancer inpatients with planned discharge home. The primary outcome was intervention and trial feasibility (recruitment and adherence). Secondary outcomes were eligibility and effects of intervention on outcomes including carer preparedness.

Results:

Of the 382 potential patient-carer dyads, twenty-five were recruited within required time frames. The intervention adherence outcome feasibility threshold of 80% of carer participants completing all three core components of CARENET was not achieved (60% completion). Trends in improvement in overall carer levels of preparedness were observed from baseline to discharge home (n=12 mean (95% CI)) 0.5 [-0.0007, 1.007]). However, a downward trend in preparedness to provide emotional care after discharge was observed (n=12 mean (95% CI)) 0.25[-0.30, 0.80]).

Significance of results:

Delivering all elements of the CARENET intervention to address carers' needs in the discharge planning context was not feasible. However, some elements were feasible, including identifying and responding to carer need, whilst completing elements after discharge were less feasible. Findings can be explained by problems with adherence, eligibility, and clinician barriers to fitting a multi-staged carer intervention

into an acute healthcare setting. Future research should test a more adaptable intervention and delivery model that is accessible for all carers across and compatible with acute care settings.

Key words: advanced cancer, carers, discharge planning, palliative care

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Introduction

Moving from hospital to home for people with advanced cancer can be a time of heightened stress and uncertainty for both patients and their carers, where most of the care responsibilities shift onto family or friends(Adejoh et al. 2021). This transition of care is associated with uncontrolled symptoms for the patient and excessive burden on carers who are frequently unaware of what to expect in taking on the caring role for a person with advanced cancer (Lawson et al. 2006). This patient cohort typically undergo a rapid and sudden decline in function in the last 40 days of life (Morgan et al. 2019).

Carers are critical to patients having a successful discharge from hospital to home at the end of life (Higginson et al. 2013; Laugaland et al. 2012). Firstly, they provide most of the care when a person returns home from hospital, which often incurs an emotional, physical and financial cost (Adejoh et al. 2021; Wang et al. 2018). Secondly, their capacity to provide care remains one of the main factors that influences a person's ability to remain at home and avoid readmission to hospital (IHigginson et al. 2013; Laugaland et al. 2012). Thirdly, they have a set of unique needs that are different from the patient, and routinely remain unmet. These needs include detailed communication and information provision related to support and practical aspects of caring (Harding et al. 2012; Wang et al. 2018).

International policy recommends that carers are included in discharge planning models and their support needs are addressed across the continuum of care (National Institute for Health and Clinical Excellence 2004; Naylor et al. 2017; World Health Organisation 2016; Carers UK 2021). However, carers of people with advanced disease are under-represented in interventions and service initiatives aimed at improving hospital discharge. A recent systematic review of the reporting quality of hospital-to-home transition intervention studies found that only 22% of studies included carers in intervention design, delivery, and outcomes; and even less so for people with advanced cancer (Marston et al. 2022).

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The Carer Support Needs Assessment Tool- Intervention (CSNAT-I) has shown promise as a potential intervention model that could be delivered in the hospital discharge setting (Aoun et al. 2015; Ewing et al. 2018; Hall et al. 2020). Originally developed for community palliative care settings, the CSNAT-I is a systematic 5-stage process that creates opportunities for addressing carers' needs and has been demonstrated to improve their ability to cope with care at home (Courvoisier et al. 2015; Grande et al. 2017; Toye et al. 2016). These improvements include significant reduction in prolonged grief (Grande et al 2017), carer strain (Courvoisier et al. 2015) and sustained increased preparedness and quality of life (Toye C 2016).

Carers and clinicians in a UK study recommended that CSNAT-I be implemented in hospital settings to expand the discharge planning focus to include carers. This could address 'unrealistic expectations' of what care at home would entail; and may reduce the likelihood of breakdown of care at home after discharge (Ewing G et al. 2018). Carers in this study also recommended implementing this tool as early as possible during hospital admission, with a review upon the initial transition home(Ewing et al. 2018). Recent evaluation of the CSNAT-I implemented by palliative care nursing staff in a UK hospital, revealed behavioural and organisational challenges impacting its delivery (Hall et al. 2020). The structure and focus of the CSNAT-I was considered acceptable; however, there was uncertainty regarding the "fit" of carers' needs in the health systems and which health professional should be responsible for delivery of the CSNAT-I (Hall et al. 2020).

To investigate this further, we examined the CSNAT-I in an Australian inpatient acute cancer setting as part of routine care by occupational therapists (Marston et al. 2023). Occupational therapists play an important role in facilitating discharge home at end of life through interventions that optimise patients' functional performance and carers' capacity to care (Eva Get al. 2018; Marston et al. 2015) The CSNAT-I was accepted by patients, carers, and clinicians as an integrated part of existing discharge planning that should reach across hospital and home and target practical needs of caring (Marston et al. 2023). Study

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findings informed the development of a modified delivery model for the CSNAT-I – Caring for carers of people with advaNced cancer at hospiTal discharge (CARENET). The CARENET model was then used to proceed to the next phase of feasibility testing in a controlled trial. Feasibility refers to the practicality of an intervention; whether it is fit for purpose in a specific context (Bowen et al. 2009; Klaic et al. 2022). Three key areas of feasibility that were assessed were practicality, implementation and limited efficacy based on Bowen's framework (Bowen et al. 2009). Practicality refers to the extent an intervention can be delivered within the given resources and circumstances. Implementation refers to the extent an intervention can be successfully delivered as intended within a defined context or according to protocol (i.e. fidelity). Limited efficacy refers to the intended effects of an intervention on relevant outcomes (Bowen et al. 2009). Thus, this study aimed to determine the feasibility of (1) delivering the CARENET intervention to carers of advanced cancer patients in an acute oncology setting as intended and (2) the study design to inform a phase three trial.

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Methods

Design

A single arm open label study design was employed to determine the feasibility of the CARENET intervention and the study design. The selected study design aligns with the feasibility and piloting stage recommended in the Medical Research Council (MRC) framework for design and evaluating complex interventions (Skivington et al. 2021). Feasibility was assessed using three key areas of focus recommended by Bowen's framework for feasibility studies (Bowen et al. 2009) – practicality, implementation (fidelity) and limited efficacy, with links of areas of focus to trial aims and measure detailed in Table 1. Quantitative data were collected prospectively to address trial aims. Qualitative data

exploring feasibility using brief carer and clinician interviews are reported elsewhere. CONSORT guidelines were used for reporting structure (Eldridge et al. 2016).

Participants

Participants were adult inpatients with advanced cancer and their informal carers (patient-carer dyad). For the purposes of this study carers were defined according to NICE definition: "Lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management" (National Institute for Clinical Excellence , 2004). All people with advanced cancer and identified carers were potentially eligible and screened for the study. Eligibility criteria included: English speaking, identified as a carer of a person with a diagnosis of advanced cancer with a planned discharge home and able to provide informed consent. Participants were excluded if patients had a planned discharge to residential care or subacute settings. Patients who were part of the dyad and were able to provide informed consent, or had proxy written consent, were eligible and invited to participate if interested.

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Procedure

The study protocol was prospectively registered with the Australian New Zealand Clinical Trials Registry (ANZCTR) Registration No: ACTRN12622001325796. Ethical approval was obtained by Peter Mac Callum Cancer Centre Ethics Committee (HREC No. 83438 and UTS Ethics Committee (ETH22-7440). From November 2022 – July 2023 potential participants were identified and referred for eligibility screening. Eligible participants were invited to partake in the study followed by formal consent process. Carers were consented first, then if they consented, the patient consent process would occur. The proposed

sample size was 20-30 patient-carer dyad participants as per 'general rule of thumb' for feasibility studies (Totton et al. 2023) and based on pragmatic findings from the preliminary study.

Interventions:

The features of the CARENET intervention are described in Supplementary File 1 and represented in Figure 1. CARENET consisted of the CSNAT-I, and a modified intervention delivery mode whereby the CSNAT-I was delivered by occupational therapists as an integrated part of usual discharge planning practices across hospital and home settings. During the hospital stay, carers completed three components: (1) an assessment and prioritization of their needs using the paper-based CSNAT-I tool (Needs assessment), and (2) an action plan to address their needs (Responding to needs) via support directly from treating occupational therapists or signposting other avenues of support for the carer to initiative themselves, and (3) within 72 hours after returning home from hospital, the carers received a review of their needs via a phone call (Review). The assessment part of the CSNAT-I that was embedded in the first component consisted of 15 domains of support need for the carer to choose from. They related to the practical aspects of caring as well as their own personal needs as a carer (Ewing et al. 2013). Occupational therapists (OT) completed training and participated in a planned implementation strategy to support the delivery of the intervention. This included a ninety-minute individual online learning module on the CSNAT-I (2022) and two one-hourly group education sessions on the CARENET intervention protocol and trial processes, before recruitment commenced. During recruitment, clinician support and monitoring of adherence occurred via: (1) Assignment of OT clinical champions, (2) Expert working group of OTs, researchers and consumers; and (3) File audit and informal assessment of clinician compliance (conducted by research assistant (MLT) and primary investigator (CM) [Supplementary File 3].

