

# **Post-hospital Transitions for Older Adults and their Carers**

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## SUMMARY

Older adults with an unplanned hospital admission can be at risk of premature admission to residential aged care (RAC). The process by which this occurs frequently results in a sense of disempowerment. A range of policy initiatives including Transition Care (TC) have been implemented to reduce this potential risk. However, minimal research has examined patient experiences of TC. The present thesis addresses this gap in the literature.

The program comprised three lines of enquiry. The first focused on TC, with two related studies examining the perceptions of service providers, older adults and proxies regarding the extent to which TC is goal oriented, patient-centred and restorative, and provides a seamless transition from hospital to home or RAC. The second line of enquiry examined decision making about entry to RAC from the perspectives of older adults, carers, social workers and community members. The level of community support for a cash entitlement at the point of entry to RAC was also assessed. The third line of enquiry described a randomised controlled trial of a health literacy and coaching intervention in residential TC.

More specifically, the first study examined the level of congruence between the 'key requirements' of a TC program, as set out in the Guidelines, and actual performance as self-reported by TC services. Low levels of General Practitioner and Geriatrician involvement in TC were reported as well as challenges in meeting the requirement for pharmacist-led reconciliation of medicines and securing adequate services for clients at discharge from TC, compared with the Guidelines. Having identified these mismatches between guidelines and practice, the second study reported the development of a measure of older adults' experiences of TC to enable the consumer's view to be documented. Initial testing was undertaken as part of a national telephone survey of TC recipients three months after discharge from TC.

Overall, sound reliability and validity of the measure was demonstrated.

As the perceptions of relocation of the three key actors in the decision to move from hospital to RAC (the patient, family and social worker) have rarely been explored, the third study examined pathways to hospitalisation and consequent RAC entry. Older adults expressed a desire to participate in decisions about their future care, regardless of outcome. Spouses generally provided substantial care prior to relinquishing this role. While social workers indicated that families should plan ahead for RAC, adult children reported resistance to anticipatory conversations with ageing parents about their future living arrangements. TC was thought to provide a better environment for older adults, both generally and for those waiting for a RAC bed. However, medical imperatives sometimes made this option unsuitable.

The views of ‘ordinary Australians’ about the proposal for an aged care entitlement that would provide older adults with a real choice about where they receive care have also not been canvassed previously. The fourth study therefore reported the findings of a series of questions on this topic posed to a representative sample via a Health Omnibus Survey. A preference for a cash entitlement was indicated, although this declined with advancing age. The final study reported is a randomised controlled trial to assess the efficacy of a health literacy and coaching intervention in a residential TC setting. The study aimed to support patients to take a more active role in their health care and equip carers for the role of health advocates for older persons. Older adults and carers in the intervention group reported higher scores on a measure of the quality of care transitions compared with a ‘usual care’ group.

These five novel empirical studies provide valuable information for clinicians developing targeted intervention programs designed to enhance patient and carer participation in planning for future care. Such interventions have the potential to improve the transition experience and reduce adverse outcomes commonly associated with care transitions.

## DECLARATION

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Stacey Masters

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## ABBREVIATIONS

ABS, Australian Bureau of Statistics

ACAT, Aged Care Assessment Team

ACEM, Australasian College for Emergency Medicine

ACFA, Aged Care Financing Authority

ACFI, Aged Care Funding Instrument

ACH, Aged Care and Housing

ACSA, Aged and Community Services Australia

ACSQHC, Australian Commission on Safety and Quality in Health Care

AD, Alzheimer's disease

ADL, Activities of daily living

AHMAC, Australian Health Ministers' Advisory Council

AHRQ, Agency for Healthcare Research and Quality

AIHW, Australian Institute of Health and Welfare

ALSA, Australian Longitudinal Study on Ageing

ANZSGM, Australian and New Zealand Society of Geriatric Medicine

APA, American Psychiatric Association

APA, Australian Postgraduate Award

ARC, Australian Research Council

ATSI, Aboriginal or Torres Strait Islander

BCOS, Bakas Caregiving Outcomes Scale

BMI, Body Mass index

CACP, Community Aged Care Package

CCDE, Cash and Counseling Demonstration and Evaluation

CCI, Charlson Comorbidity Index

CDC, Consumer Directed Care

CHSP, Commonwealth Home Support Programme

CI, Cognitive impairment

COACH, Coaching Older Adults and their Carers to have their preferences Heard

COAG, Council of Australian Governments

COAWG, Care of Older Australians Working Group

CPI, Consumer Price Index

CTI, Care Transition Intervention

CTM<sup>®</sup>, Care Transition Measure

DCE, Discrete choice experiment

DHS, Department of Human Services

DNCB, Domiciliary Nursing Care Benefit

DoH, Department of Health

DoHA, Department of Health and Ageing

DP, Direct Payments

DSM, Diagnostic and Statistical Manual of Mental Disorders

DSS, Department of Social Services

EACH, Extended Aged Care at Home

EACH-D, Extended Aged Care at Home (Dementia)

ED, Emergency Department

EPC, Enhanced Primary Care

EQ-5D, Euroqol 5 Dimension

ERA, Emerging Researchers in Ageing

GDP, Gross Domestic Product

GDS, Geriatric Depression Scale

GEM, Geriatric evaluation and management

GP, General Practitioner

HACC, Home and Community Care

HCPP, Home Care Packages Programme

HLC, High Level Care

HMA, Health Management Advisors

HMMR, Home Medication Management Review

HOS, Health Omnibus Survey

HSR, Health Services Research

HSRAANZ, Health Services Research Association of Australia and New Zealand

IADL, Instrumental activities of daily living

IB, Individual Budgets

IC, Intermediate Care

ICD, International Classification of Diseases

ICRS, Intermediate Care Rehabilitation Services

interRAI, international Resident Assessment Instrument

IRT, Item Response Theory

LLC, Low Level Care

LSOPI, Long Stay Older Patient's Initiative

MAU, Medical Assessment Unit

MBI, Modified Barthel Index

MCI, Mild cognitive impairment

MHLC, Multi-dimensional Health Locus of Control

MMSE, Mini-Mental Status Examination

NACA, National Aged Care Alliance

NDR, National Data Repository

NETCP, National Evaluation of the Transition Care Program

NFP, Not-for-profit

NGO, Non-government organisation

NGSE, New General Self-Efficacy Scale

NHHRC, National Health and Hospitals Reform Commission

NHMRC, National Health and Medical Research Council

NHS, National Health Service

NLIU, Nurse-led inpatient unit

NQF, National Quality Forum

NSW, New South Wales

PC, Productivity Commission

QOL, Quality of life

QPL, Question prompt list

RAC, Residential aged care

RCS, Resident Classification Scale

RCT, Randomised controlled trial

RGH, Repatriation General Hospital

SA, South Australia

SA HOS, South Australian Health Omnibus Survey

SCRGSP, Steering Committee for the Review of Government Service Provision

SDAC, Survey of Disability, Ageing and Carers

SDM, Shared decision making

SES, Socioeconomic status

SMMSE, Standardised Mini-Mental State Examination

SPPB, Short Physical Performance Battery

SRH, Self-rated Health

TC, Transition Care

TCP, Transition Care Program

TIE, Transition Care: Innovation and Evidence

UK, United Kingdom

UN, United Nations

US, United States

WHO, World Health Organization



# CHAPTER 1

## *OVERVIEW OF THE RESEARCH PROGRAM*

### ***1.1 Background***

Life expectancy has increased dramatically since 1881 (the date from which public records are available). In Australia in June 2007, 1.6% of the population was aged 85 years or older but this is projected to increase to 7.3% by 2056 (Australian Bureau of Statistics [ABS], 2008). Based on current information and trends, those aged 85 years or older are likely to receive some form of government subsidised care, which by 2050 is estimated to be 3.5 million Australians who will access aged care services each year (ABS, 2008). The economic implications of Australia's ageing population are likely to be considerable, with the Treasury projecting an increase in health spending from 3.8% of gross domestic product (GDP) in 2006-07 to 7.3% in 2046-47 (Treasury & Swan, 2010).

Many of the tensions experienced by governments as they grapple with the economic implications of ageing populations have their roots in historical decisions. The present thesis first describes the care of older Australians from this historical perspective and then offers a contemporary perspective. Understanding the historical context of the care of older Australians highlights unintended consequences of policy decisions (Kendig & Duckett, 2001), including a community expectation of nursing home entry to be a normal part of ageing (Cullen, 2003), and the substantial public expenditure required to meet this expectation. Contemporary reforms to the financing of aged care aim to limit the impact of an ageing population on growth in public expenditure through the introduction of competition in the provision of aged care services as well as increased consumer contributions to the cost of care (Productivity Commission [PC], 2011).

Hospitals and residential aged care (RAC) services in Australia maintain high levels of bed occupancy and effective interactions between services are critical for efficient patient flow and financial performance. For older Australians, a hospital admission is often accompanied by a decrease in physical function (Covinsky et al., 2003), loss of autonomy (Lothian & Philp, 2001) and an increased risk of admission to RAC (National Data Repository [NDR], 2009). The experience of moving from hospital to RAC can contribute to disempowerment of consumers as choice of RAC is limited and older adults and families feel under pressure to accept the first available bed (Thetford & Robinson, 2006).

A census of all older people in public hospitals in Australia in 2002 found that one in five were staying longer than necessary because they had to wait to access rehabilitation or RAC (Care of Older Australians Working Group [COAWG], 2004). This fuelled concerns about older people impeding access to hospital beds while other patients waited in emergency departments (access block) (Braitberg, 2007), along with concerns that older people were being pushed toward permanent admission to RAC without adequate time to recover from injury or illness (Whitehead, Wundke, Williamson, & Finucane, 2001). A lack of discharge options for patients who no longer required acute care but were not well enough to go home without intensive support contributed to the establishment of the Transition Care Program (TCP) in Australia in 2005.

It was anticipated that TCP would improve the transition from hospital to home or RAC in terms of patient experiences, restoration of physical function and a reduction in admissions to RAC. The evaluation of the Innovative Care Rehabilitation Services (ICRS) pilot (an antecedent of the TCP) did demonstrate promising results for restoration of physical function (Health Management Advisors [HMA], 2005). However the absence of a comparator group limited the conclusions that could be drawn concerning the effectiveness of TCP in reducing readmissions to hospital or entry to RAC in the months following discharge from the ICRS

program. Although recipients of ICRS services were encouraged to record their level of satisfaction with the program via a questionnaire at discharge, there was no discrimination of responses by the location in which care was received (home or residential care setting). Nevertheless, free text comments suggested concerns about aspects of care usually associated with RAC (e.g., availability and timely responses of staff), which are consistent with broader concerns about the residential model of intermediate care in the United Kingdom (UK; Ebrahim, 2001; Grimley Evans & Tallis, 2001). Therefore, on the balance of available evidence at the commencement of this program of research, the researcher determined that the next step in the evaluation of intermediate (or transitional) care in Australia should focus on the following central question:

*What is the experience of older Australians as they transition from hospital to home or RAC via an intermediate care program?*

## ***1.2 Transition care***

In 2004 Australian states and territories agreed to work with the Commonwealth Government to address problems associated with increasing demand for public hospital beds and inefficiencies in the discharge of (mostly older) patients. A new program of post-acute and restorative care known as the TCP was implemented nationally in 2005-06, building on the success of earlier trials in South Australia and other states and territories (HMA, 2005).

The studies comprising the present thesis were initiated in 2007-08 and reflect aged care policy developments and priorities at that time. The Australian Government sought to determine whether TCP was successful in achieving program aims and to identify the factors associated with better functional outcomes and reduced readmissions to hospital.

### ***1.3 Key research questions***

The researcher first describes the questions addressed through a review of relevant literature before outlining the questions that informed the empirical studies in this program.

#### ***1.3.1 Contextual research questions***

The thesis begins with an historical overview of the care of older Australians. The challenge of older persons in hospital (extended length of stay contributing to access block) is described in some detail as it provides the context for the emergence of TCP in Australia in 2005-06. A longitudinal perspective of aged care policy describes landmark reports that have shaped, and continue to shape, the reform process in health and aged care. The key question addressed by this historical review was:

1. What is the historical and policy context for the program of research described in this thesis? (Chapter 2)

One landmark study (with respect to subsequent aged care reform) was the *Review of Pricing Arrangements in Residential Aged Care* (Hogan, 2004). Hogan (2004) proposed a series of options for the future financing of RAC services, including an option to provide older persons with a voucher for care and accommodation (an aged care entitlement or subsidy) that would enable them to choose the RAC provider of their choice. Hogan acknowledged that choice was contingent on maturation and deregulation of the aged care industry as well as provisions for older adults with cognitive impairment who do not have a substitute decision maker.