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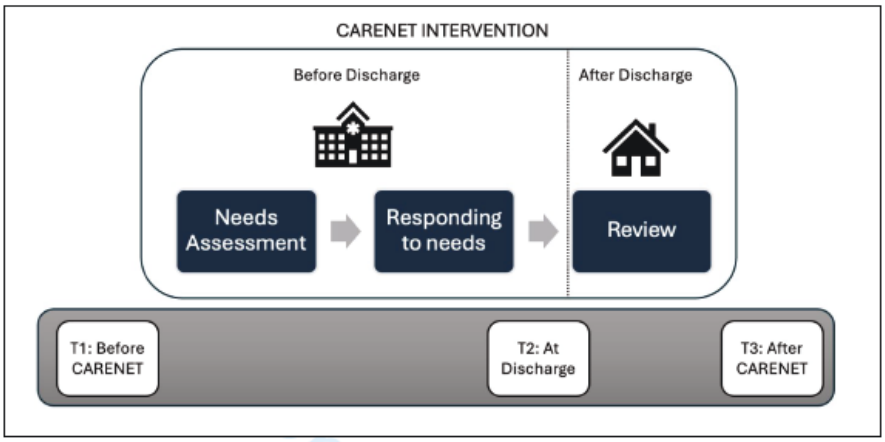

Figure 1: Intervention components (Needs Assessment, Responding to Needs and Review) and data collection timepoints (T1 – Before CARENET, T2 – At Discharge, and T3 – After CARENET).

Outcomes

The primary outcome was intervention and trial feasibility (recruitment and adherence). Secondary outcomes were eligibility/attrition (practicality) and intended effect of intervention on patient and carer outcomes (limited efficacy). Alignment of these outcomes with research questions, areas of feasibility, measures and endpoints are presented in Table 1.

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Table 1: Feasibility Outcomes and alignment with research questions.

Research Questions	Areas of focus for feasibility (Bowen et al 2009)	Components	Endpoints/measures
Primary Outcomes			
Can participants be recruited to CARENET trial within the required timeframe?	Practicality	Recruitment.	20 participants enrolled in study within 9 months.
Can CARENET and its critical elements be delivered to intended carer participants in a controlled setting?	Implementation	Intervention adherence	At least 80% of enrolled carer participants would have had all three aspects of intervention delivered (needs assessment, responding to needs and after discharge review).
Secondary Outcomes			
To what extent can CARENET be successfully carried out with intended carer participants using existing means and resources?	Practicality	Eligibility, attrition/dropouts	Recruitment rate and eligibility data (including reasons for non-recruitment and withdrawal) via screening log and project specific electronic Case Report Form (eCRF)
Does CARENET show promise of improving outcomes for carers in an acute oncology context?	Limited efficacy/Practicality	Completion rates of measures. Intended effects of intervention on outcomes	Service and process data via project specific eCRF Variances in patient and carer-related measures**(to power for larger study). Patient measures: AKPS, EQ-5D-5L, RUG-ADL, SAS, carer measures: Carer Preparedness Scale, CarerQoL-7D

*Secondary feasibility outcomes as evaluating using qualitative data derived from carer and clinician interviews. Reported elsewhere.

**Supplementary File 2 for measurement properties. AKPS = Australian Karnofsky Performance Scale;, RUG-ADL= Resource Utilisation Groups – Activities of Daily Living; EQ-5D-5L = EuroQol 5-Dimensions-5-Levels; SAS=.Symptom Assessment Scale; CarerQoL -7D= Carer Quality of Life (QOL) Instrument.

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DATA COLLECTION:

Measures used for data collection are presented in Table 1. Patient and carer-related data were collected via standardised measures and questionnaire. Service, process and costing data via medical records and project specific case report forms, and these will be reported in subsequent manuscript. Data collection at the three time points (T1, T2 and T3) for study measures was as follows: T1 1- 3 days before intervention, T2 1-2 days before discharge, during intervention, and T3 1 week after discharge, discharge, post intervention. Patient and carer outcome measures were the only measures collected across all three time points. Patient-related measure were the Australian Karnofsky Performance Scale (AKPS) (Abernethy et al. 2005), Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) (Fries et al. 1994), Symptom Assessment Scale (SAS) (Daveson et al. 2021), and EuroQol 5-Dimensions-5-Levels (EQ-5D-5L)(Herdman et al. 2011). Carer-related measures were Preparedness for Caregiving Scale (Archbold et al. 1990), and Carer Quality of Life (QOL) Instrument (CarerQOL-7D) (Hoefman et al. 2017). The main carer-related outcome was carer-preparedness measured via Preparedness for Caregiving Scale (Archbold et al. 1990), where high score reflects improved preparedness were the only measures collected across all three time points. Features of these valid and reliable measures are summarized elsewhere [Supplementary File 2]. Demographic data were collected at baseline (T1), on-cost surveys, as well as adherence, process and service data were collected at T3.

DATA ANALYSIS:

Data analysis was conducted using Excel (Microsoft Office V23.08) and IBM SPSS v28 software. Mean and standard deviation will be reported for continuous normally distributed data and interquartile range and median for data deviating from normal distribution. Results of the categorical variables will be presented as percentage and frequency. All questionnaires were scored according to their respective

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scoring guidelines. To evaluate changes in patient and carer-related measures (i.e., functional performance, quality of life and carer preparedness) between T1 and T3, we calculated difference scores and 95% confidence interval (CI). Additionally, we conducted paired sample t-tests and Wilcoxon Signed-Rank Tests to assess the statistical significance of these changes.

Results

Participant recruitment and eligibility

Twenty-five dyads were recruited across the 8-month accrual period (Figure 2). A high number (n=336; 87%) of identified eligible participants were not invited to participate. Rapid and unpredicted hospital discharge was the primary reason for not inviting identified eligible participants. There was a 54% consent rate for the remaining dyads. Figure 2 shows lower completion rates of T2 measures compared to measures at T1 and T3. Reasons included research assistant unable to contact the carer at time of discharge.

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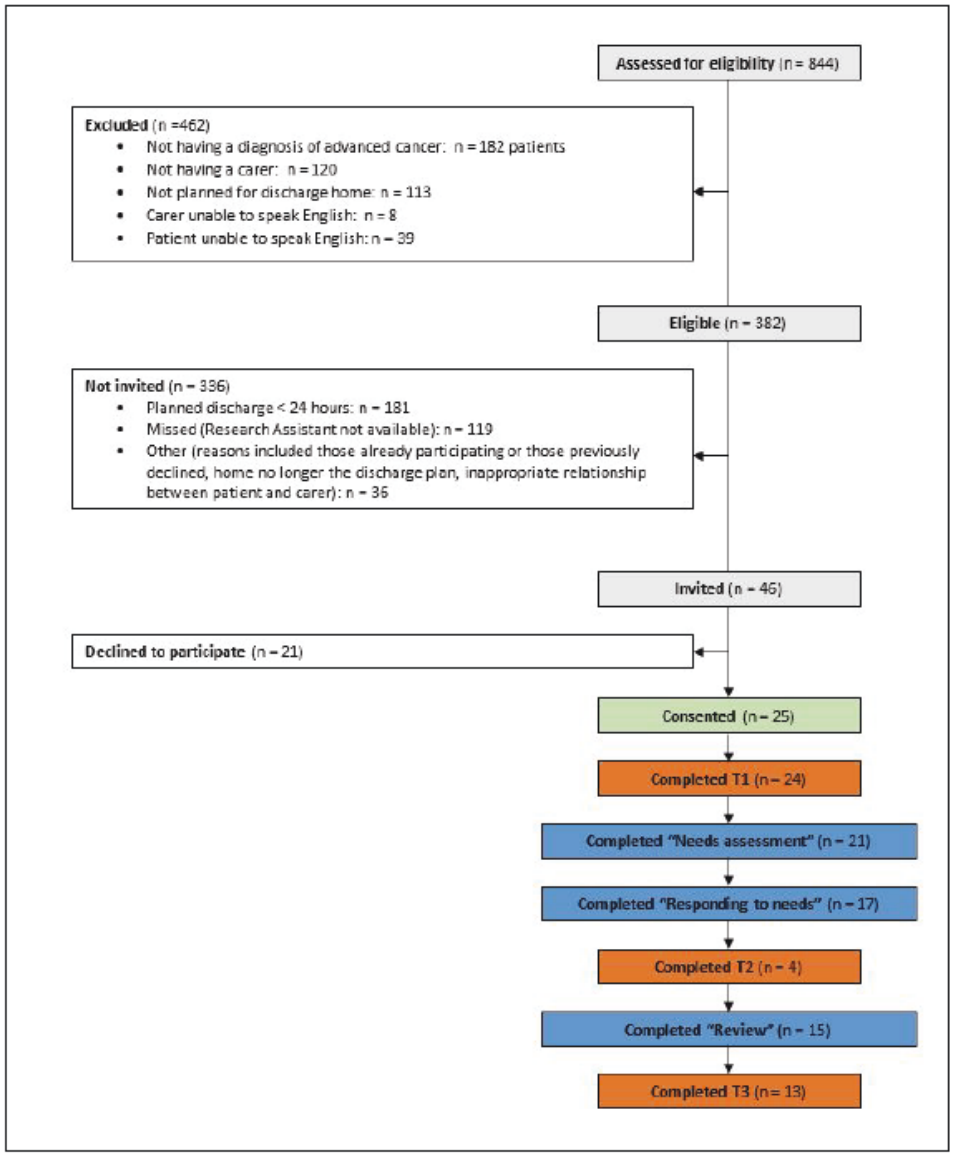
Figure 2. Recruitment and participation



T1 = Timepoint 1 – Before CARENET, T2 = Timepoint 2 – At discharge, T3 = Timepoint 3 – After CARENET

Clinician adherence

Partial adherence was reached with 60% of enrolled participants completing all three intervention components (Figure 2). Adherence to components occurring before discharge was higher than the review component occurring after discharge, with 84% of carer participants completing the needs assessment, and 68% completing the needs assessment and creating an action plan to respond to needs. Reasons for non-adherence included patient death prior to completing the intervention (n=5), patient discharge too early (n=1), transfer to palliative care ward (n=1), unable to contact carer (n=2), and unknown (n=1).