Discussions about consumer choice and the allocation of an aged care subsidy to the individual (via a direct payment or individual budget) continued (Bruen & Rees, 2007; Tilly & Rees, 2007), and in 2011 the Australian Government began trialling consumer directed care (CDC) in home care and carer respite programs. When reviewing this literature, the key research question was:

2. What is the international experience of CDC in home care for older adults and what are the lessons for Australia? (Chapter 3)

### ***1.3.2 Empirical research questions***

Following a review of relevant literature and in the shadow of the National Evaluation of the Transition Care Program (NETCP) a series of empirical research questions were developed. The first question concerned TC service provider adherence to goals and key requirements as described in the TCP Guidelines (Department of Health and Ageing [DoHA], 2005). The specific question addressed by the researcher was:

3. To what extent are Transition Care (TC) services compliant with program requirements relating to care plans, general practitioner (GP) and family involvement, medication management and other aspects of care? (Chapter 4)

TC services are required to provide self-reported data on the quality of care provided to recipients and the NETCP afforded the researcher an opportunity to develop and test a measure of *patient experience* that was aligned with the requirements of the TCP. The principal question addressed by the researcher related to the feasibility of administration of the measure of patient experience as well as its reliability and validity.

4. How feasible is it to ask TC recipients about their experience of setting goals for TC and the extent to which they experience care as restorative and patient-centred? (Chapter 5)

An important feature of the TCP in Australia is that it was designed to minimise the risk of premature or inappropriate admission to RAC. This aim is achieved by optimising the functional independence of the older person through the application of physical, occupational and other therapies as well as providing TC recipients and families with adequate time to

consider and plan for ongoing needs for care and accommodation (DoHA, 2005). TCP strives to reduce the pressure on hospital beds as well as the stress experienced by older persons and families (Travis & McAuley, 1998) who may otherwise be required to make a decision about entry to RAC within a few days of being admitted to hospital. Researchers and clinicians alike have expressed concern that decision making about entry to RAC from a hospital bed often ignores the wishes of the older person (Bowers et al., 2009; McAuley & Travis, 1997). However few researchers have spoken to the older person, family carers and social workers in the hospital setting, particularly around the time that a decision to enter RAC is made. Therefore in the context of TCP, the following research question was posed:

5. How is the decision made to enter RAC from a hospital bed? (Chapter 6)

CDC is posited as a way to improve quality of care through competition and user choice (Hogan, 2004). As an extension of the literature review in Chapter 3 and the study described in Chapter 6, the researcher chose to explore community perceptions about entry to RAC and preferences concerning a personal aged care subsidy (or voucher) that could provide consumers with more choice about who would provide their care and in what setting (Bruen & Rees, 2007).

6. What does a community survey contribute to our understanding of: (i) the reasons older persons enter RAC, and (ii) preferences for a voucher at the point of entry to RAC? (Chapter 7)

Older adults who transfer from hospital to residential TC generally require more assistance with activities of daily living (ADL) and are at higher risk of transfer to permanent RAC compared with those who receive TC at home (Giles et al., 2008). Many TC recipients interviewed as part of the NETCP reported that they did not know what to expect from TC prior to entry and were not involved in setting goals for their care. Against this backdrop, the

researcher was closely involved in the design of a randomised, controlled trial (RCT) of a multi-component health literacy and coaching intervention in a residential TC setting. The Care Transition Measure (CTM-15<sup>®</sup>) assesses the quality of preparation for care transitions and was the primary outcome for the RCT. The key question addressed by the research was:

7. Do patients and carers allocated to the intervention group report higher scores on the CTM-15<sup>®</sup> compared with those who receive usual care? (Chapter 9)

#### ***1.4 Conceptual and methodological frameworks***

A review of CDC literature informs a conceptual framework for the thesis and health services research (HSR) provides a methodological framework for the empirical studies.

CDC is posited as a mechanism to enable older Australians in receipt of publicly subsidised home care to participate in discussions about the type of care they receive and how that care is delivered. Home care recipients are advised of the monetary value of their package and receive monthly statements that detail the cost of services received as well as administrative fees. Care recipients are able to choose their preferred level of involvement in managing their package and from 27 February 2017 funding will follow the consumer. This will allow a consumer to choose a provider that is suited to them and to direct funding to that provider (Department of Health [DoH], 2016).

CDC is part of a broader set of reforms in aged care as Australia moves towards a more consumer-driven, market-based and less regulated system (DoH, 2016). Consumer contributions to the cost of care have increased with means testing applied to receipt of home care from 1<sup>st</sup> July 2015 and changes to means testing for RAC to include assets as well as income. These changes were introduced as part of the *Living Longer Living Better* package announced by the Government in April 2012 (de Boer & Yeend, 2013).

Considerable attention has been directed to the benefits of CDC including older adults having a stronger voice in care planning and more choice about the type of care and service provider. The concepts of voice and choice are present in the empirical studies presented in this thesis. Chapters 4, 5, 8 and 9 are concerned with voice (Katz, Holland, & Peace, 2013) and interventions that can assist TC recipients to participate in discussions about their present and future care arrangements (Kinnersley et al., 2008), while Chapters 6 and 7 are concerned both with voice in decision making as well as the extent to which older adults are able to exercise choice. Concepts of *voice* and *choice* as embodied within CDC (Vamstad, 2015) are key constructs within the conceptual framework for the thesis.

The empirical questions posed in Section 1.3 encompass a range of study designs and methods including document analysis, development of a standardised measure of patient experience, qualitative and survey research and a pragmatic RCT (a trial to determine whether an intervention works in everyday practice) (Tosh, Soares-Weiser, & Adams, 2011). The questions posit an examination of the settings in which care is delivered (structure), components of care (process) and outcomes (recovery, restoration of function), all representing essential considerations for evaluating the quality of health care (Donabedian, 1966).

HSR emerged as a field of enquiry in the United States (US) around 1965 and Donabedian's ideas were influential in the development of the field (Ayanian & Markel, 2016). Several definitions of HSR have been proposed with one of the most frequently cited definitions having been developed by the Agency for Healthcare Research and Quality (AHRQ). The AHRQ defines HSR as comprising three key elements: access, cost and outcomes of health care (2002). HSR incorporates research methods from a number of disciplines including epidemiology, sociology, economic analysis and public policy (Shi, 2008), as well as evidence based medicine, clinical informatics and quality improvement (Scott & Campbell,



2002). Therefore, a wide range of qualitative, quantitative, descriptive and analytical research methods are utilised.

HSR is concerned with current issues in healthcare policy as well as the financing, organisation and delivery of care and is described as applied science that seeks to generate relevant knowledge for policy makers, administrators and clinicians (Shi, 2008). HSR is rarely value-free with much of the funding coming from government bodies that set the research agenda (Bowling, 2014). Nevertheless, HSR provides the methodological framework for the program of research presented in this thesis.

### ***1.5 Specifics of the research program***

The research program comprised three distinct lines of enquiry (Figure 1.1). The first focused on the TCP, with two related studies examining the perceptions of service providers, older adults and proxies regarding the extent to which TC is goal-oriented, patient-centred and restorative, and provides a seamless transition from hospital to home or RAC. The second line of enquiry examined decision making about entry to RAC from the perspective of older adults, carers, social workers and a community sample. The level of community support for a cash entitlement at the point of entry to RAC was also assessed. The third line of enquiry describes a RCT of a health literacy and coaching intervention in a residential TC setting and includes selected results. Further details of each of the empirical studies are presented below.

#### ***1.5.1 Chapter 4: Assessing quality in the TCP***

The first TC services were established in October 2005 and the NETCP commenced in 2006. The NETCP provided an opportunity to examine the implementation of a new program at the interface between the hospital and aged care systems. Although TCP is only a small program the expectations are considerable. The first study examines the level of congruence between

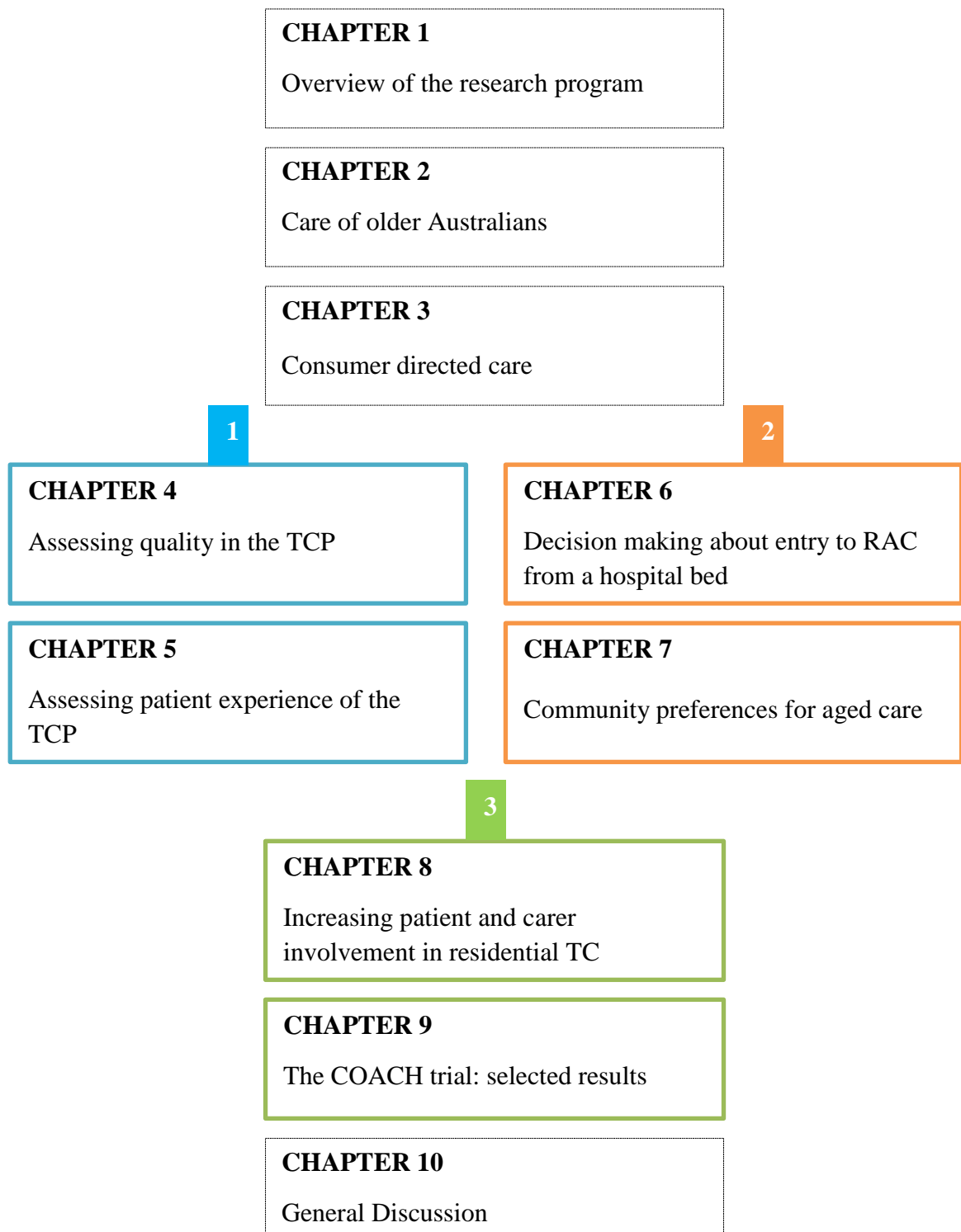


Figure 1.1 Flowchart of the three lines of enquiry

the key requirements of the program, as set out in the TCP guidelines (DoHA, 2005), and performance as self-reported by TC services.

### ***1.5.2 Chapter 5: Assessing patient experience of the TCP***

The second study involves the development of a measure of older adults' experience of TC as goal-directed, restorative, patient-centred and seamless. The aim is to align TC services' self-reports (Chapter 4) with a standardised measure of patient experience. Initial testing comprises part of a national telephone survey of TC recipients three months after discharge from TC.

### ***1.5.3 Chapter 6: Decision making about entry to RAC from a hospital bed***

The experience of searching for and selecting a RAC facility for older people who are to move from hospital has been the subject of previous studies (e.g., Cheek & Ballantyne, 2001). However most interviews have occurred with older people and family members in the months following the move to RAC and the perspectives of health professionals have rarely been canvassed. Previous accounts have documented the high level of stress experienced by family members who are searching for a RAC facility and this may account for a perceived reluctance of researchers to ask how the decision is made and enquire about the respective roles of patients, family members and hospital staff. Specifically, there appear to be no previous studies that have explored the perceptions of the three key actors (the patient, family and social worker) in the decision to move from hospital to RAC. These gaps are addressed through a series of interviews with patients awaiting entry to RAC, and family members, to examine the pathways that lead to hospitalisation and consequent RAC entry.