Participant characteristics

Key characteristics of patient-carer dyads are shown in Tables 2 and 3. Carer participants had a mean age of 56.79 (SD=15.54), were more likely to be female (56%, n=14), born in Australia (76%, n=19), English speaking at home (80%, n=20), and a spouse or partner to the person they were caring for (72%, n=18). Seventy-two per cent (n=18) lived with the person they cared for and 48% (n=12) were still employed. Patient participants had a mean age of 59.72 (SD=15.89), almost two thirds (64%, n= 16) were female. Most patients spoke English at home (84%, n=21), more than half were born in Australia (64%, n= 16), and 40% (n= 10) were still employed. There was high variance (heterogeneity) in the participant diagnosis, a median (IQR) length of stay in hospital of 17.0 (IQR=(14.5, 34.5)) days, and home was the discharge destination for 76% (n=19) of patient participants.

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Table 2: Demographic characteristics of consented carer participants (n=25)

	Carer participants
	n (%)
Gender	
Male	11 (44)
Female	14 (56)
Age (years)	
Mean (SD)	56.79 (15.54)
Median (IQR)	57 (53.0, 71.0)
Missing (n)	6
Relationship to the patient	
Spouse/partner	18 (72)
(Adult) child	4 (16)
Other (e.g., parent, sibling, friend) n	3 (12)
Level of education (completed?)	
Primary	0 (0)
Secondary	9 (36)
Tertiary	11 (44)
Missing	5 (20)
Employment status	
Employed	12 (48)
Unemployed	3 (12)
Retired	6 (24)
Missing	4 (16)
Primary language spoken at home	
English	20 (80)
Other	1 (4)
Missing	4 (16)
Country of birth	
Australia	19 (76)
Other	2 (8)
Missing	4 (16)
Length of time caring for the patient (months)	
Mean (SD)	14.52 (20.93)
Median (IQR)	5 (2.0, 16.0)
Missing (n)	4
	n(%)
Availability of carer	
Lives with patient	18 (72)
Lives with others	5 (20)
Missing	2 (8)

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Other caregiving responsibilities	
Children n	4
Spouse/partner n	1
Other n	5

Table 3: Demographic characteristics of consented patient participants (n=25)

	Patient participants
	n(%)
Gender	
Male	9 (36)
Female	16 (64)
Age (years)	
Mean (SD)	59.72 (15.89)
Median (IQR)	63 (53.0, 72.5)
Level of education	
Primary	1 (4)
Secondary	10 (40)
Tertiary	8 (32)
Missing	6 (24)
Employment status	
Employed	10 (40)
Unemployed	3 (12)
Retired	8 (32)
Missing	4 (16)
Primary language spoken at home	
English	21 (84)
Other	3 (12)
Missing	1 (4)
Country of birth	
Australia	16 (64)
Other	9 (36)
Type of cancer	
Gynaecological	5 (20)
Lung	4 (16)
Haematological	3 (12)
Lower Gastro-intestinal	3 (12)
Skin & Melanoma	3 (12)
Upper Gastro-intestinal	2 (8)
Other*	5 (20)
Patient length of stay (days)	

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Mean (SD)	23.84 (15.81)
Median (IQR)	17 (14.5, 34.5)
Number of readmissions within 30 days	
Mean (SD)	0.53 (0.61)
Median (IQR)	0 (0-2)
Missing (n)	6
	n(%)
Actual discharge destination	
Home	19 (76)
Passed away in hospital	5 (20)
Still in hospital at end of study	1 (4)

*Other = Breast, Head and Neck, Urological, Cancer of Unknown Primary, Neurological; IQR Interquartile Range

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Efficacy

Table 4 presents patient and carer outcomes (n=12) assessed before (T1) and after (T3) the CARENET intervention. Upon returning home (T3), patients demonstrated a trend toward increased care needs compared to their hospital stay (T1), though they remained able to manage their own needs with limited physical assistance [AKPS mean (SD) = 68.89 (12.96) at T1 vs. 61.11 (24.21) at T3]. Symptom burden also showed an upward trend upon returning home [SAS mean (SD) = 6.44 (4.56) at T1 vs. 11.11 (12.23) at T3].

Carers exhibited mixed outcomes, reporting a decreased sense of preparedness for addressing patients' emotional needs but improved preparedness for practical caregiving tasks, including obtaining system support, managing emergencies, finding services, and providing physical care. The Preparedness for Caregiving Scale revealed increases in mean scores across practical domains, although these changes were not statistically significant. Overall preparedness improved marginally from 2.75 (SD = 0.86) at T1 to 3.25 (SD = 0.62) at T3 (p = 0.05).

Notably, carers' quality of life showed a significant improvement, increasing from 78.95 (SD = 14.09) at T1 to 79.45 (SD = 12.45) at T3 ($p = 0.01$). While trends toward improvement were observed across several domains, including physical care, support from the health system, and overall preparedness, statistical significance was limited to carers' quality of life and marginally to overall preparedness.

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Table 4: Patient and carer outcome measures take before (T1) and after CARENET (T3) (n=12)

Outcome	T1 Mean (SD)	T3 Mean (SD)	Difference (T1-T3)^	95% CI
Preparedness for Caregiving Scale				
For physical care	2.50 (0.91)	2.83 (0.84)	-0.33	(-0.90, 0.23)
For emotional care	2.50 (1.01)	2.25 (0.87)	0.25	(-0.30, 0.80)
For service finding/set up	2.75 (0.87)	2.92 (0.79)	-0.17	(-0.70, 0.36)
For stress of caregiving	2.33 (1.07)	2.42 (0.10)	-0.08	(-0.82, 0.66)
To make caregiving pleasant	2.82 (0.75)	2.73 (0.79)	0.09	(-0.38, 0.56)
To handle emergencies	2.64 (1.03)	3.09 (0.83)	-0.46	(-1.27, 0.36)
To get support from the health system	2.75 (1.06)	3.17 (0.72)	-0.42	(-0.99, 0.16)
How prepared overall	2.75 (0.86)	3.25 (0.62)	-0.50	(-1.01, 0.01)

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Total scores	21.09 (5.52)	22.36 (4.13)	-1.27	(-3.48, 0.94)
AKPS	68.89 (12.96)	61.11 (24.21)	7.78	(-5.41, 20.97)
RUG-ADL	4.44 (1.33)	7.33 (4.87)	-2.89	(-5.95, 0.17)
Symptom Assessment Scale	6.44 (4.56)	11.11 (12.23)	-4.67	(-12.15, 2.83)
Carer Quality of Life*	78.95 (14.09)	79.45 (12.45)	-10.47	(-17.10, -3.85)
EQ-5D-5L VAS Self -assessed health rating (0-100)	49.11 (31.17)	59 (35.92)	-0.51	(-9.46, 8.44)

* (0–4 scale, response options 0 = not at all to 4 = very well prepared), MCID = 0.25 point difference per item or more than 2 point difference overall (REF)

AKPS = Australian Karnofsky Performance Status, RUG-ADL = Resource Utilization Group – Activities of Daily Living, EQ-5D-5L = EuroQol 5-Level-5-Dimensions.

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Discussion

This was the first phase 2 trial to test the feasibility of delivering the CSNAT- I as an integrated part of discharge planning practices to assist with discharge from hospital to home for carers of people with advanced cancer. Our findings have shown that while the recruitment target was reached, there were several challenges to the feasibility of the intervention and study conduct.

Firstly, a limited group of carers received the intervention, while a larger group identified as eligible at screening did not participate. This is most likely because of a mismatch between the hospital discharge context and the eligibility process employed by the trial. Rapid discharge home for people with palliative care needs is commonplace in acute hospitals and can happen quickly, often within 24 hours (Department of Health Victoria 2021; Australian Instititue of Health and Welfare 2024) We found that for people planning to return home in 24 hours there was insufficient time to complete all aspects of the intervention and study measures according to the protocol. Another reason for smaller recruitment numbers could be clinician "gatekeeping" that excluded patient-carers with perceived high levels of distress. Another CSNAT-I trial reported that clinicians who seek to avoid overwhelming carers may inadvertently limit support for those with greater needs (Lund et al. 2020).