### ***1.5.4 Chapter 7: Community preferences for aged care***

The views of 'ordinary Australians' about the proposal for an aged care entitlement that would provide older adults with a choice about *where* they receive care, have not been

canvassed in a representative sample. The Health Omnibus Survey (HOS) is a large representative survey of households in South Australia (SA) conducted at least annually since 1990 (Wilson et al., 1992). Chapter 7 reports on the findings of a series of questions about moving to RAC that were included in the HOS in 2008.

#### ***1.5.5 Chapter 8: Increasing patient and carer involvement in residential TC***

Chapter 8 describes a protocol termed Coaching Older Adults and their Carers to have their Preferences Heard (COACH) trial. The study aims to determine whether a coaching intervention delivered by a geriatrician and specialist nurse in residential TC might improve older adults' and carers' assessment of the quality of preparation for care transitions, as measured by the CTM-15<sup>®</sup>. A secondary question is whether the approach improves quality of life (QOL) and reduces health care utilisation compared with usual care.

#### ***1.5.6 Chapter 9: Selected results of the COACH trial***

This chapter reports on analyses of the primary outcome for the COACH study, the CTM-15<sup>®</sup>. Results are those allocated to the researcher for her own program of research.

#### ***1.5.7 Chapter 10: General discussion***

Chapter 10 provides the opportunity to review the research program and underline key findings from the three lines of enquiry: perceptions of TC; decision making about entry to RAC; and the efficacy of a coaching intervention in TC as well as reflection on the degree to which the overarching research question was answered. The benefits and limitations of the research undertaken are discussed and consideration of the implications for future research and practice are presented. The chapter concludes with recommendations for future research in developing the knowledge base around older persons' experiences of post hospital transition.

## CHAPTER 2

### *CARE OF OLDER AUSTRALIANS*

#### ***2.1 Introduction***

This chapter first describes the care of older Australians from a historical perspective and then offers a contemporary view. The history of government and not-for-profit organisation (NFP) support for older adults who are unable to meet their own needs is described, followed by a consideration of concerns about older adults in hospital who are waiting for alternative care or accommodation. Innovations at the interface of the hospital and aged care sectors to assist in transitioning older adults from hospital to home (or alternative care) are then reviewed. The chapter concludes with a consideration of the objectives of the TCP, contemporary trends in provision of home care and RAC utilisation as well as gaps in the evidence concerning pathways to RAC.

#### ***2.2 Historical perspectives on support of older people***

Homes for the aged are a recent invention. In the eighteenth century in Britain needy older people without family support took refuge in alms-houses together with other impoverished and socially excluded groups. The first specific homes for the aged were established in the early nineteenth century by women's and church charities to spare older adults from the degradation of these alms-houses. Far from being accessible to all older people, Haber and Gratton (1994) report that the first homes were to accommodate older adults who were members of a church or charity group. Notably, even today, government subsidies for the care of older Australians have not seriously challenged the right of NFP providers to choose which approved applicant they will accept into their RAC facility.

Fine (1999) describes four periods in the history of aged care in Australia since 1788: (i) establishment of 'indoor relief'; (ii) income support and nursing care; (iii) commodification

and entitlement; and (iv) pluralism and community care, with an overall trend towards formalisation and public support of aged care provision. The following sections provide an overview of these four periods.

### ***2.2.1 The first period (1788-1850): establishment of 'indoor relief'***

During this time aged care policy was driven by the view that care was primarily, if not exclusively, the responsibility of families. Economically better off households had domestic servants or were able to purchase other forms of private assistance (Fine, 1999). Older people needing more care than could be provided by their families, and older people without families, were generally dealt with in the same manner as the indigent and consigned to asylums for the destitute, euphemistically termed 'indoor relief' centres (Cullen, 2003).

Fine (1999) describes an active role for state governments in this period. For example, by supporting the establishment of the Benevolent Society of New South Wales in 1918 and funding the building and operation of the Sydney Asylum for the poor, blind, aged and infirm in 1821 (Cullen, 2003; Fine, 1999), the majority of residents of which, in 1930, were aged 60 years or older (Fine & Stevens, 1998).

### ***2.2.2 The second period (1860s-1950): income support and nursing care***

This period was characterised by emerging concerns about public health and health care as well as a series of Royal Commissions and other public enquiries into the care of older adults in asylums. Inspections of publicly subsidised institutions commenced in 1866 and, following the arrival of trained Nightingale nurses in the 1870s (Fine, 1999), the New South Wales (NSW) government required institutions that provided care to frail or destitute people to appoint trained nurses (Cullen, 2003). The introduction of the old-age pension in 1909 was driven by a need to relieve pressure on asylums, which were accommodating impoverished older adults alongside those with incurable disease (Fine, 1999). The passage of the *Invalid*

*and Old-age Pensions Act 1908* was the vehicle for the introduction of a non-contributory pension with universal coverage to assist older adults (Cullen, 2003). From 1909 to 1963, Benevolent Asylums were paid maintenance subsidies on behalf of pensioners with subsidies equivalent to the pension rate (DoHA, 2010b). Cullen's account of this period draws attention to the role of state funded hospitals, as well as asylums, as a source of accommodation security for frail older people.

### ***2.2.3 The post war period (1950-1980): commodification and entitlement***

The term commodification refers to the process by which something which does not have an economic value (e.g., the care of older adults) is assigned a value, in this case through a personal care subsidy. Commodification of care occurs when caring activities previously provided on an informal basis are redirected toward the market (Claassen, 2011).

For Australians born between 1901 and 1910 and entering their senior years during the post war period, life expectancy had increased to 55.2 years for males and 58.8 years for females (ABS, 2008). Key achievements of the post war period included housing support to meet the needs of older adults and the introduction of nursing home subsidies in 1963. These achievements are briefly discussed below.

In addition to housing support delivered through mainstream housing programs, the Australian Government provided targeted housing support for older adults through grants for capital works administered under the *Aged Persons Homes Act 1954* (Cullen, 2003). The Australian Government matched the contributions of NFP organisations to build alternative accommodation for older people who were independent but required housing more appropriate to their needs (Fine, 1999). Kendig and Duckett (2001, p. 5) report that the first units were built for mostly ageing couples as it was “virtually unquestioned that single people would live with their families, and ‘sick’ older people would go to hospital”. Thus, the

Australian Government's first direct involvement in the capital funding of homes for the aged was essentially a housing initiative, rather than the provision of both care and accommodation.

The early 1950s also saw representations from the Hospital and Charities Commission of Victoria requesting financial assistance from the Australian Government to respond to the problem of overcrowding in hospitals arising from long term residents with chronic disease and disability (Cullen, 2003). Older people needing nursing home care were frequently drawn into the public hospital system as a result of private hospital insurance arrangements during this period. The *Hospitals Benefits Act 1951* excluded the chronically ill and elderly as poor insurance risks (Fine, 1999). By the mid-1950s, the Victorian Hospital and Charities Commission was requesting assistance to fund 5000 nursing home beds. This and similar representations from the other States gave rise to the Australian Government's first direct involvement in the recurrent funding of aged care (rather than as income support) with the introduction of a subsidy for nursing home care in 1963. Nursing home benefits were argued on the grounds that privately run nursing homes were a cheaper alternative than long-term hospital care and cheaper than increasing the pension for all to enable older adults in nursing homes to self-fund their care (DoHA, 2010b).

Kendig and Duckett (2001, p. 6) describe the allocation of grants arising from the *Aged Persons Homes Act 1954* as "quick political decisions that could not anticipate the consequences [and which] set in train the massive public expenditure on care". A review of Cullen's (2003) chronicle of legislative and policy changes reveals a period of high activity as the Menzies government implemented successive changes to the funding of care and accommodation for older people, seemingly in reaction to the unexpected consequences and market distortions that arose from earlier decisions. Although it is not informative to describe



in full the legislative and policy changes during this period, the following provides an outline of key decisions, their rationale and the impact on housing support for older adults.

1. The introduction of nursing home benefits in 1963 led to rapid growth in nursing home care. Between 1963 and 1968 the number of nursing home beds increased by 48.4%, with the majority (68.6%) of beds operated by the private for-profit sector. Significant pressure for this growth came from public hospitals that were now able to discharge older adults to affordable nursing home accommodation. As described above, the cost of nursing home accommodation to the individual had previously been prohibitive due to hospital insurance arrangements at that time.
2. Nursing home operators were able to set their own fees and by 1967, the lack of regulation of nursing homes again raised concerns about affordability for residents as well as concerns about cost minimisation by operators through the selection of residents with lower care needs with a corresponding reduction in standards of care.
3. In 1969, a Senate Select Committee of Medical and Hospital Costs found that a reasonable proportion of nursing home residents could have been classed as patients of acute hospitals and that nursing home operators providing intensive nursing support were struggling to fund the cost of that care. This led to the introduction of a supplementary benefit for residents requiring intensive nursing care, as certified by a medical practitioner (later tightened to require endorsement by an Australian Government medical officer).
4. A subsequent review of nursing home residents in the early 1970s found that a substantial number (widely accepted to be around 25%) were inappropriate admissions. That is, the residents had recovered from their hospital admission or had been admitted from the community and required minimal assistance with ADL. The

reviewers cautioned that the continued practice of admitting older persons to nursing homes without reference to medical need would foster community expectations of permanent nursing home entry as a normal part of ageing (Cullen, 2003).

5. A personal care subsidy (care entitlement) was introduced in 1969 to provide recurrent support for hostel<sup>1</sup> operators and the *Aged Persons Hostels Act 1972* provided capital subsidies to encourage the provision of additional hostel accommodation for older adults who did not require nursing home care.
6. New regulations in the early 1970s sought to restrict the profits of private hostel operators by requiring approval from the Department of Social Security for increases in fees as well as evidence of increases in the costs of delivering care. In addition, controls on admissions to, and the growth of, all non-government nursing homes were introduced (Cullen, 2003).

Although the discussion to this point has focused on growth in aged care accommodation, there were also attempts to develop community-based aged care services during the post war years. Policy implementation was through a series of States Grants Acts including the *Home Nursing Subsidy Act 1956*, *Home Care Act 1969*, *Paramedical Services Act 1969* and the *Delivered Meals Subsidy Act 1970*. Although these attempts did not curb the growth of for-profit nursing homes, the role of NFP organisations as a major provider of community aged services was established (Fine, 1999).

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<sup>1</sup> The terms 'hostel' and 'nursing home' were used to describe homes for the aged that provided personal and/or nursing care for older adults with low and high care needs respectively. Nursing homes were first defined in the National Health Act 1953. The terms 'hostel' and 'nursing home' were replaced with the generic term 'residential aged care' in 1997.

#### ***2.2.4 The fourth period (1980- 2002): pluralism and community care***

Pluralism in aged care refers to a diverse mix of services, providers and funding arrangements (Saunders & Fine, 1992). A growing awareness of the economic implications of population ageing contributed to bipartisan support for a reorientation towards community care as well as continual change in aged care policy and administration. There were two major reform processes during the fourth period: the *Age Care Reform Strategy 1983-1996* and the *Aged Care Act 1997*, which are described below. The mid-term review of the aged care reform strategy in 1990-91 resulted in a raft of recommendations that are also described.

##### ***2.2.4.1 Age Care Reform Strategy 1983-1996***

The *Age Reform Strategy* had two primary strands: the introduction of the Home and Community Care (HACC) Program in 1985 and the 1986 Nursing Homes and Hostel Review.

The HACC Program brought together funding from earlier community aged care and disability initiatives and provided the platform for a significant expansion of community-based care (Kendig & Duckett, 2001). HACC was jointly funded by the Australian Government and States/Territories with the clear objective of preventing premature or inappropriate admission to nursing homes. That is, it was supported by a philosophy of promoting independence and was available to people with profound and moderate to severe disability, and their carers, as well as older adults (Steering Committee for the Review of Government Service Provision [SCRGSP], 2012). Service providers were predominantly NFP organisations.

In 1992, Community Aged Care Packages (CACP) were introduced to provide more intensive home-based care for older adults (DoHA, 2010b). Through the CACP, older adults

assessed by an Aged Care Assessment Team (ACAT)<sup>2</sup> as eligible for low level (hostel) care, and who express a preference to receive care in their home, are provided with a package of services to meet their individual care needs. Assistance may include domestic assistance, meals at home and other food services, transport services, home or garden maintenance, social support, personal care, counselling, equipment and home modifications, respite care and linen services (Australian Institute of Health and Welfare [AIHW], 2010a).

A key outcome of the 1986 Nursing Homes and Hostel Review was the linking of hostels (from Social Security) and nursing homes (from Health) within a single bureaucratic structure. At the same time, funding for the cost of care was separated from funding for the cost of accommodation, within an overall policy objective of reducing the historical funding disparities between hostels and nursing homes. Subsidies for accommodation and related services were based on fixed unit costs while subsidies for nursing and personal care services were based on resident need, as assessed by a 5-point Resident Classification Instrument (RCI) in nursing homes and a 3-point index in hostels (Cullen, 2003).

A requirement for an ACAT approval to enter a hostel or nursing home was introduced to reduce inappropriate admissions as well as increase referrals to community services (Kendig & Duckett, 2001). In addition, a population-based approach to the allocation of nursing home beds was implemented to directly link aged care beds to the number of older people in a region (DoHA, 2010b). The initial target in 1986 was 100 beds per 1000 persons aged 70

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<sup>2</sup> An ACAT is a comprehensive assessment of the level of assistance required by an older person to undertake ADL and care needs relating to their health conditions, including behaviours associated with dementia and mental health conditions. ACAT assessments in hospitals generally involve geriatricians and social workers, in conjunction with other allied health staff, whereas those conducted in the community setting routinely involve a single assessor (NDR, 2009).

years or older (comprising 40 nursing home and 60 hostel beds), benchmarked against operating resources. This planned approach to the allocation of subsidies for aged care places as well as the reallocation of bed licences that were unused or forfeited led to a progressive shift in the balance of low care, high care and community aged care provisions over time (Kendig & Duckett, 2001). Restrictions in the number of nursing home beds for which a subsidy was payable also enabled funds to be diverted to community-based services and provided greater coverage of aged care service provision (Fine, 1999).

#### ***2.2.4.2 The mid-term review of the aged care reform strategy (1991-1996)***

The mid-term review recommended that benchmarks for community care be applied in conjunction with benchmarks for hostel and nursing home beds to bring about changes in the balance of care. This was achieved through a progressive substitution of community aged care places for hostel beds while also providing a gradual increase in the planning provision ratio (see above) to 113 places per 1000 persons aged 70 years or older in 2011 (DoHA, 2010b). A simple table is included to illustrate the shift of balance towards community care since 1986 (see Table 2.1).

A second recommendation to arise from the mid-term review was that ACAT assessment should apply to HACC services to ensure that the needs of high dependency clients are a priority. Although this recommendation was not actioned at the time, the intention is to integrate the Commonwealth Home Support Programme (CHSP; formerly HACC) with the Home Care Packages (formerly CACP and Extended Aged Care at Home (EACH) packages (see 2.2.4.3) from July 2018 (DoH, 2016). A single gateway for access to aged care services (*My Aged Care*) was established in July 2015 and helps to ensure that older adults with complex needs receive an ACAT assessment and referral for an appropriate level of care (Australian Government, 2015). Income testing was also applied to CHSP fees from July 2015 both to improve program sustainability and address the financial disincentives for

clients to move from the CHSP to Home Care Packages as their care needs increased (DoH, 2015).

Table 2.1 Adjustments in the benchmarks for aged care provision 1986-2011

	<b>1986</b>	<b>2011</b>
High care residential (nursing home)	40	44
Low care residential (hostel)	60	44
Low care community (CACP)	0	21
High care community (EACH)	0	4
Total places per 1000 persons aged 70 years or older	100	113

A third recommendation of the mid-term review was the redesign of recurrent funding to enable hostels to care for more dependent residents. This was achieved through the development of a single resident assessment instrument across hostel and nursing home residents, the Resident Classification Scale (RCS), and the introduction of ‘ageing in place’ whereby residents whose care needs increase from low to high level can continue to receive care in the same RAC facility. This flexibility is achieved through funding being tied to the assessed care needs of the client rather than to the services provided by the facility (SCRGSP, 2012).

The Review of the Structure of Nursing Home Funding in 1992-93 found that 11% and 13% of nursing homes did not meet fire safety and health authority standards, respectively, and 15% could not meet Nursing Home Outcome Standards without being rebuilt. Regulation of the number of aged care beds that attracted a government subsidy had resulted in high occupancy, limited competition and a lack of incentives for investment in RAC. This lack of investment was more noticeable in the nursing home sector. Hostels, by comparison,

provided a higher level of amenity and compliance with building standards as a result of accommodation bonds (essentially an interest free loan to the operator), paid by residents on entry, and daily fees often higher than those in nursing homes (Cullen, 2003). Structural reform of aged care to address these anomalies began with the *Aged Care Act 1997*.

#### **2.2.4.3 *Aged Care Act 1997***

The *Aged Care Act 1997* increased the emphasis on consumer contributions to capital funding for aged care. A proposal to extend market-driven accommodation bonds to include high level RAC facilities was overturned in November 1997, with the exception of “extra services” places which provided a higher level of amenity and hotel like services (PC, 2011). In place of accommodation bonds, a daily accommodation charge was applied to high level residential (nursing home) care (Cullen, 2003). Income testing of RAC subsidies was introduced alongside the RCS for residents in high and low care. These measures ensured that residents’ subsidies were commensurate with an assessment of the resident’s income and assets and were paid on the basis of the assessed needs of the individual.

The legislative framework of the *Aged Care Act 1997* incorporates a comprehensive list of the *Specified Care and Services* that residents are supposed to receive and provides consumers with information within which to frame their expectations and experiences of care (DoHA, 2010b). The introduction of accreditation of RAC services and improved access to complaints resolution procedures addressed ongoing concerns about the quality of aged care (Fine, 1999; PC, 2011).

Further community care adjustments were realised with the introduction of EACH and Dementia specific EACH packages (EACH-D) in 2001-02 and 2005-06 respectively (PC, 2011). EACH and EACH-D provide community-based care to older people who are assessed by ACATs as having complex high care needs, but who have expressed a preference to live at

home and are able to do so with assistance (SCRGSP, 2012). EACH and EACH-D packages substitute for RAC and provide an average of 18-22 hours of care per week. The type of care available is similar to a CACP (see 2.2.4.1), but to a higher degree, and may include nursing and allied health care. EACH-D may include care and services to manage behaviours associated with dementia.

### ***2.3 Older adults in hospital***

Historical accounts of the care of older adults in Australia provide important insights regarding the role of hospitals as a safety net for those who could not access a nursing home bed or could not afford the fees. As a counterpoint to the references to older people inappropriately occupying hospital beds, Cullen's account of the situation in the late 1960s described concerns that some nursing home residents required a level of care that could have been classed as hospital care (Cullen, 2003).

Despite early recognition of the cost of providing care for older adults in acute hospitals, it is only more recently that the role of hospitals as a safety net for older adults with dependency needs has been challenged in a sustained way. The following section reviews the situation of older adults in hospital in the 21<sup>st</sup> century with a specific focus on those who are unable to return home and require alternative accommodation in the short or longer term.

#### ***2.3.1 Hospital beds and aged care beds***

Understanding the relationship between the health and aged care systems is of particular importance given that people aged 65 years or over account for around 50% of all patient days in public hospitals (AIHW, 2010b). Interactions between health and aged care services are critical for the performance of both systems. For example, the number of operational RAC places can affect demand for public hospital beds, and throughput of older patients in acute and sub-acute care (e.g., rehabilitation, palliative care, sub-acute mental health, psycho-



geriatric services, and geriatric evaluation and management) has a substantial effect on the demand for residential and community aged care (SCRGSP, 2012). The residential care system has almost three times the number of places of the acute health system, but both systems maintain over 95% bed occupancy (Flicker, 2011). Rehabilitation is targeted to those assessed as having the potential for functional gain and takes place in a relatively small number of sub-acute beds. Regional disparities in the provision of rehabilitation and geriatric evaluation and management (GEM) resources, however, limit the extent to which these sub-acute beds act as a buffer between hospitals and aged care (Flicker, 2011; Giles, Halbert, Gray, Cameron, & Crotty, 2009). The waiting time for permanent RAC is dependent on the number of locally available beds and the fluctuation in these beds, due to creation and decommissioning of places. The relative dearth of high level beds in some regions, due to the inability to attract providers to build new beds, creates additional tensions within those regions (Flicker, 2011). Hospitals become a safety net to accommodate people with high-care needs who cannot be admitted to RAC in a timely manner (Travers et al., 2008).

The Australian Government funds RAC and prior to 1 July 2012<sup>3</sup>, the States funded public hospital care. These funding boundaries created incentives for cost-shifting between levels of government and contributed to fragmentation of patient care and blame shifting. The final report of the National Health and Hospitals Reform Commission (NHHRC, 2009) was one of many reports to identify the problems inherent in the split funding arrangements for health and aged care and the consequences whereby governments can make decisions that have fiscal and other impacts that extend far beyond their own programs (DoHA, 2010a).

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<sup>3</sup> On 2 August 2011 all states and territories signed the National Health Reform Agreement through which the Australian Government and states and territories have joint responsibility for funding public hospital services.

Cameron et al. (2010) point to particular tensions at the interface between hospitals and RAC with the States eager to shift older adults from acute to aged care (and the cost of care to the Australian Government) while the Australian Government was concerned that older adults are being admitted to RAC prematurely.

### ***2.3.2 Bed management***

To determine the critical steps in discharge planning for hospitalised patients who require residential care as well as the timing of each step, Whitehead et al. (2001) undertook a prospective audit of 100 consecutive referrals to an ACAT from an acute hospital. The study was conducted as part of Phase 2 of the National Demonstration Hospitals Program (1997-98), an Australian Government initiative aimed to improve hospital efficiency through improvements in bed management for all admissions (DoHA 1999). The study found that an average of 8.4 days elapsed before a decision to seek residential care was first recorded in the patient notes and a further 4.5 days elapsed before ACAT referral, 4.6 days before ACAT approval, and 9.7 days before a RAC bed became available. In total, 63% of patients were discharged to RAC, 11% died, 10% returned home and 16% went to another facility. The authors concluded that it takes time to determine the extent to which acute medical problems are remediable and that premature ACAT referral can lead to inappropriate decisions, as 10% of those referred for an ACAT assessment recovered sufficiently to return home (Whitehead et al., 2001). A subsequent study reported return home rates of between 7% and 9% in a similar population of older adults who had an ACAT approval for permanent RAC (Crotty et al., 2005).

In 2007-08, older adults in Australia were about twice as likely (relative risk 2.1) to be recommended to residential care if an ACAT assessment occurred in an acute hospital setting compared with an assessment in other locations (NDR, 2009). On the other hand, an ACAT

assessment in hospital is normally only performed when a return to home is already considered unlikely (Karmel, Gibson, Anderson, Wells, & Duckett, 2012).

### ***2.3.3 A national census of public hospital beds in 2002***

A census of all older people in public hospitals in Australia in 2002 found that one in five were staying longer than necessary because they had to wait to access rehabilitation or residential care (COAWG, 2004). This fuelled concerns about older people blocking access to hospital beds while other patients slept on trolleys in emergency departments because they were unable to transfer to a hospital ward (Australasian College for Emergency Medicine [ACEM], 2004; Braitberg, 2007). At the same time, concerns were raised that older people were being pushed down the path to permanent admission to RAC without having adequate time to recover from illness or injury (Whitehead et al., 2001) and that, once underway, the process of moving to RAC, which may involve the sale of property to fund aged care, is almost impossible to reverse (Australian and New Zealand Society of Geriatric Medicine [ANZSGM], 2011).

In 2001-02 more people aged 65 and over were admitted to permanent RAC from hospital (n = 21,800) than the 16,600 admitted from the community (AIHW, 2008). It was also found that respite beds in residential care were being used to provide short term care for older adults following a hospital admission and that more than one-half of older adults who moved from hospital to a respite bed had returned to live in the community at 12 weeks. About a quarter (23%) of older adults moving from hospital to respite care remained in care at 12 weeks (AIHW, 2008) and given the 63 day limit on respite care in a financial year (DoHA, 2006), are likely to have been waiting for a permanent RAC place.

### ***2.3.4 What happens to older adults in hospital?***

Hospital admission has a significant, frequently detrimental, effect on older adults (Lakhan et al., 2011). Many experience a decline in physical function. Illness and surgery may lead to delirium which is often slow to resolve and some affected persons will not return to premorbid levels of cognitive functioning. Finally, hospital admission can be a disempowering experience for older persons (Cornwell et al., 2012; Lothian & Philp, 2001).

Older adults often present to the emergency department with nonspecific symptoms such as incontinence, immobility, instability, acute delirium or confusion, making timely and accurate diagnoses more difficult (Kilshaw, 2008; Thomas & Brennan, 2000). A lack of physiological reserve, resulting in rapid onset of illness, delayed recovery and increased incidence of complications compared with younger patients, may also compromise an admission (Cooper & Mulley, 2009). Multiple medications add to the complexity of care needs of older adults and further increase the risk of harm from errors in care (Thomas & Brennan, 2000).

#### ***2.3.4.1 Decline in physical function***

Older persons admitted to hospital often experience a decline in functional status during hospitalisation (as assessed by ADL), leading to more severe disability at discharge (Covinsky et al., 2003). It is estimated that each day spent in bed results in a 5% decrease in muscle mass and the resulting loss of strength contributes to an increase in dependency (Creditor, 1993). Older adults with cognitive impairment are at particularly high risk of functional decline (Pedone et al., 2005), and both conditions increase the risk of institutionalisation (NDR, 2009).