Secondly, in this trial, delivery of all intervention components as intended was difficult, particularly the review after discharge. Recorded reasons for not completing all components (i.e., availability of carers, patient death) were like other trials delivering adapted CSNAT-I models (Patchwood et al. 2021; Toye et al. 2016). However, it is possible that problems with delivering the CARENET as planned may be because of the shortfalls in the implementation process and subsequent impact on clinicians' proficiency. The recommended implementation and training strategy was used for the CSNAT-I component (The

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University of Manchester/University of Cambridge 2022). However, this was impacted by high staff turnover, as well as reduced access to clinical champions, and the research staff for support and fidelity monitoring. Previous CSNAT-I studies recommend that these features are important for successful implementation in both trial and usual practice settings (Diffin et al. 2018; Hall et al. 2020).

It is also possible that difficulty with delivering CARENET could be attributed to using a protocolised, multi-staged delivery model that is not congruent with fast-paced and dynamic nature of the hospital discharge context. Discharge home from hospital can occur along different pathways and timelines, compared to more stable and predictable community and home-based settings where most trials testing the CSNAT-I have previously occurred (Aoun et al. 2015; Grande et al. 2017; Lund et al. 2020).

Thirdly, the study showed that there were difficulties with completion of the selected outcome measures. Obtaining data from patients and carers was difficult to achieve at discharge (T2), compared to before and after intervention (T1 and T3). The positive trends observed for carer quality of life and overall levels of preparedness after intervention, align with findings of other CSNAT-I trials (Grande et al. 2017; Toye et al. 2016) supporting the use of these outcome measures to test the impact of carer-targeted interventions. However, results must be interpreted with caution given the small sample size and the large group of carers deemed eligible but discharged prior to recruitment

Implications and future directions

Our trial has highlighted the opportunities and the challenges of conducting carer-focused interventions in a compressed and unpredictable hospital discharge context. Foremost is the need to consider a study design that will increase access to a more diverse group of patient-carer dyads (i.e., age, ethnicity, higher care needs) and ultimately improve the clinical translation of this type of intervention. This could include adopting a more flexible and multi modal approach to the eligibility process, allowing for recruitment to occur at different times and settings that support carer need and their different

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pathways home (Gustavson et al. 2024). An example of this could be an opt-out "early" approach, where carers are automatically recruited to the study upon patient admission and have the choice to opt-out.

A modifiable intervention model could also improve access for all carers who need support at discharge. This could entail intervening with carers at different levels with tailored delivery modes to accommodate their needs and circumstances. Research into carers of older hospitalised people supports flexible and adaptable models that offer single and multistage approaches and are considered feasible and effective (Levoy et al 2020). For carers of hospitalised people with advanced cancer, further research is required to understand the degree of modifications that can occur without compromising the efficacy of the intervention itself (Levoy et al. 2022). This could include a review of what aspects of CARENET are considered core and those where flexibility of inclusion may apply. Tools to assist with adapting existing interventions are recommended to systematise this process and achieve balance between access and impact (Kirk et al. 2020).

Stepped-care intervention models could offer a stratified approach where level of care (or carer support) is matched to the level of complexity of the condition or individual need (Genenral Practice Menthal Health Standards Collaboration 2017). Stepped care models are well established in mental health care and are used to optimise access and efficiencies within given resources(Berger et al. 2022; Mughal et al. 2023) Similarly, cancer prehabilitation models use a stepped care approach (MacMillan Cancer Support 2019) where all people having surgery are offered prehabilitation but scope and intensity will vary. CARENET could similarly be implemented in this stepped-care approach whereby intensity of support may differ according to need. For example, carers of people experiencing escalating carer needs would need a greater intensity of intervention to assist with discharge planning compared to carers of people whose care needs remain unchanged. If this approach was applied, additional feasibility studies would be needed to ensure intervention models are fit for purpose before proceeding to a larger scale study.

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It can also be argued that understanding the impact of a person-centred intervention like CARENET should be informed by the carers' engagement with the intervention, not just clinician adherence to protocol. Assessing fidelity of enactment is considered a measure of engagement, specifically whether the intervention content leads to a change in behaviour that is then enacted in daily life (Walton 2024). Even though consensus has not been reached in the literature regarding the best way to measure enactment, there is shared opinion that high levels of enactment equate to good outcomes. Given that CARENET relies on carers responding to the needs assessment and the support offered for it to work, this aspect of fidelity should be considered in future feasibility study design alongside fidelity of delivery and receipt (Walton 2024).

Several limitations of this study should be noted. Firstly, while the trial design testing feasibility is aligned with recommendations of the MRC framework (Skivington et al. 2021), the single arm design with no comparable control group limited our scope to assess against usual care outcomes. Secondly the generalisability of the findings to other carer groups and different hospital settings is limited. Thirdly, the small sample size limits the ability to comment upon the efficacy of CARENET on patient-carer outcomes. However, this was a feasibility trial where a pragmatic sample size was selected to help determine where the conduct of chosen outcome measures was practical and fit for scaling up for large efficacy trials.

Conclusion

In conclusion, our trial supports the understanding that carers of people with advanced cancer or palliative care needs will continue to need significant support during the transition from hospital to home, no matter what the context. However, delivering a protocolised multi-staged intervention for carers in this discharge setting may have limited feasibility and compromise access to more support for

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all carers. Further exploration of what intervention content and delivery is needed in order to benefit all carers and the people they are caring for; before proceeding to larger scale trials.

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Disclosures

There are no conflicts of interest to declare.

Acknowledgements

The authors extend their appreciation to all patients and families who participated in this study. Thanks to the carer consumers (Catherine Nguyen and, Ros Alcot), Professor Brian Le, Catherine Ludbrook, Occupational Therapy Department at Peter MacCallum Cancer Centre for their inputs into the study. Special acknowledgment to the original developers of the Care Support Needs Assessment Tool – Intervention (CSNAT-I), Dr Gail Ewing and Professor Gunn Grande who provided support and mentorship throughout the study.

Author contributions

All authors meet the criteria for authorship as defined by the International Committee of Medical Journal Editors (ICMJE). CM, MRA, JP, and DM were responsible for study concept and design, and drafting of article. CM and MLT were responsible for the acquisition of the data. All authors contributed to the analysis and interpretation of the data and critical revision of the article. All authors approved the final version of this article to be published.

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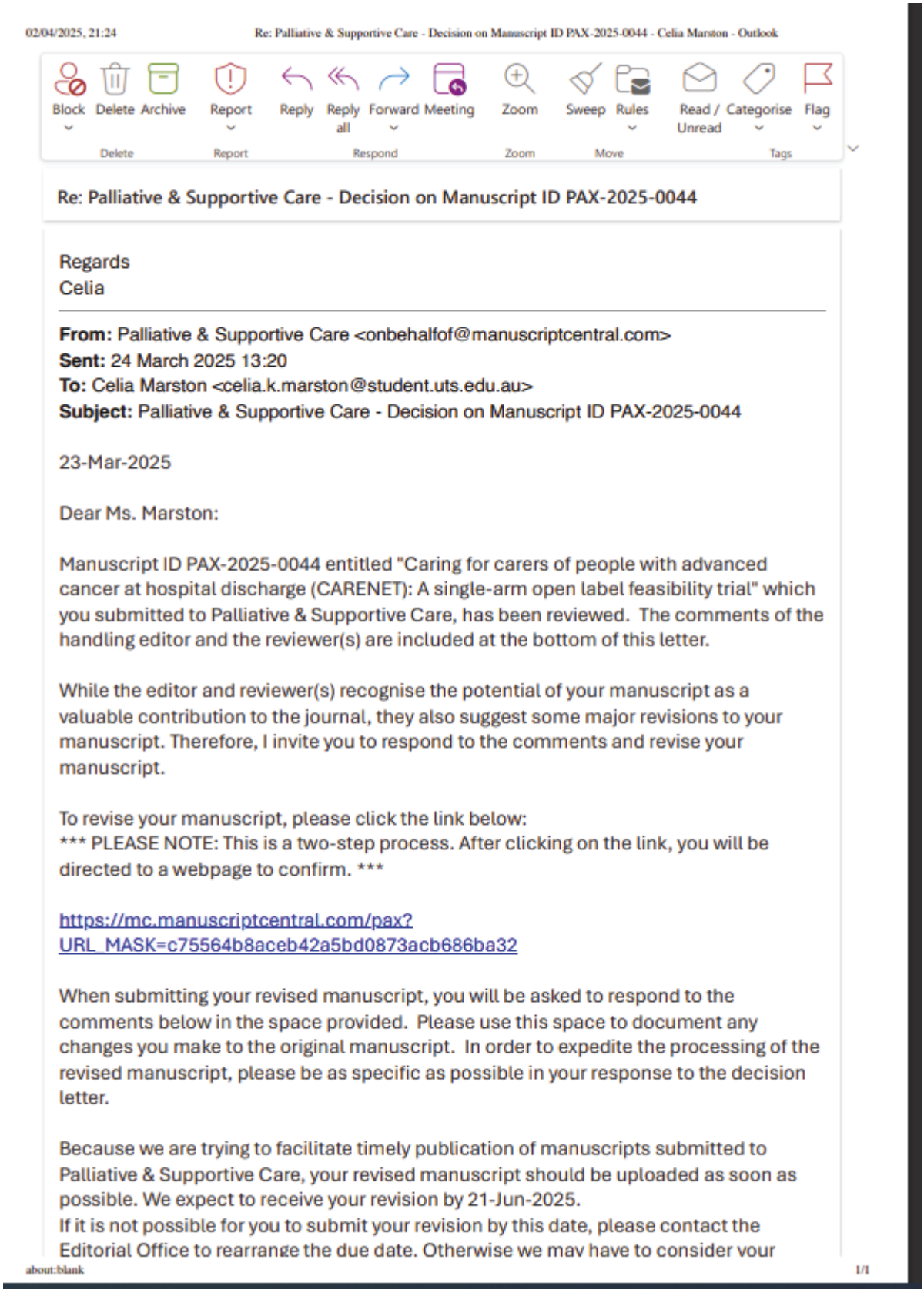