#### ***2.3.4.2 Delirium and cognitive decline***

Up to 50% of older medical patients experience delirium (Siddiqi, House, & Holmes, 2006) and many have pre-existing dementia (Elie, Cole, Primeau, & Bellavance, 1998; Fick, Agostini, & Inouye, 2002). Delirium is a cognitive disorder characterised by acute onset, fluctuating course and disturbances in consciousness, orientation, memory, thought, perception and behaviour. Dementia, on the other hand, is characterised by insidious onset, normal level of consciousness and a slowly progressive decline in mental function (American Psychiatric Association [APA], 1994). Prevalence rates for dementia increase rapidly with age from around 3.4% of people aged 70-74 years to more than 21% of those aged 85-89 years (Access Economics, 2009).

The symptoms of delirium can persist for several months or longer. A systematic review and meta-analysis of studies of hospital patients aged 50 years or over with delirium found that one quarter had persistent delirium at 3 months, with the proportion only falling to 21% at 6 months. Moreover, the outcomes (mortality, nursing home placement, function, cognition) for patients with persistent delirium were consistently worse than the outcomes of those who had recovered from delirium (Cole, Ciampi, Belzile, & Zhong, 2009). A recent study of hospitalised older adults with Alzheimer's disease (AD) reported that cognitive deterioration following delirium proceeds at twice the rate in the year after hospitalisation compared with patients with AD who did not develop delirium, adjusting for dementia severity, comorbidity and demographic characteristics (Gross et al., 2012). Moreover, the study found that patients who had developed delirium maintained a more rapid rate of cognitive deterioration throughout a 5-year period following hospitalisation.

#### ***2.3.4.3 Disempowerment***

The term empowerment can be used in a variety of contexts. For the purpose of this brief discussion, it is defined as having a range of competencies which provide individuals with the

experience of controlling their lives as well as having a belief that they are mostly in charge of their lives (Tones, 1991). This definition provides for the interaction between individual competencies, experience and self-efficacy (mastery) through which the hospital environment and care processes can be experienced as either empowering or disempowering. Increasing older patients' exposure to controllable (or empowering) circumstances is associated with increased levels of activity and 'zest for life' (Langer & Rodin, 1976), while many aspects of hospital care such as interruptions to privacy and rest are uncontrollable in that they are likely to occur irrespective of the individual's response (Faulkner, 2001).

At a policy level, the emphasis has been on involving older patients in decisions about their care. In Australia, COAWG developed *Age-friendly principles and practices* on behalf of the Australian Health Ministers' Advisory Council (AHMAC) to provide a national framework for the care of older adults in hospitals. In addition to a requirement that older people receive information about their conditions and are involved in planning their care and treatment, the document called for expansion of the level of ambulatory services to "enable older people to receive the care they need in the least intrusive setting" (COAWG, 2005, p. 13).

In stark contrast to these ideals, there is a concern in the United Kingdom (UK) that the National Health Service (NHS) is failing to meet even the basic needs of older adults (Parliamentary and Health Service Ombudsman, 2011), while three high-level hospital inquiries in NSW in the period 2003-09 revealed a system where demands frequently exceed the capacity of hospitals to provide safe care (Van Der Weyden, 2009). In relation to the care of older people specifically, the Human Rights Commission has identified hospital-initiated Guardianship applications as an additional problem (Australian Human Rights Commission, 2012). Case studies reveal situations where older persons are excluded from participating in decisions about where they will live as well as decisions based on incomplete and flawed information.

In a health system where demand exceeds capacity it is perhaps unsurprising to find that the complex needs of the oldest and most dependent patients are unwelcome. Parke and Chappell (2010, p. 122) examine the ‘fit’ between different groups of older people and the hospital environment as a culturally-based service delivery system that “privileges activities that gain efficiencies.” They suggest that older adults who are functionally independent, cognitively aware and who can make a conscious decision to fit into the hospital environment are considered appropriate, while those who are hard to care for, require more time and are unable to function independently, quickly overstay their welcome. Drawing on interview transcripts with hospital staff in Canada, Parke and Chappell (2010) describe how designation of the older person’s status as ‘alternate level of care’ (the equivalent status in Australia is ‘maintenance care’; AIHW, 2012), leads to a further reduction in the attention received.

Writing in the Australian context, Hitchcock (2012) draws on her own experience to describe the difficulty in ‘selling’ the medically complex older person to medical teams who specialise in single organ systems. She describes how the older person in the emergency department (ED) fares poorly in a system designed to “sort, package and sell patients to [medical] teams” (Hitchcock, 2012, para. 10). Submissions to the Special Commission of Inquiry: Acute Care Services in NSW Public Hospitals (Garling, 2008), identified a range of derogatory terms used to describe the elderly in hospitals, including ‘gomers’ (get out of my emergency room), ‘turfs’, ‘sloughs’, ‘crumbles’ and ‘bed blockers’. One submission noted that some of these terms “entered the lexicon with the publication of Samuel Shem’s classic novel: *The House of God* in 1979” (Garling, 2008, p. 115).

In comparing estimates of the mortality associated with excess waiting times in ED in Australia (about 1500 deaths in 2003) to the national road toll, Hitchcock’s essay renders a sobering image; older persons in EDs who are “engaged in slow-motion crashes that we cannot see until the final metres, by which time it is too late” (2012, para. 4). These emotive

statements warrant closer attention. The figure of 1500 deaths drew upon a review prepared for the ACEM (Forero & Hillman, 2008), although the association between overcrowding and mortality has also been reported in Canada (Guttmann, Schull, Vermeulen, & Stukel, 2011). One of the primary studies cited in the review found that the excess mortality associated with ED overcrowding is concentrated in older patients (Richardson, 2006) which lends credence to Hitchcock's suggestion that older adults often die slowly and without fanfare in an overcrowded ED. This raises the discussion about inappropriate transfers of older adults from RAC at the end of life (see for example, Arendts, Reibel, Codde, & Frankel, 2010) that, while acknowledged, is beyond the scope of current considerations.

One response to the problem of increasing numbers of acutely unwell older adults with complex medical conditions presenting at ED has been the establishment of the short stay Medical Assessment Unit (MAU) in Australia and New Zealand (Jenkins, Thompson, & Barton, 2011). A recent survey of MAUs reported considerable heterogeneity of function and resources, consistent with the short time that units had been operational. In the majority of MAUs, the emphasis was on facilitating discharge rather than managing patients with high acuity of illness (McNeill et al., 2011). Although MAUs were also established to assist hospitals to meet 4 hour ED targets, all MAUs reported that between 10% and 19% of potential admissions required diversion to other medical units (McNeill et al., 2011).

The myth that older adults are responsible for overcrowded EDs has been debunked by several authors who assert that the root cause of the problem is hospital capacity (Forero et al., 2010; Richardson & Mountain, 2009). While the number of hospital beds per 1000 people in 2006-07 was similar to 1998-99 rates (2.65 vs 2.60 beds per 1000), the number of ED presentations almost doubled in this period (Richardson & Mountain, 2009).



Delayed discharge and poor availability of sub-acute and intensive home care for older patients who no longer require acute care but are not well enough to go directly home, can contribute to access block<sup>4</sup> (Newnham, Thompson, Jenkins, & O'Brien, 2009). The paucity of options for discharging patients led to the establishment of the TCP in Australia in 2005.

### 2.3.5 *'Moving them on'*

One of the consequences of regulating the number of aged care beds in Australia has been waiting lists for admission to RAC. The lack of available RAC beds, in turn, is identified as one of the reasons why the majority of admissions to RAC are through hospitals (Rosenberg, 2012). Older adults in hospital are accorded priority access to RAC because of the pressure for acute hospital beds (PC, 2011) and in 2012, more than 59% of Australians entering permanent high level RAC were assessed in hospital (DoHA, 2012).

Waiting times for ACAT assessments differ by location (hospital, RAC or community) and while the mean number of days from ACAT referral to first face-to-face contact for patients assessed in hospitals and RAC settings<sup>5</sup> remained relatively stable, at 5 and 14 days respectively from 2004-2008, waiting times for assessments in the community increased from less than 24 days to 31 days (NDR, 2009). Hospitalisation thus confers a distinct advantage in reducing the wait for services when there is a change in the older person's care needs.

The role of hospitals as a conduit to permanent RAC has changed over time. For example, the number of ACAT assessments undertaken in hospitals, expressed as a proportion of all ACAT assessments, decreased from 34.3% in 1995-96 to 28.9% in 2007-08. The national

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<sup>4</sup> 'Access block' refers to delays in admission of patients to hospital inpatient areas from emergency departments.

<sup>5</sup> Since July 2004, ACAT assessments are only required for residents in low level care being recommended to high level care in another facility.

figures, however, belie wide variation in the proportion of hospital-based ACAT assessments across jurisdictions in the early part of this period (range 10% to 44% in 1998-99). In 2007-08, variation across jurisdictions was within the range of 22% to 35%, indicating greater consistency in the proportions of hospital-based assessments over time.

For families struggling with the burden of informal care and decision-making about entry to RAC, hospitalisation of the older person has both advantages and disadvantages. The advantages include that hospitals provide timely access to an ACAT assessment compared with waiting times for an assessment in the community<sup>6</sup>. Additionally, hospital-based ACAT assessments routinely involve geriatricians and social workers, in conjunction with allied health staff, who make a recommendation about the most appropriate setting to meet the long term needs of the older person. This helps to distance the primary carer from the decision to institutionalise and indeed, health professional validation is widely cited as a key factor in the decisions of older adults and family members for entry to permanent RAC (Jorgensen, Arksey, Parsons, Senior, & Thomas, 2009; McAuley & Travis, 1997; Minichiello, 1987; Strang, Koop, Dupuis-Blanchard, Nordstrom, & Thompson, 2006).

Conversely, rationing of aged care beds can contribute to disempowerment as choice is limited and older adults and families feel under pressure to accept the first available bed. This sense of urgency may be compounded by hospital expectations relating to the number of aged care facilities at which families should 'list' (complete an application for admission) and urging families to consider all offers of a RAC bed in their preferred locality. Thetford and Robinson (2006, p. 4) argue that the rationing of finite resources impacts on "what individual people are entitled to and thus what choices they may have and the degree of control they

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<sup>6</sup> A submission to the Caring for Older Australians Inquiry reported waiting times of 6-9 months for ACAT assessments in Sydney (PC, 2011).

have over their situation.” Against this background, it is significant that the Audit Office of NSW published the following statement in 2006, affirming the rights of older adults to make a considered decision about their future care and accommodation.

*The older person applies for a place in RACFs of their choice after being approved by an ACAT. Each RACF, however, decides whether it will offer a place to an approved person. All approved clients are entitled to decline as many offers as they wish and to choose which RACF they want to live in. Neither the ACATs, nor the families, nor hospitals can force an RACF to take a client, or a client to accept an offer of a place in an RACF (NSW Health Audit Office, 2006, p. 15-16).*

### **2.3.6 Who makes the decision to move from hospital to RAC?**

A range of events and circumstances can lead older people into hospital and, from there, into RAC. Once in hospital, family members’ concerns about the older person’s safety and capacity to continue to live in the community may appear more salient due to rapid deconditioning as well as disempowerment in the hospital environment (Dwyer, 2005). Hospital staff are under pressure to finalise discharge arrangements at the earliest opportunity and once the process of placement has commenced, it becomes more difficult for the older person to speak up. Loss of confidence following a fall or other health event, and dependence on others to meet personal and instrumental care needs (e.g., paying bills), may contribute to ambivalence on the part of the older person about returning home. For these reasons it has been suggested that different assessment circumstances could lead to different decisions about the older person’s long term care needs (Magro & Ferry, 2005).

#### **2.3.6.1 The role of crises in transitions to RAC**

Despite acknowledgements that decisions about entry to RAC are often made at a time of crisis (Cheek & Ballantyne, 2001; Dellasega & Mastrian, 1995) and that relocation to RAC may precipitate a crisis (Chenitz, 1983), few studies have critiqued the role of hospitals as the primary site where final decisions to enter RAC are made. Chenitz (1983, p. 94) suggests that

hospitalisation can “upset the delicate balance carefully maintained by elders between their management of chronic illness and their dependency.” The author illustrates this point with a quote from an older woman describing how she begged her daughter not to call the ambulance following a fall at home. This reminds us that older adults may be finely attuned to the fragility of their status as community dwelling, and relatively autonomous, individuals. Chenitz also discusses the importance of legitimation (the finding of a plausible reason for the admission that allows elders to see themselves as other than a "typical nursing home patient"), for the process of acceptance of admission to RAC (1983, p. 94).

Older adults may be admitted to hospital as a result of a health crisis, or a crisis episode in caregiving (Sims-Gould, Martin-Matthews, & Gignac, 2008), with either potentially precipitating decision-making regarding entry to RAC. Taylor and Donnelly (2006) suggest that it is not the level of physical needs *per se* but how these relate to the level of confidence, family support and availability of publicly funded services, as perceived in ‘the crisis’, that determine the need for institutional care. From the perspective of health professionals, hospitalisation of an older adult requires urgent attention to the task of discharge planning and an assessment of risk relating to the reason for hospitalisation and comorbid conditions. For family members the crisis of hospitalisation may be seen as evidence that something needs to change (Strang et al., 2006). For many older adults, the factors leading to institutionalisation happen over time and the decision may be best seen as a process rather than an event (Pruchno, Michaels, & Potashnik, 1990). In the context of waiting lists for residential care however, hospitalisation makes the need for institutionalisation plausible for all parties and provides an opportunity to move near the top of the waiting list.

Moving into residential care from the community may also be precipitated by major changes in health, social support and ability to cope (Johnson, Schwiebert, & Rosenmann, 1994; Retsinas, 1991). Irrespective of the site of decision-making, the relinquishments of home and

caring responsibilities are major life events for older persons and carers respectively (McAuley, Travis, & Safewright, 1997; Nolan & Dellasega, 2000).

### **2.3.6.2 Decision processes**

Service providers tend to report that it is older people who make the decisions about accessing some form of care, yet describe a decision-making process that is out of their control and in which access to resources is restricted by professionals, presenting considerably limited choices (Bowers et al., 2009; Thetford & Robinson, 2006). Older peoples' expressed needs and wants are therefore filtered, or funnelled, by a range of professionals throughout the decision-making process (Power 1989). A "contradiction arises between the rhetoric of choice, control and independent living and a system driven by eligibility criteria, budgets and responsibilities" (Bowers et al., 2009, p. 20).

The decision-making processes involved in the movement of older people to RAC are not a well-researched area (Dwyer, 2005). It is usually other people (families, general practitioners, social workers) who are in control of decisions, arrangements and financial transactions at this critical period (Bowers et al., 2009; Edwards, Courtney, & Spencer, 2003; McAuley & Travis, 1997). Indeed, it is not unusual to find studies that consider only the carers' perspective in decisions to institutionalise older adults (Davies & Nolan, 2004; Hagen, 2001; McAuley & Travis, 1997; Noonan, Tennstedt, & Rebelsky, 1999; Penrod & Dellasega, 2001; Travis & McAuley, 1998).

*In terms of long-term care policy, and in service delivery, the voices of older people with high support needs are so quiet as to be practically silent, or indistinguishable from the other people who speak on their behalf (professionals, relatives, commissioners, policy-makers and politicians)... If you have no voice, you cannot exercise choice and control over your support, or indeed any aspect of your life.*  
(Bowers et al., 2009, p. 5)

### ***2.3.6.3 Care options for older adults with high care needs***

The decision to enter RAC reflects consideration of alternative options for care and accommodation, availability of desired services and an assessment of risk (of falls, medication misadventure, or an acute medical event). In the Australian context, relevant questions include the impact of restricted numbers of EACH and EACH-D packages on the options that are presented to older persons with high care needs who express a preference to remain living at home.

The SCRGSP (2012) reports a median elapsed time between ACAT approval and entry of 47 days for CACP and 65 days for EACH packages in 2010-11. However, the SCRGSP figures come with caveats and appear to exclude those who die or accept alternative services while waiting for a package. A submission to the Caring for Older Australians Inquiry (PC, 2011) reported waiting times of 6-18 months for CACP and EACH packages in North Sydney. A hypothesis that ACAT recommendations for CACP and EACH packages are responsive to restrictions in the number of funded packages and local demand is supported by the 2009 report on the Aged Care Assessment Program which noted that “increases in recommendations for packaged care are likely to be a response to the release of new packages” (NDR, 2009, p. 124). For this reason, the announcement of significant growth in the number of home care packages from 1 July 2012, and unprecedented growth in high care packages in particular (DoHA, 2012), were well received by the aged care sector.

Most EACH and EACH-D recipients rely on carers to assist with their daily needs. Among EACH-D clients in 2009, 94% had carers, four-fifths of whom were living with the recipient. Among EACH clients, 88% had carers and three-quarters were living with the recipient (AIHW, 2009). The lack of an informal carer increases the likelihood of admission to RAC (NDR, 2009).

### ***2.3.7 Trends in the movement of older adults from hospital to RAC***

In the absence of routine linkage of hospital and aged care datasets, information concerning trends over time and the impact of policy initiatives on the movement of older adults between the hospital and aged care sectors is patchy. In 2010-11, there were 551,670 separations from Australian hospitals (public and private) of adults aged 85 years or over, of which 31,913 were discharges to RAC (including admission to respite and permanent care but excluding patients returning to their usual place of residence), and there were 22,127 deaths (AIHW, 2012). These figures suggest that even in advanced age, only a small proportion of older adults move directly from hospital to RAC. In 2009-10, the total entry to permanent RAC was 57,937 people (AIHW, 2011b).

Despite criticism of the ageism implicit in terms such as “bed blockers” (Flicker, 2011; Howe, 2002) and recognition that older adults are core business for hospitals (DoHA, 2005a), moving older adults from hospital to alternative care settings continues to be pursued as the solution to access block in hospitals (Schriever, 2011). Sustained policy initiatives at local state and national levels to provide more appropriate care for long stay older patients in hospitals are discussed in Section 2.4.

### ***2.3.8 Reduced survival in those who move from hospital to RAC***

Older people admitted to permanent RAC from hospital have reduced survival times compared with all admissions to permanent RAC. Using survival analysis with 2001-02 data, the AIHW estimated that 25% of people admitted to permanent RAC from hospital would die within four months compared with an estimated survival time of just over seven months for all admissions (AIHW, 2008). Level of care needs on admission to RAC is reported to be the most important variable in predicting survival time although health conditions are also influential (Karmel et al., 2012). More than 59% of people entering permanent high care are assessed in hospital and, of this group, 34% die within six months of entry (DoHA, 2012).

## ***2.4 Care of older Australians at the hospital-aged care interface***

COAWG was established by AHMAC in 2001 to improve the interface between acute hospital care and community and RAC services to ensure older people received timely access to appropriate care.

### ***2.4.1 National Action Plan 2004-2008***

In 2004, COAWG developed a National Action Plan. Under the *Pathways Home Program*, the Australian Government provided funding to increase rehabilitation and step-down care capacity to support older adults in making the transition from hospital to home. A major focus for all jurisdictions was the roll out of the jointly funded *Transition Care Program* (TCP), beginning in 2005. This program was introduced to assist older people after a hospital stay, providing short-term support and active management to optimise their functional capacity (COAWG, 2004). Additional funding was provided under the *Long Stay Older Patient's Initiative (LSOPI)* to address issues associated with long-term aged care in rural hospitals as well as those associated with care needs better able to be met outside the hospital system (SCRGSP, 2012).

## ***2.5 Transition Care Program***

The TCP targets older patients at the conclusion of a hospital episode who have been assessed as eligible for at least low-level RAC and who would benefit from a period in a non-hospital environment to optimise their functional recovery (DoHA, 2005b). The program is designed with specific focus on reducing long stay older patients through managing the interface between hospital and home, as well as RAC. A secondary focus is to avoid premature admission to RAC by improving the recovery process for the older person and providing more time to decide on the appropriate setting to meet long term care needs. This flexibility is achieved through the program being delivered as a package of home care and



therapy services, or in an institutional setting, most often using specially designated RAC beds. Recipients of TCP are also able to transfer between institutional and home care as their care needs change. Unlike intermediate care programs in the UK, the Australian program does not include a hospital avoidance strategy.

A major goal of the TCP is to optimise older persons' independence and functioning and most TC services provide a range of physical, occupational, speech and dietetic therapies. TC is time-limited, with the median length of stay in 2008-09 being 7 weeks (AIHW, 2011a). Most TC in Australia is delivered in the community and providers are a mix of health and aged care organisations.

### ***2.5.1 TC outcomes***

There were 12,232 completed episodes of TC in 2008-09, including 7,874 females (64.4%). Women tended to be older, with 40.7% aged at least 85 years compared with 30.4% of men. Half of all discharges were to the community, including 24% with HACC services, 11% with a CACP, EACH or EACH-D package and 15% without community care assistance. Fewer than one in five recipients of TC (19%) were discharged to RAC, although 13% went to high care. More than one in five (22%) returned to hospital and 2% died (AIHW, 2011a).

The proportion of TC recipients who went into RAC in 2008-09 varied considerably across jurisdictions, from 3% in Queensland to 45% in Victoria. These differences reflect disparities in the distribution of sub-acute services (such as geriatric evaluation and management), post-acute care and aged care options and thus the context in which the TCP operates. In Victoria for example, older adults could access physiotherapy, occupational therapy and personal care services in their homes following a hospital admission through existing subacute ambulatory care programs, before the TCP was established (Victorian Department of Human Services [DHS], 2003). As a consequence, Victoria has a higher proportion of TC places that are

provided in residential settings to meet the needs of older adults with higher levels of disability, who are more likely to require permanent RAC (AIHW, 2011a).

### ***2.5.2 Trends in long-stay older patients***

The performance of government services, including health and aged care, is assessed and reported on an annual basis. Key performance measures across all government services include considerations of equity, efficiency and effectiveness and align with National Agreements such as the *National Healthcare Agreement 2012*.

The long term objective of governments related to aged care is that “older Australians receive appropriate high quality and affordable health and aged care services” (Council of Australian Governments [COAG], 2012, p. A-4). One of the performance measures related to this objective is the “number of hospital patient days used by those eligible and waiting for residential aged care” (COAG, 2012, p. A-4). This is an indicator of governments’ objective to minimise the incidence of long term aged care in public hospitals and improve patient flow through the hospital system.

In 2007-08, the proportion of all hospital patient days (for overnight separations only) used by patients who were waiting for RAC was 14.6 per 1000 patient days (COAG Reform Council, 2012) and in 2010-11 the figure had fallen to 11.7 per 1000 patient days (AIHW, 2012). The national rates, however, obscure significant differences across jurisdictions with rates in South Australia of 26.2 per 1000 patient days in 2009-10 compared with 3.8 per 1000 patient days in Victoria. Since inception of *LSOPI* (described in Section 2.3.1) the number of long stay older patients in hospitals has significantly declined, from around 2,100 in 2002-03 to around 1,400 in 2009-10 (DoHA, 2012).

### 2.5.3 *Trends in RAC use*

It is estimated that the demand for community and RAC services for people aged 70 years or over will more than treble by 2056 (SCRGSP, 2012). The likelihood that a person will enter permanent RAC in their lifetime is increasing because people are living longer, leading to a larger proportion of people living to an age where they require care services. The age of entry to RAC, however, has been steadily increasing over the last decade for both men and women and, if the trend continues, will result in demand for services not increasing as rapidly as the population is ageing (DoHA, 2011).

Between 1 July 2009 and 30 June 2010 there were almost 58,000 admissions to permanent RAC. The majority of residents (74%) admitted to permanent care were aged 80 years and over, with those aged 85 to 89 years accounting for 29% of admissions. By comparison, only 64% of people admitted to permanent RAC were aged 80 years and over in 1998-99. While the age of entry to RAC has been increasing, usage rates per 1,000 population aged 80 years or over have declined markedly. Usage rates in the 85 years and over age group dropped from 263.2 per 1,000 in 2000 to 229.7 per 1,000 in 2010, and in the 80–84 years age group, usage rates fell from 90.5 to 75.5 per 1,000 population. Consistent with increasing longevity, the average completed length of stay in RAC increased from 131.3 weeks in 1998-99 to 145.1 weeks in 2009-10 (AIHW, 2011b).

A preference to remain living in the community and growth in the number and range of home care and post-acute programs are likely to have contributed to the decline in usage rates of permanent RAC (per 1,000 persons aged 80 years or older) reported above. At 30 June 2010 there were 43,300 CACP, 8,167 EACH and 2,698 TC places, compared with a total of 13,896 CACP in June 1999 (AIHW, 2011b). EACH and TC places did not exist in 1999.

#### ***2.5.4 Trends in community care provision***

In 2010-11 there were 46,126 operational CACP and flexible community places<sup>7</sup> (SCRGSP, 2012), indicating little growth in the period June 2010 to June 2011. However, significant growth can be seen in the number of high care community places, with 12,345 EACH, EACH-D and high level CDC places (see Chapter 3) at 30 June 2011, compared with just 8,167 at June 2010 (SCRGSP, 2012).

Despite funding more than 59,900 home care (CACP, EACH and CDC) packages in 2012, “demand for these packages far outstrips supply, leaving many older Australians forced to wait for the care they need” (DoHA, 2012, p. 29). The 10 year aged care reform package announced on 20 April 2012 provides for an additional 84,000 packages over the next decade, including more than 29,000 high care packages (DoHA, 2012). Based on these figures the number of high care packages as a proportion of all home care packages will increase from about 20% to more than 34% over the 10 year reform period, leading to intensification of care. As in the UK, home care services will need to adapt to provide for higher levels of disability among their users (Rostgaard, Timonen, & Glendinning, 2012).