02/04/2025, 21:24 Re: Palliative & Supportive Care - Decision on Manuscript ID PAX-2025-0044 - Celia Marston - Outlook

Block Delete Archive Report Reply Reply all Forward Meeting Zoom Sweep Rules Read / Unread Categorise Flag

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Re: Palliative & Supportive Care - Decision on Manuscript ID PAX-2025-0044

Regards
Celia

From: Palliative & Supportive Care <onbehalfof@manuscriptcentral.com>
Sent: 24 March 2025 13:20
To: Celia Marston <celia.k.marston@student.uts.edu.au>
Subject: Palliative & Supportive Care - Decision on Manuscript ID PAX-2025-0044

23-Mar-2025

Dear Ms. Marston:

Manuscript ID PAX-2025-0044 entitled "Caring for carers of people with advanced cancer at hospital discharge (CARENET): A single-arm open label feasibility trial" which you submitted to Palliative & Supportive Care, has been reviewed. The comments of the handling editor and the reviewer(s) are included at the bottom of this letter.

While the editor and reviewer(s) recognise the potential of your manuscript as a valuable contribution to the journal, they also suggest some major revisions to your manuscript. Therefore, I invite you to respond to the comments and revise your manuscript.

To revise your manuscript, please click the link below:
*** PLEASE NOTE: This is a two-step process. After clicking on the link, you will be directed to a webpage to confirm. ***

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When submitting your revised manuscript, you will be asked to respond to the comments below in the space provided. Please use this space to document any changes you make to the original manuscript. In order to expedite the processing of the revised manuscript, please be as specific as possible in your response to the decision letter.

Because we are trying to facilitate timely publication of manuscripts submitted to Palliative & Supportive Care, your revised manuscript should be uploaded as soon as possible. We expect to receive your revision by 21-Jun-2025.
If it is not possible for you to submit your revision by this date, please contact the Editorial Office to rearrange the due date. Otherwise we may have to consider your

about:blank 1/1

Appendix 16. Ethics Approval: CARENET

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Victoria Australia

GOVERNANCE AUTHORISATION

SITE SPECIFIC ASSESSMENT (SSA) APPROVAL TO CONDUCT A RESEARCH PROJECT PETER MACCALLUM CANCER CENTRE

EPIC Study Code: PMC83438

Peter Mac No: 22/43L
Title: Caring for carers of people with advaNced cancer at hospiTal discharge (CareNET): A single-arm open label feasibility study
Principal Investigator: Ms Celia Marston

Reviewing HREC: Peter MacCallum Cancer Centre Ethics Committee (EC00235)
HREC Reference: HREC/83438/PMCC
HREC Approval Date: 01 August 2022

SSA Project ID: SSA/83438/PMCC
SSA Authorisation Date: 01 August 2022

I am pleased to advise that the above project is authorised to be conducted at the **Peter MacCallum Cancer Centre**. This approval is subject to compliance with the conditions set out below and any conditions specified by the reviewing HREC.

Approved Documents:

Document	Version	Date
Protocol	7	15 July 2022
Appendix 2 Cost questionnaire	2	05 May 2022
Appendix 3 Qualitative Participant Interview Schedule	1	09 February 2022
Appendix 4 Clinician Interview Schedule	1	25 August 2021
Appendix 5 CSNAT-I	2	05 May 2022
Appendix 6 CSNAT-I Staff Protocol	1	09 March 2022
Appendix 7 Patient Carer Invitation script	2	05 May 2022
Appendix 8 PMCC Participant Information Sheet and Consent Form Carer	2	05 May 2022
Appendix 9 PMCC Participant Information Sheet and Consent Form Patient	2	05 May 2022
Appendix 10 PMCC Participant Information Sheet and Consent Form Clinician	1	09 March 2022
Appendix 15 PMCC Participant Information Sheet and Consent Form Person Responsible	4	15 July 2022
Appendix 11 Email invitation for staff	1	09 March 2022
Appendix 12 EQ-5D-5L	1	09 March 2022
Appendix 13 Carer Qol English	2	05 May 2022
Appendix 14 Preparedness for Caregiving Scale	--	09 March 2022

Noted Document	Version	Date
Appendix 1 Summary of CSNAT Trials	1	09 March 2022

Use of the Electronic Medical Record for Research

Accessing identified patient information from health services other than your own for research purposes is NOT permitted. Precinct polices regarding appropriate access MUST be followed. Identified patient information must ONLY EVER be accessed after governance authorisation or quality assurance (QA) approval from the appropriate health service.

Research Governance

As Principal Investigator, you are required to:

1. Comply with the Investigator's responsibilities as outlined in the *Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95).*
2. Submit a copy of this letter to the person responsible for radiation safety at Peter MacCallum Cancer Centre. **This condition only applies if** the project involves exposure to ionising radiation that exceeds dose constraints, and the Medical Physicist's report has advised that the project needs to be added to the site's *Licence for Research Involving Human Volunteers* issued by the Department of Health Radiation Safety Section (for more information, visit www.health.vic.gov.au/radiation/). *Note: If the Medical Physicist's report has advised that the project needs to be added to the site's licence, the project cannot commence at site until you have confirmed that the project has been added to the site's licence.*
3. Notify the Peter MacCallum Cancer Centre Research Governance Office (RGO) of:
    - The actual start date of the project at Peter MacCallum Cancer Centre.
    - Any amendments to the project after these have been approved by the reviewing HREC.
    - Any adverse events involving patients of Peter MacCallum Cancer Centre, in accordance Peter MacCallum Cancer Centre Governance Guideline001 www.petermac.org/research/doing-research-us/ethics-governance .
    - Any changes to the indemnity, insurance arrangements or Clinical Trial Research Agreement for this project. This includes changes to the project budget or other changes which may have financial or other resource implications at Peter MacCallum Cancer Centre.
    - Your inability to continue as Principal Investigator or any other change in research personnel involved in this project.
    - Failure to commence the study within 12 months of the Governance authorisation date or if a decision is taken to end the study at this site.
    - Any other unforeseen events.
    - Any other matters which may impact the conduct of the project at Peter MacCallum Cancer Centre.
4. Ensure that HREC approval remains current for the entire duration of the project. Investigators undertaking projects without current Reviewing HREC approval risk their indemnity, funding and publication rights.

5. Submit an annual progress report every 12 months for the duration of the project. Continued SSA approval is contingent on receipt of an annual report by the RGO. In addition, a comprehensive final report should be submitted to the RGO upon completion of the project.

You must also abide by the following requirements:

6. Where applicable, ensure that the CTN has been electronically lodged to the TGA by the sponsor.

7. For clinical trials where Peter MacCallum Cancer Centre is the Sponsor, you are required to contact the Office for Cancer Research [ocr@petermac.org] to organise submission of the electronic Clinical Trial Notification (e-CTN) to the TGA. This must be completed before commencement of your project.
8. It is the Principal Investigator's responsibility to ensure that copies of the complete submitted e-CTN and TGA issued acknowledgement are included in the study Site File for the project at this site.
9. Ensure that the Clinical Trial Research Agreement (CTRA) and Indemnities (or other research agreements as applicable) are fully executed, i.e. signed by all parties; and an original version (or copy) placed in the study file.

Please note: Template forms for reporting Amendments, Adverse events, Annual/Final reports, etc. can be accessed from: www.petermac.org/research/doing-research-us/ethics-governance

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The RGO may conduct an audit of the project at any time.