With respect to the service provision ratio, the number of operational places (residential and community) will increase from 113 per 1,000 of the population aged 70 years and over, to 125 places. Within this overall target, the number of community places will increase from 25 to 45, with a corresponding reduction in residential places. Alignment of care needs and funding across community and residential care will be facilitated by refinement of the Aged Care Funding Instrument (ACFI) as a single assessment tool for publicly funded aged care services (DoHA, 2012).

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<sup>7</sup> The number of flexible community places includes TCP and other small programs.

### **2.5.5 Challenges in assessing pathways to RAC**

An examination of the movement of older adults from hospital to RAC in Australia requires linkage of health and aged care datasets that is not routinely undertaken. The final report of the Inquiry into the Care of Older Australians expressed concern about the lack of publicly available data and policy-relevant evidence in the area of aged care (PC, 2011). Linked data sets would enable a more informed assessment of the impact of policy changes across jurisdictions and other policy areas. Specifically,

*...how the care needs of older people change over time; how these changes trigger interactions between different parts of the aged care system (and between the aged care system and the broader health and community welfare system); and how efficiently and effectively the care needs of older people are being met (PC, 2008, p. 90).*

## **2.6 Summary**

This chapter has presented an historical review of aged care, including incremental changes to the proportion of community and RAC places and the introduction of a new program of post-hospital care for older adults, TC. Chapter 3 considers the introduction of CDC in Australia and lessons from the international experience. A conceptual framework is advanced, based on the concepts of choice and voice as they relate to CDC as well as personalisation and marketisation. Each of the empirical studies that comprise the thesis can be described as HSR. Chapter 3 therefore examines methodological aspects of the study designs that are used in Chapters 4 through 8.

## CHAPTER 3

### *OLDER ADULTS AS CONSUMERS OF AGED CARE*

#### **3.1 Introduction**

Chapter 2 described the care of older Australians, including the development of new forms of care specifically designed to avoid premature entry to RAC from a hospital bed. The current chapter provides insight into a range of initiatives that aim to provide older adults with greater choice and control over their care. First, historical and international perspectives on CDC are presented before attention is directed to the way in which CDC has been conceptualised in the Australian context. Second, conceptual and methodological frameworks are provided for the empirical studies comprising this thesis.

#### **3.2 Historical and international perspectives on CDC**

##### **3.2.1 An overview**

Doty, Mahoney and Simon-Rusinowitz (2007) trace the origin of CDC to disability rights activists in the US in the 1960s and 1970s who asserted the importance of people with disabilities having the right to employ, train, supervise and dismiss personal care attendants as well as schedule services to meet their specific needs and preferences. This was termed the *Independent Living Model* and subsequently renamed *Consumer Directed Personal Assistance Services* (Doty et al., 2007). In both the UK and US, CDC emerged as an alternative to agency managed care in disability services and was later expanded to include older adults generally (Alakeson, 2008; Benjamin, 2001). In Australia, a model of CDC was specifically designed for older people (KPMG, 2012) and implemented as part of a broader program of aged care reform.

A plethora of terms have been used to describe policy initiatives that share the common aim of increasing the choice and control that clients can exercise over the social care support and

services they receive while also seeking to contain costs. In the UK the terms *Direct Payments* (DP; Glendinning, Halliwell, Jacobs, Rummery, & Tyrer, 2000) and *Individual Budgets* (IB; Glendinning et al., 2008) differentiate models in which funds are managed by the client who purchases from a list of approved care services (DP) from those in which funds may be managed by a provider who negotiates the services to be purchased (IB). In the US the *Cash and Counseling Demonstration and Evaluation* (CCDE) program describes a hybrid model in which clients may receive assistance in managing an individual care budget and employing care staff (San Antonio et al., 2010).

In Australia, the preferred term is *CDC* (Aged and Community Services Australia [ACSA], 2008; Bruen & Rees, 2007; DoHA, 2012). CDC was piloted at a local level in disability services in Victoria (Ottmann, Laragy, & Haddon, 2009), and first trialled nationally in home care packages for older adults (KPMG, 2012). The term CDC was initially applied to pilot studies of a personal aged care subsidy held by home care providers together with counselling to increase older adults' selection of services (from the one provider) to meet their needs (KPMG, 2012). Older Australians receive regular financial statements that detail expenditure of their aged care subsidy and from February 2017, subsidies will be allocated to individuals, enabling transfer across providers. In Australia the terminology has remained consistent while the model of care has evolved.

Progressive implementation of CDC was designed to enable aged care providers to adjust to the new approach to care, reduce their reliance on government funding and prepare for the introduction of competition in aged care. It has also provided time for clients and family carers to become familiar with the cost of aged care services and the purchasing power of their subsidy.

### 3.2.2 *CDC in Australia*

Driven by the fiscal imperative to delay admission to RAC and client dissatisfaction with traditional home care services (Howe, 2003), attention in Australia turned to alternative models of aged care delivery that provide older adults with greater control over their daily lives and more flexibility in the services they receive. In 2010 CDC was introduced as an alternative to a defined number of low and high care community packages (CACP, EACH and EACH-D) and carer respite. However, a shortcoming of the Australian pilot studies (KPMG, 2012) was the failure to randomly assign participants to CDC or usual care.

Notably, high care users and their informal carers were the strongest advocates of CDC in accord with the finding of Moran et al. (2013) in the UK that the benefits of CDC accrue with the increasing value of the personal subsidy. This finding may have additional salience in the Australian context however, as EACH and EACH-D packages substitute for high level RAC.

In March 2012 the Australian Government (DoHA, 2012) announced two additional home care packages to bridge the gap between low care (CACP) and high care (EACH). This initiative provided a more transparent and standardised alignment of resources and care needs, discouraging providers from distributing resources across more users than packages. Specification of personal budgets also provided older adults with information about the pricing of the services they received and to choose between services offered by the provider.

Other announcements in 2012 included an ongoing commitment to CDC for community care and a proposal to undertake a pilot of CDC in RAC in 2012-13 (DoHA, 2012). This initiative aligned with developments in the US (Rahman & Schnelle, 2008) and the UK (Bowers et al., 2009) in the incorporation of CDC principles in institutional care whereby residents have greater autonomy and choice about the care they receive. It is also an example of how the term CDC is used as a philosophy of care, embodying 'care entitlement', rather than being limited to 'cash-for-care' (KPMG, 2014). Although the Australian pilot of CDC in RAC did



not eventuate (Belardi, 2015), a study of the effectiveness of interventions to assist RAC providers to implement CDC has received funding from the Dementia Collaborative Research Centres (Keast, 2016).

### **3.2.3 *Models of CDC***

Some of the better known interventions that embody CDC principles include DP, IB and CCDE as described in 3.2.1. The scope for consumer direction within each model varies widely and a simple typology is presented to illustrate the key characteristics.

Models of CDC vary in relation to:

- Choice of who provides services, and when and how services are provided (e.g., approved provider vis-à-vis family carer or other employee);
- Choice in how funds are received (DP vis-à-vis provider as fund holder);
- Choice in how funds are expended (approved service vis-à-vis any service that may enhance quality of life);
- Option to purchase financial and case management services.

Notably, when recipients of the Veterans Home Care (VHC) program were offered a choice of provider, the majority elected to remain with their existing provider (Howe, 2003).

Aged care providers in Australia have expressed interest in consumer directed models of care similar to those adopted internationally (PC, 2008; Tilly & Rees, 2007; UnitingCare Australia, 2009) whilst successive reviews of aged care have recommended deregulation and a shift in funding to consumers that would enable older Australians to choose between using their care subsidy for community or residential care (Hogan, 2004, 2007; NHHRC, 2009; PC, 2011a). This option is further described in 3.2.6.

### ***3.2.4 CDC and aged care***

Concerns have been expressed internationally and in Australia about the acceptability of CDC to older consumers and their capacity to manage their own support arrangements (Howe, 2003). Willingness to engage with CDC models has generally been lower among older adults than among younger age groups (Tilly & Wiener, 2001). While cognitively impaired older adults who are supported by an informal carer are able to benefit from models of CDC (Tilly & Rees, 2007), CDC is unlikely to reduce the risk of admission to RAC of persons with cognitive impairment who do not have an informal carer (Howe, 2003).

Evaluations of CDC undertaken in the US (Doty et al., 2007) and UK (Glendinning et al., 2008) have specifically examined the expectations and experience of CDC of older adults (Moran et al., 2013; San Antonio et al., 2010). The CCDE projects in the US were based on a liberal model of CDC that enabled users to expend their budget on a broad range of goods and services, including payments for informal carers. A robust evaluation (with random allocation to CCDE or usual care) found that across all age groups, those assigned to CCDE were more likely to receive paid care, reported greater satisfaction with their care, and had fewer unmet needs compared with the usual care (Medicaid services) group (Carlson, Foster, Dale, & Brown, 2007; San Antonio et al., 2010).

By contrast, the evaluation of the IB pilot projects in the UK (2005-07) found higher levels of psychological ill health, lower wellbeing and worse self-perceived health in older persons who were randomly assigned to receive IB, compared with those assigned to conventional services (Moran et al., 2013). The IB pilots were also designed to allow resources to be spent more creatively than the former DP model deployed in the UK and older adults could elect not to manage their own budget, if desired. IBs could also be used to purchase support from family and friends and, superficially, there were few apparent differences between the IB and CCDE pilots. However, the value of IB was consistently less for older adults compared with

younger disabled persons with similar restrictions on their ADL. The researchers concluded that “the potential benefits of IBs ... can only be fully realized with a sufficiently large IB” (Moran et al., 2013, p. 20). Notably, some IB support plans were still not in place six months after randomisation, which impacted on the assessment of outcomes. However, social care outcomes were better for older adults for whom the IB support plan had been implemented.

### **3.2.5 A discourse of choice**

CDC has both proponents and critics and can be viewed as a philosophical (KPMG, 2012) or ideological (political) shift in the way government funding for care is devolved (Howe, 2003). Critics argue that choice and consumerism have become dominant in policy discourse across welfare states such as the UK, US, Canada, Australia, Denmark and Sweden (Moffatt, Higgs, Rummery, & Jones, 2012) and divert attention from greater targeting and means-testing of services for the purpose of cost containment (Da Roit & Le Bihan, 2010; Glendinning, 2012). Despite the promise of user choice, only those with ‘substantial’ or ‘critical’ support needs are able to access publicly-funded home care in the UK (Glendinning, 2012; Rostgaard, Timonen, & Glendinning, 2012) and small CDC budgets are expended on personal care with little money left for social or leisure activities (Moran et al., 2013).

With most developed countries experiencing a substantial increase in the size of the population aged 60 years or older (United Nations, 2015), CDC has an innate appeal to governments because of the potential reduction in administrative costs compared with agency-managed care (PC, 2011b). Actual savings depend on any discount that is applied when monetary values are assigned to CDC budgets and the amount (cost) of support that is provided to assist users to manage their budget and services. A PC document reports that, in Germany, “cash benefits are roughly half the value of the service benefit amount, are the predominant form of benefits for home care, and are mostly spent on informal carers” (PC, 2011b, p. D19). For the purpose of this discussion, it is sufficient to note that, in the UK,

researchers have identified cost benefits for younger people with disabilities but not in older age groups (Glendinning et al., 2008; Woolham & Benton, 2012).

Variation with regard to the counselling and support that users can access, monitoring of expenditure and whether informal carers can be paid, limits the generalisability of findings concerning the impact of CDC. Rigorous evaluation of social care programs is complex and costly and authors have commented on the modest evidence base for CDC and the disjunction between rapid program diffusion and (slower) accumulation of research evidence on program impact (Benjamin, 2001; Glasby, 2012).

In Australia, 'ageing in place' provides an example of policy that focuses on consumer choice while diverting attention from greater targeting (higher intensity) of RAC. The *Aged Care Act 1997* aimed to promote ageing in place through the "linking of care and support services to the places where older people prefer to live" (SCRGSP, 2012, p. 13.95). The Act served the dual purpose of responsiveness to user preferences (particularly beneficial in enabling couples to remain in the same service when the care needs of one spouse increased) as well as reforming the profile of residents in RAC. In 2011, 78.5% of all RAC residents were assessed as having high care needs (DoHA, 2012), despite the provision ratio of equal numbers of high and low care RAC places per 1000 population. In this way, ageing in place fulfils economic rationalist objectives while also providing older adults with an opportunity to receive additional services as their care needs increase without having to relocate.