Yours sincerely,

Dianne Biermann Digitally signed by Dianne Biermann Date: 2022.08.01 12:49:32 +10'00'

Dianne Biermann
Human Research Ethics & Governance
T: (03) 8559 7540
E: ethics@petermac.org

From:	Research.Ethics@uts.edu.au
To:	Research Ethics; Celia Marston; Meera Agar; catherine.ludbrook@petermac.org; Deidre Morgan; jphilip@unimelb.edu.au; lara.edbrooke@petermac.org; Sungwon Chang; alicia.martin@petermac.org; amy.noble@mh.org.au
Subject:	UTS HREC Approval - ETH22-7440
Date:	Tuesday, 25 October 2022 4:27:37 PM
Attachments:	Ethics Application.pdf

Dear Applicant

Re: ETH22-7440 - "Caring for carers of people with advaNced cancer at hospiTal discharge (CareNET): A single-arm open label feasibility study."

[External Ratification: Peter MacCallum Cancer Centre Ethics Committee (EC00235) HREC approval - SSA/83438/PMCC - 01/08/2022 to 01/08/2027]

The UTS Human Research Ethics Executive Review Committee has reviewed the above-named application, 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.

Your approval number is UTS HREC REF NO. ETH22-7440.

Approval will be for the period specified above and subject to the provision of evidence of continued support from the above-named Committee.

This research must be undertaken in compliance with the Australian Code for the Responsible Conduct of Research and National Statement on Ethical Conduct in Human Research.

You should consider this your official letter of approval. If you require a hardcopy please contact the Ethics Secretariat.

To access this application, please click here, a copy of your application has also been attached to this email.

We value your feedback on the online ethics process. If you would like to provide feedback please do so here.

If you have any queries about your ethics approval, or require any amendment to your research in the future, please don't hesitate to contact the Ethics Secretariat and quote the ethics application number (e.g. ETH20-xxxx) in all correspondence.

Yours sincerely,
The Research Ethics Secretariat

on behalf of the UTS Human Research Ethics Executive Review Committee
C/- Research Office
University of Technology Sydney

Appendix 17. CARENET Intervention & Implementation Strategy

What:
Materials:
The 5-staged licensed Carer Support Needs Assessment Tool - Intervention (CSNAT-I) was used (Ewing et al 2013). It consisted of a validated paper-based form that included 15 domains of need, criteria to rate and prioritise needs, and a template to outline action plans to address needs (csnat.org). Domains fell into two categories – Support domains to enable the carer to care (e.g. "Do you need more support with understanding your relative's illness?") and support domains for carers themselves (e.g., "Do you need more support with having time for yourself in the day?") This paper-based form was a record that carers kept and clinicians' documented summary in the electronic medical record. Online learning modules were used to train intervention providers and were accessible via the website once license was approved (csnat.org). A local protocol was developed and used to assist with intervention delivery and documentation into electronic medical record.

Procedures:
The intervention included three components: (1) Needs Assessment - identification and prioritisation of needs, (2) Responding to needs - development of action plan for prioritised needs and (3) Review of whether needs have been addressed, and structured handover of outstanding needs. Specific stages of the CSNAT-I were embedded within these components and is described below.

Needs Assessment
After the Occupational Therapist (OT) completed an initial assessment with patients to determine their needs related to achieving discharge home (e.g., functional limitations, physical care needs, Quality of life (QOL) goals); they met with the carer to determine their discharge needs using the CSNAT-I paper based tool (Stages 1-3). This occurred face to face, via telehealth or the phone depending on carer preference and access. The assessment process involved providing carers with the 14 domains of need, carers self-rating how much support they thought they needed and describing how the need relates to them. For example, the domain "needing help with equipment" may relate to a carer wanting to know how to use a manual lifting device. The carer then chose three needs they described that they wished to prioritise and seek support with before discharge home.
Responding to needs:
The OT identified what actions were required to address prioritised needs with the carer (Following Stage 4 of CSNAT-I). The OT and carer then determined together which actions needed to be communicated to the patient and team. Actions included direct OT interventions, referrals to other disciplines and providers; or carer-led initiatives. These were documented on the CSNAT-I and copies kept by both the carer and OT. The OT actioned the relevant items. A pre-discharge review occurred if needed by the carer e.g., to check they had all the equipment delivered to their house. Proposed and enacted action plans were communicated to the patient and team members as required.
Review:
Prior to discharge the OT asked the carer to nominate the preferred method and time

of review required after discharge. Options were: (1) treating OT to phone at time proposed by carer; (2) another key contact chosen by the carer (social worker, nurse coordinator) will contact carer instead of the OT, or (3) carer contacts treating OT or key contact person at preferred time. Shared review (Stage 5 CSNAT-I) involved (1) checking if the action plan had been completed, and (2) addressing outstanding or new needs identified by, or referring to, relevant service providers (e.g., GP, community palliative care service, nurse coordinators). In addition to the CSNAT-I, usual discharge planning processes were followed and tailored to the patient and the carer.
Who: Trained occupational therapists facilitated the delivery of the intervention. Multi-disciplinary interventions were delivered (in response to CSNAT-I) and based on individual need
How: Components 1 and 2 were delivered either face-to-face, telehealth or via phone; component 3 was delivered via telehealth or via phone and involved the OT and the carer for the patient.
Where: Components 1 and 2 occurred during acute admission and component 3 occurred once the patient was discharged from the acute hospital. Treating occupational therapists delivering the intervention were hospital-based.
When and how much: Components 1 and 2 were delivered during hospital stay and when discharge home had been decided. Component 3 was delivered within 72 hours after discharge (or other times nominated by carer, but no more than 1 week after discharge). Components 1 and 2 occurred as separate or combined contacts between the OT and carer. It was anticipated that these components would take between 20-40 minutes; and component 3 between 5 -20 minutes. However, this depended on individual needs and whether it occurred within other bundles of care e.g. psychoeducation. If the person with advanced cancer had a change in planned discharge destination, anticipated care needs, length of stay in hospital; different stages of the intervention could be repeated Tailoring A person-centred model allowed for the intervention delivery process, the actions and care generated to be adapted to the individual carer and their own preferences.

Implementation Strategy

- Based on data from earlier acceptability study, clinician education and training occurred in the following ways:
    - Individual training of the CSNAT-I using evidence based online learning (1 month before data collection starts)
    - Group training on CARENET intervention protocol (2 weeks before recruitment starts)
    - Assigned clinical champions to lead working group and 1:1 support for intervention delivery. Frequency of this group was determined by need.

- Training for all treating staff occurred via online modules, and the research team provided local training of adapted delivery protocol and trial processes.
- A working group of the treating OTs, consumers and researchers was established to optimise alignment to protocol and provide opportunity to address issues with fidelity.
- Education and training took place 1 month before data collection
- A simple study operational manual was developed
- The primary investigator and the RA attended the site and promote fidelity to study protocol, assisted with training and education and address any issues impacting on intervention delivery and study conduct.

Appendix 18. Summary of patient and carer measures

Summary of measures

Name	Author	Purpose	Subscales	Items	Item scores	Range	Validity and Reliability
Preparedness for Caregiving Scale	Archbold et al (1990)	Shows change over time in caregiving preparedness (3 time points). MCID* is 2 points or more in total score or more than 0.25 points per item (REF).	None	8	0=not at all to 4=very well prepared	0-32	Satisfactory internal consistency, reliability and stability, and one-dimensionality (Archbold et all, 1990, Henriksson er al, 2012)
Australia-Modified Karnofsky Performance Scale (AKPS)	Abernethy et al (2005)	Provides an indication of the patient's overall performance status.	None	1	0=dead to 100=normal; no complaints; no evidence of disease	0-100	High inter-rater reliability and is sensitive to changes over time (Abernathy et al, 2005).

Resource Utilisation Groups – Activities of Daily Living (RUG – ADL)	Fries et al (1994)	Measures patients' functional performance according to levels of assistance and resources needed when completing activities of daily living.	None	4	Bed mobility, toileting, transfer (1=independent/supervision to 5=two-person assist); eating (1=independent/supervision to 3=extensive assistance/total dependence/tube feed)	4-18	High inter-rater reliability and good reliability (Bjorkgren, 1999).
EuroQol 5-Dimensions-5-Levels	Herdman et al (2011)	Measurement of health-related quality of life.	VAS Health	6	Mobility,self-care, usual activities, pain/discomfort, anxiety/depression (1=no problem to 5=extreme problems/unable to); VAS health (0=worst health you can imagine to 100=best health you can imagine).	Mobility, self-care, usual activities, pain/discomfort, anxiety/depression (0-25); VAS Health (0-100)	Demonstrated validity in health settings (Fermont, 2017).
Carer Quality of Life (QOL) Instrument	Hoefman et al (2013)	Shows the quality of life of carers and the subjective burden of caring.	CarerQOL VAS	8	No=1 to A lot of=3; CarerQOL VAS (0=completely unhappy to 10=completely happy).	7-21; Carer QOL VAS (0-10)	Valid measure for carer research & economic evaluations (Hoefman et

							al, 2013) and (Voormolen et al, 2021)
Symptom Assessment Scale (SAS)	Daveson et al 2021	A measurement of distress in the most common palliative care symptoms.	No	7	0=Absent to 10=Severe.	0-70	Valid and reliable across palliative care settings (Daveson et al 2021).

*MCID = minimal clinically important difference

Appendix 19. On-cost survey

We are going to ask you some questions now relating to what health services you have used, your current work involvement and the approximate costs involved in these since the start of your participation in this study. We are also going to ask some questions about your relationship with other people.

HOSPITAL SERVICES
This refers to any contacts you (or your friend/family member) make with the hospital. This includes overnight stays in hospital and emergency department visits.

Have you (your friend/family member) had:

Hospital inpatient stay (>24 hours, or with an overnight stay)
If yes, how many times did you (or your friend/family member) stay in the hospital overnight? _____
How many nights in total were in hospital? _____

Other unscheduled hospital attendance (<24hrs without an overnight stay; e.g. emergency department visit)
If yes, how many times? _____

Did you (or your friend/family member) require ambulance transport for any of these readmissions?
If yes, how many times? _____

COMMUNITY AND PRIMARY CARE SERVICES
This refers to all health care that is **not** based in the hospital. This includes your (or your friend/family member's) GP, practice or community nurse, dietitian, physiotherapist, etc.

Since your last completion of this survey,					
Type of service	**Have you used the service?** *(tick if yes)*	**Total number of clinic visits**	**Total number of home visits**	**Total number of telehealth contacts (e.g., video link or telephone)**	**Did you pay for these services (total or gap fee)?** **If yes, estimate how much per visit**

GP surgery, doctor	☐				
GP surgery, nurse	☐				
Psychologist	☐				
Physiotherapist	☐				
Dietitian	☐				
Exercise physiologist	☐				
Other (please specify)					

I have not used any community, GP or primary care services since I participated in this study ☐

TRAVEL

This section refers to how much you spent on travel to attend hospital, GP or other health care appointments, including any unplanned visits.

Have you travelled to any hospital, GP or other health care appointments since you participated in this study?

Yes/No

If yes, please indicate:

Approximately how far (kilometers) in total have you travelled by car?
_____KM

Approximately how much in total have you spent on health care related parking?
$_____

Approximately how much in total have you spent on public transport, taxis, Ubers, etc?
$_____

EMPLOYMENT AND SUPPORT

When you are answering these questions, **please consider your situation since you participated in this study.**

(Carer participants only) Were you in paid employment before you received the treatment in this study? Please tick one box for the category that describes your employment status

If yes,		If no,	
In full time employment (30 hours or more a week)		Retired	
In part time employment (less than 30 hours a week)		Not in paid employment	
Employed but on sick/medical leave			

Are you currently in paid employment?
Please tick one box for the category that describes your employment status

If yes,		If no,	
In full time employment (30 hours or more a week)		Retired	
In part time employment (less than 30 hours a week)		Not in paid employment	
Employed but on sick/medical leave			

If yes, how much time have you take off work?
_____ days per week
If yes, how much income have you lost?
$_____

Have you received help or support from your family or friends?
Yes ☐
No ☐

If yes, how much time have they typically spent helping you?
___ hours per week

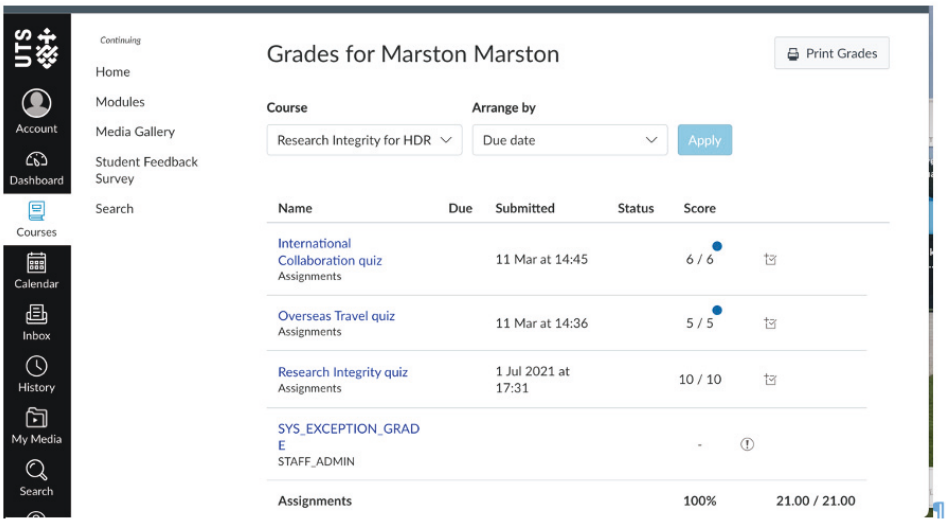
Did they take any time off work to help or support you?
Yes ☐
No ☐
If yes, how much time did they typically take off?
_____ days per week

STAGE 3 APPENDIX 2: TIMELINE

TIMELINE:

Year (part time)	1	2	3	4	5	6
	2020	2021	2022	2023	2024	2025
Project 1: Systematic Review	Design, data collection and analysis		Publication			
Project 2: Mixed Methods	Design, data collection and analysis		Data analysis and publication (qualitative study 2a)	Data analysis and publication (qualitative study 2a)	Mixed methods synthesis	
Project 3: Feasibility Trial.	Design		Data Collection	Data collection and analysis	Publication	Publication
Overall thesis	Design	Develop critical analysis		Synthesis		Submission

STAGE 3: APPENDIX 3: RESEARCH INTEGRITY MODULE



STAGE 3 APPENDIX 4: DATA MANAGEMENT PLAN

DATA MANAGEMENT PLAN

STASH was not used for projects because the primary site was an external health service – Peter MacCallum Cancer Centre, Melbourne.

In line with UTS policy, a discussion was had and decision made to manage data through the health services data management plan, This was documented and approved through two ethical approval processes. Copies of the protocol for both projects stipulating the data management plans are presented below:

Project 2: HREC 66596

> ***6.2 Participant/data (de-)identification procedures***
>
> *The participant data will be kept strictly confidential according to the National Statement on Ethical Conduct in Human Research 2007 and the Australian Code for Responsible Conduct of Research 2007.*
>
> *Identifiable participant data will be replaced with a code/unique number. The master list of names and matching codes will be stored electronically and password protected by the PI / or kept in locked facilities of the Peter MacCallum Cancer Centre (in the Department of Occupational Therapy).*
> *Only members of the project team will have access to this data. All computer files will be password protected. No identifying information will be made available during the study report or publications. Data will remain confidential, and will be kept securely for at least 7 years.*
>
> *Participant data will be only be transferred and analysed in a coded form*
> *Individual participants will not be identifiable from the presented or published material.*

Project 3: HREC 83438

Data Collection, Management and Record Keeping

Data Capture

Data will be collected using electronic case report forms (eCRFs). Electronic CRFs will be completed using a Sponsor-designated, 21 CFR Part 11 compliant electronic data capture system (eDC system). Site(s) will be trained in the eDC system and will be provided with guidelines to ensure eCRFs are correctly completed.

Designated and authorised site staff must complete the eCRFs and supporting documentation for each patient within a timely manner of the visit occurring. All persons appointed by the site principal investigator to enter eCRF data must be indicated on the Site Signature and Delegation of Authority Log.

All corrections and alterations to eCRF data must be made by site(s) in a timely manner and according to the instructions provided. Addition, deletion, or alteration to the data in the eCRFs will be recorded in a secure, computer-generated, time-stamped audit trail, including the reason for the change.

Completed eCRFs must be reviewed and signed electronically by the site principal investigator or delegate before data are released to other parties (e.g., trial statistician, HREC, sponsor/CRO, or other regulatory authority).

Data (De-) identification procedures

The participant data will be kept strictly confidential according to the National Statement on Ethical Conduct in Human Research 2007 and the Australian Code for Responsible Conduct of Research 2007.
Identifiable participant data will be replaced with a code/unique number. The master list of names and matching codes will be stored electronically, and password protected by the PI / or kept in locked facilities of the Peter MacCallum Cancer Centre (in the Department of Occupational Therapy).

Only members of the project team will have access to this data. All computer files will be password protected. No identifying information will be made available during the study report or publications. Data will remain confidential and will be kept securely for at least 15 years. Participant data will only be transferred and analysed in a coded form.

Individual participants will not be identifiable from the presented or published material.

Source Documents

The investigator is required to prepare and maintain adequate and accurate medical records designed to record all observations and other data pertinent to the trial for each trial participant. The medical records must contain adequate information to allow for verification of patient identity throughout the trial. Source data must be attributable, legible, contemporaneous, complete, consistent, original and accurate.

Any data recorded directly on the CRF, for which no other written or electronic record exists, will be considered source data (e.g., quality of life questionnaire). CRFs and source documents must be always available for inspection by authorised representatives of the Sponsor and regulatory authorities, such as the TGA or US Food and Drug Administration (FDA).

The investigator is required to maintain a patient identification code list to allow unambiguous identification of each patient included in the trial. This list should contain the patient's full name, data of birth, and dates of participation and the trial identification number. This list is held in confidentiality at the Investigator's site.

Archiving of Trial Documents

Trial data and other essential documentation must be retained for a period of at least 15 years (MHRA Guidelines).

It is the responsibility of the Sponsor to inform the Investigator(s) / site(s) when these documents need no longer be retained. No trial document or image will be destroyed without prior written agreement with the Sponsor. Should the Investigator(s) wish to assign the trial records to another party or move to another location, advance written notice will be given to the Sponsor.

Access to Data

After final database lock, the investigator(s) will receive a copy of patient-level data for archiving at the investigational site. The Sponsor is responsible for the final trial dataset.

STAGE 3 APPENDIX 5 GRADUATE RESEARCH STUDY PLAN

General Information

Notes to Student

GRADUATE RESEARCH STUDY PLAN

The Graduate Research Study Plan (GRSP) is an opportunity to take ownership of your unique research journey, from beginning to end. By identifying development goals and specific steps to achieve those goals, you'll ensure that you are making the most out of your HDR study and progressing toward a meaningful conclusion.

The **UTS HDR Capability Framework** can guide your approach to your GRSP. Its five interlocking components highlight the capabilities required to develop research-based knowledge and skills that are necessary to producing a variety of research outputs and relevant to a diverse range of careers.

If you have created multiple draft form, please delete them, as any duplicates for this form still in "draft" will be deleted from the system.

Need help?

If you need assistance to complete the form (technical issues) or having difficulty contacting your supervisor (due to supervisory conflict or no response or your supervisor being away), please seek advice for assistance by contacting:

Faculty - first point of contact

Please contact your faculty's **Research Officer (RO).** You may be referred to contact the Responsible Academic Officer (RAO) in your faculty who is responsible for overseeing research student matters.

University GRS - if issues are not resolved

If your issue cannot be resolved at faculty level you should seek advice from the **Graduate Research School (GRS)**.

Please refer to the **Graduate Research Candidature Management, Thesis Preparation and Submission Procedures** for information regarding how to manage your candidature, including candidature variations, progress and thesis submission.

Note: Personal details listed on this form are in accordance with **MyStudentAdmin.** Any enquiries in relations to candidature details please contact **GRS**.

Candidature details

UTS Student Number:
13788423

First Name:
Celia

Surname:
Marston

Course Code/Name:
Doctor of Philosophy

School/Faculty:
FoH.IMPACCT

Current EWS Date:
25/07/2028

Study Load:
Part-time

Your current thesis title is:
Optimising transitions from inpatient care to home for people with palliative care needs

Are you a collaborative degree student? Collaborative degree student means your PhD project is jointly supervised by academics at UTS and one of our international partnering institutions and you have signed a candidate agreement that formalises your collaborative research study at UTS.*

○ Yes
◉ No

Supervisor details

Is your principal supervisor available to sign off this form? If your principal supervisor is not available (such as on leave for some time and unable to sign this form) select "No".*

- (●) Yes
- ( ) No

Signatory supervisory panel: Note: By default, your application will be sent to the person who holds the sign-off delegation. To view details select supervisor and click open.

1	Sign-off delegate?	No
	Active?	Yes
	Position	Co-Supervisor
	Preferred First Name	Tim
	Preferred Last Name	Luckett
	Preferred Full Name	A/Prof Tim Robert Luckett
	Email Address	Tim.Luckett@uts.edu.au
2	Sign-off delegate?	Yes
	Active?	Yes
	Position	Principal Supervisor
	Preferred First Name	Meera
	Preferred Last Name	Agar
	Preferred Full Name	Prof Meera Agar
	Email Address	Meera.Agar@uts.edu.au

Non-signatory supervisory panel:

1	Active?	Yes
	Position	External Supervisor
	Preferred First Name	Jennifer
	Preferred Last Name	Philip
	Preferred Full Name	Professor Jennifer Philip
	Email Address	jphilip@unimelb.edu.au
2	Active?	Yes
	Position	External Supervisor
	Preferred First Name	Deidre
	Preferred Last Name	Morgan
	Preferred Full Name	Deidre Morgan
	Email Address	Deidre.morgan@flinders.edu.au

Graduate Research Study Plan

Graduate Research Study Plan

Please specify the last Candidature Stage Assessment that you were assessed at:*

- ( ) No assessment completed yet
- ( ) Candidature Stage 1 - confirmation of candidature
- ( ) Candidature Stage 2 - confirmation of advanced progress
- (●) Candidature Stage 3 - confirmation of readiness to submit thesis for examination

Development goals:

For each of the following capability areas, identify specific development goals for this session, using SMART goals. (You can learn more about setting SMART goals here). Include the activities you will undertake to progress toward those goals and how you will assess whether you achieved them. Please note that any listed goals and activities which are not achieved in this session can be carried over to the next session.

Research Knowledge and Skills:

Researchers need a strong foundation in disciplinary knowledge, developing research questions, and research methods. To understand what this capability might look like at different stages of candidature, please refer to the UTS HDR Capability Framework on the GRS website.*

By submission of Stage 3, I will be able to
Conduct sophisticated analysis, and present a coherent and well formed story of my research, across all my projects and final synthesis.
Demonstrate near completion of thesis - pending formatting and references.
Present new evidence and contributions to research and practice.

Research Communication:

Researchers need to be able to communicate their research and its implications to a diversity of audiences, using a range of media, from the thesis and journal articles for academics and scholars, to presentations, broadcasts, videos and social media aimed at audiences in the community, including journalists and funders. To understand what this capability might look like at different stages of candidature, please refer to the UTS HDR Capability Framework on the GRS website.*

By submission of final thesis I will be able to:
Successfully argue the nature and impact of of my contribution to research, practice and policy through stage 3 oral presentation and numerous conferences and forums as outlined in my thesis. (national and internationally over the last 5 years)
Contribute to new knowledge and conversation around the inclusion of carers in hospital discharge models and service delivery in Australia and the broader carer research community in the UK and Europe. This has also included providing consultation into the National Care Strategy for 2024.

Research Governance and Research Management:

Researchers have a responsibility to act with integrity, engage in ethical research practices, and understand the policies that govern the management of research projects and programs. To understand what this capability might look like at different stages of candidature, please refer to the UTS HDR Capability Framework on the GRS website.*

I have obtained ethical approval and governance for my projects. It has now closed and I have followed the required processes.
I have maintain ethical conduct and practices in the writing of my thesis (i.e. acknowledging ethical approval), publications and adhere to data management plans as per the clinical setting the study took place (e.g. stored in password protected files).

Impact, Engagement and Collaboration:

Successful researchers learn to look beyond themselves and their own project, as they create and develop relationships within scholarly and professional networks. Through these networks, they can engage with real world problems and with the direct and indirect impact their research makes. To understand what this capability might look like at different stages of candidature, please refer to the UTS HDR Capability Framework on the GRS website.*

I have demonstrated knowledge exchange and clinical translation throughout my projects and dissemination of my work that have reached across a range of research, clinical and policy level networks, nationally and internationally, These include:
- Membership of European Research Interest Group - building future research opportunities.
- Member of the CST and PASCCS groups at UTS.
- Funded for Travel Fellowship in 2025 allowed me to establish international networks in carer research.
- Seen as expert in carer research across Royal Melbourne Hospital and Peter Mac Cancer Centre.

Career Planning:

HDR study prepares graduates for leadership roles in the widely diverse range of industries and organisations that rely on research or research skills to solve real-world problems, including but not limited to academia, business, government, cultural and community organisations. Planning for a fulfilling career after graduation involves developing an awareness of the researcher's specialised knowledge and skills, and how to present those skills to optimise career potential. To understand what this capability might look like at different stages of candidature, please refer to the UTS HDR Capability Framework on the GRS website.*

Next steps:
Apply for clinical leadership roles that compliment my research portfolio in Melbourne. e.g. post doc opportunities in carer and pall care research.
Apply for WCMICS grant ($200k) to progress my next steps with co-design and implementation of carer support model for CALD populations.
Consider joint appointments at universities.
Continue leadership roles in CST, Peter Mac

Enrolment and Training

Subjects as per your Study Plan are:

1	Subject Code	93001_V2
	Name	PhD Thesis: Health
	Subject Type	Thesis
	Compulsory?	No
	Year	2020
	Session	Autumn Session
	Status	Enrolled
	Faculty	FOH.Faculty of Health

Your thesis subject is attached to your course code and refers to your Higher Degree Research program. The Coursework subjects are compulsory and need to be completed as part of your course requirements.

- If you require recognition of prior learning please submit a Credit Recognition request.
- If you require to vary your coursework to an alternate session please submit a Variation of Program request.

Following are the details on the training requirements applicable to your program. Please note that the links will take you to a page outside of ResearchMaster:

Training Module	Expected date of completion
Consent matters training	End of your current session
Research integrity module	No later than your Stage 1 assessment. If the link loads an "Access Denied" page after logging in, please **contact GRS**

Acceptance

Student declaration

This study plan reflects the discussions as emerged between me and my supervisor. Tick "I Agree" box below and click "Submit GRSP" to submit to the supervisor for review and/or sign-off OR click "Save" if this is not ready for submission.*

☑ I Agree

Date:

16/04/2025