### ***3.2.6 A cash entitlement for RAC***

Ideas about separating the cost of aged care from that of accommodation and living expenses associated with RAC were first expressed in the interim report of the NHHRC (2008). It was proposed that accommodation and living expenses are individual responsibilities, while care entitlements should be based on assessed needs, rather than the setting in which care is

received. Subject to alignment of assessments, care subsidies and user payments across community and RAC, there would be greater scope for older persons to choose between using their care subsidy for community or residential care (NHHRC, 2008). The intent of the proposal was that older persons with high care needs be given greater choice between community and residential care and that existing low care RAC places be converted to community places (NHHRC, 2009 p. 22). A further proposal was that older persons in receipt of community care should be given the option of determining how resources allocated for their care and support are used. As described in 3.2.2, the latter proposal was implemented in 2010, with the introduction of CDC as an alternative to CACP and EACH packages.

The NHHRC report went beyond international models of CDC in suggesting that separation of care and accommodation costs of RAC would provide a real choice between entry to RAC and remaining in the community. Several documents have since expanded on these ideas, which are more clearly described as an entitlement to aged care funds commensurate with the level of assessed need for aged care services (National Aged Care Alliance, 2012; PC, 2011b). Arguably EACH and EACH-D packages (the equivalent is a Level 4 Home Care Package) already provide older Australians with a choice between community and residential care, within the limitations of a capped supply. In 2008-09, only 22% of people approved for an EACH package were admitted to a package (PC, 2011b).

Despite planned growth in the provision of home care packages, a 2015 survey of aged care providers reported low demand for Level 1 packages and unmet demand and significant waiting lists for Level 4 packages (Egan & O'Keeffe, 2015). This is consistent with official figures that report occupancy levels of 62.1% for Level 1 packages compared with 92.1% for Level 4 packages in 2014-15 (Aged Care Financing Authority [ACFA], 2016). At June 30, 2014 there were approximately 72,000 home care packages with a target of 100,000 operational home care packages by 2017 and a further 40,000 packages by 2022 (KPMG,

2015b). If this target is achieved, and with funds following the consumer from February 2017, waiting lists for Level 4 packages may decline. Consumers with sufficient means may also choose to purchase non-subsidised services to complement (or substitute for) subsidised services (Belardi, 2015; KPMG, 2015b).

### ***3.3 A conceptual framework***

This section outlines philosophical and theoretical constructs relevant to models of CDC both in Australia and internationally. Articulation of CDC principles in Australian legislation is acknowledged and relationships between empowerment (voice, choice, autonomy and person-centred care), personalisation and marketisation (competition, deregulation, co-contribution and discounting) are considered. Figure 3.1 illustrates the relationships between these constructs that are further described in the following sections.

#### ***3.3.1 Philosophical perspectives on CDC***

In Australia, CDC is described as a ‘philosophy and an orientation to service delivery’ (ACSA, 2010; DoH, 2015a; KPMG, 2012, 2014; Rees, 2010). In the US, Phillips and Schneider (2007) identified a ‘philosophy of consumer empowerment’ as the basis of the *Cash and Counseling* model of CDC whereas in the UK, Glasby describes a ‘philosophy of personalisation’ as underpinning the development of DP and IB (Glasby, 2012).

As detailed in 3.2.1, disability rights activists were instrumental in the development of models of CDC that would enable people with a range of impairments to exercise choice and control over the way care was provided according to a ‘philosophy of the Independent Living Movement’ (DeJong & Hughes, 1982). The social model of disability (Oliver, 1986) posits that social disadvantage (i.e. barriers to participation as equal citizens) experienced by disabled people largely results from a failure of society to accommodate difference

(Dickinson & Glasby, 2010). In this model, disability is viewed as a social construct rather than an inevitable result of impairment (Hosking, 2008).

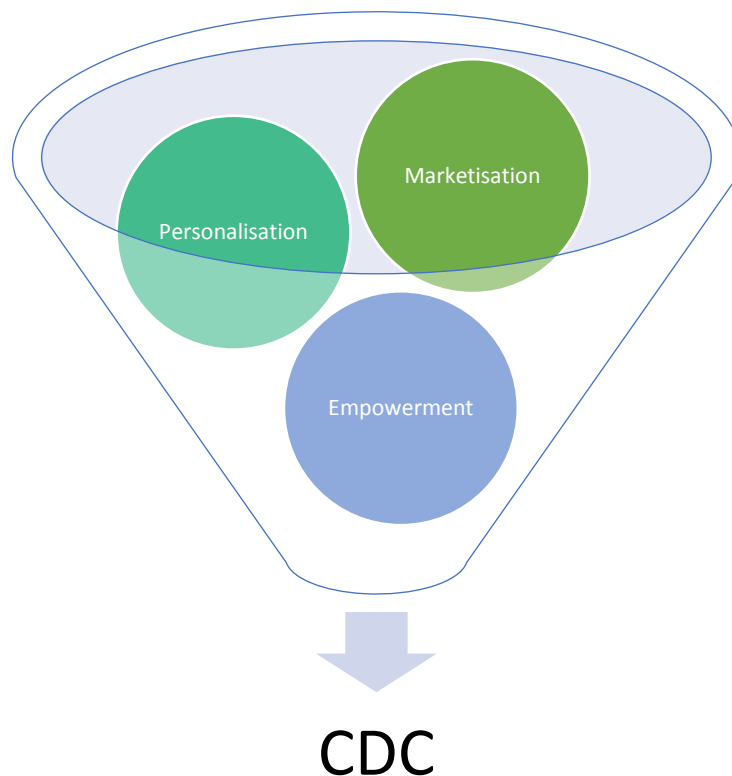


Figure 3.1 Conceptualising CDC in home care in Australia

### 3.3.2 *User rights*

Guiding principles for CDC were articulated in 2010 (ACSA, 2010) and in July 2015, amendments to the *User Rights Principles 2014* included provisions for recipients of home care packages delivered on a CDC basis (DoH, 2015a). *The Charter of Care Recipients' Rights and Responsibilities—Home Care* (Federal Register of Legislation, 2015) identifies CDC as providing recipients with specific rights in three areas: (i) choice and flexibility, including the right to make decisions relating to their own care (ii) the right to receive care and services appropriate to meeting their goals, preferences and assessed needs; and (iii) an individualised budget and monthly statements of available funds and expenditure. However,

the effectiveness of this legislative instrument in securing older persons' rights to choice and flexibility is not known. Similar charters of care recipients' rights in aged care in Australia have not necessarily translated into practice with evidence of care that contravenes both recipients' rights and nurses' ethics (Tuckett, 2005).

### ***3.3.3 Philosophy of consumer empowerment***

Constructs associated with empowerment include voice and choice, autonomy and person-centred care. Overlap between these constructs is highlighted in the following sections.

#### ***3.3.3.1 Voice and choice***

Users of aged care services are frequently described as 'recipients' (DoH, 2015b), a term that denotes passivity. With progressive implementation of CDC in home care services in Australia, the term 'consumers' has become commonplace (DoH, 2015a) and exemplifies the changed relationship between the individual and those who provide formal care.

There is debate concerning the extent to which care can be commodified (Claassen, 2011; Rummery & Fine, 2012). Some have argued for the development of a 'citizenship' approach to care (Rummery & Fine, 2012; Russell & Kendig, 1999) that recognises the rights of older people to express their views about the way care is constructed at policy level, and negotiated between individuals and care providers. A citizenship approach contrasts with reports that older people are generally grateful for care that is provided and reluctant to express dissatisfaction (Bowling, 2002) or to voice their needs and preferences (Vamstad 2016).

Building on earlier work conducted by the Joseph Rowntree Foundation (e.g., Bowers et al., 2009), Katz et al. (2013) made an important contribution to the literature by undertaking research with people with high support needs, most of whom were aged 85 years or older and had multiple impairments. A key finding was that some older persons who would have preferred more social engagement did not know "what they could ask for without impacting



their relationship with the person who was their key to the outside world” (Katz et al., 2013, p. 59). This work highlights how older people limit their own agency and aspirations in relationships with formal and informal carers.

As described in 3.2.1, home care packages in Australia will be portable from February 2017 and consumers will be able to decline services that do not meet their needs and preferences, and transfer to another service provider. In articulating the mechanisms that are available to consumers when service providers do not meet their needs, Hirschman (1980) uses the terms ‘exit’ to describe the option to leave in favour of another service provider and ‘voice’ as the option to try to effect change service provision through communication. With reference to consumer experiences of home care services in Sweden, Vamstad (2015) reports that many older people do not understand the purpose of choice of service provider and are reluctant to employ ‘exit’ or ‘voice’. Given the circumstances in which older people seek home care, many lack capacity to compare providers and to make a choice that will maximise individual benefits (Vamstad, 2015). Service providers interviewed as part of the evaluation of the IB program in England (2005-2007) reported similar concerns about older adults’ capacity and motivation to direct their own care on entry to the IB program (Moran et al., 2013).

Disparity in the value of individual budgets for older persons compared with younger disabled persons with similar ADL restrictions has been noted in the US and UK (Kane, Priester, & Neumann, 2007; Moran et al., 2013) and is attributed to more effective advocacy by younger people with disabilities (Kane et al., 2007) and the ‘collective voice’ (Barnes & Bennett, 1998) of the Independent Living Movement. In the UK, older adults randomised to the IB group (including those who elected to receive cash in lieu of services) found choice to be limited by resource allocation. After deducting the cost of personal care little was left to expend on activities to enhance quality of life and social wellbeing (Moran et al., 2013).

In Australia, the removal of age criteria for access to home care packages opens a pathway to integration of age and disability services and a common assessment and resource allocation system. While a standardised system of needs assessment could improve equity across population groups, increasing marketisation of care will reproduce social inequity. Affluent individuals will be able to choose from a broader range of care options.

### **3.3.3.2 *Autonomy***

Collopy (1988) differentiates between *decisional autonomy* (the ability and freedom to make decisions without coercion or restraint) and *executorial autonomy* (the ability and freedom to implement personal choices). Notably, the desire of older persons to be self-governing is independent of their ability to implement personal choice. CDC aims to empower older persons to make decisions about activities for which they need assistance. This is in contrast to agency-directed care where decisional autonomy is easily abrogated when the ability to implement personal choice is diminished (Collopy, 1988).

### **3.3.3.3 *Person-centred care***

The notion of person-centredness has diverse meanings depending on the particular context to which it is applied (Leplege et al., 2007). Person-centred care generally refers to an approach that attends to the uniqueness of each individual as well as practices that are oriented to the needs and preferences of the user, rather than the practitioner. Engagement in decision making is also posited to be a key attribute of person-centred care (Wilberforce et al., 2016).

Person-centredness has been interpreted in relation to general medicine (Stewart et al., 2000), nursing (Radwin & Alster, 2002), rehabilitation (Sumsion & Law, 2006) social care (Holburn, Jacobson, Vietze, Schwartz, & Sersen, 2000), and in the context of care for people with dementia (Kitwood & Bredin, 1992) and learning disabilities (Williams & Grant, 1998). While it is generally accepted that person-centredness originated in psychoanalysis (Rogers,

1949), other theoretical influences include the biopsychosocial model (Engel, 1977), social role valorisation (Wolfensberger, 1983), social constructionist perspectives of ageing (Estes & Binney, 1989) and the social model of disability (Oliver, 1986).

### ***3.3.4 Philosophy of personalisation***

Prior to the introduction of DP in the UK, adults with disabilities were assessed by professionals and assigned to services on the basis of availability (Dickinson & Glasby, 2010). This system of care was described as ‘bureau professionalism’ (Lymbery, 2014), with an emphasis on the role of the state in mediating the relationship between professionals and clients. The term personalisation was used in the UK to describe the shift from bureau professionalism to a direct relationship between the state (as funder) and disabled people as fund holders, employers and consumers (Glasby, 2012).

Personalisation is described as a shift of power from professionals to consumers through the allocation of personal budgets (Gridley, Brooks, & Glendinning, 2014). The term is also used to denote a shift from service recipients to citizens, co-production of services and self-determination (Dickinson & Glasby, 2010). In many ways, personalisation is synonymous with CDC, with both terms describing individual budgets overlaid with a philosophy (or discourse) of empowerment through consumerism (Barnes, 2011).

Discussion about the alignment of ‘the personalisation agenda’ (Lloyd, 2010) and the objectives of governments to contain costs and increase private funding of care is common in the UK literature. In Australia, reports from the PC provide transparency regarding the interests of consecutive governments in promoting individual responsibility for care and viability of the aged care industry (PC, 2008, 2011b, 2016).

### **3.3.5 Marketisation**

Scourfield (2005) argues that CDC represents a hybridisation of discourses; a mix of the ‘social rights’ discourse of the Independent Living Movement and the ‘market-consumer’ discourse of neoliberal governments (Pearson, 2000; Scourfield, 2005). The Australian experience highlights the lead time from early discussions of CDC to national implementation in home care and the scope and direction of the reform program. Notably, the interests of government in containing public expenditure have converged with those of the aged care industry in expanding the scope for discretionary spending by consumers in a quasi-market environment (PC, 2008). This section describes marketisation with regard to the mechanisms of competition, deregulation, co-contribution and (potential) discounting.

#### **3.3.5.1 Competition**

CDC is posited as a way to increase user choice and improve quality of care through competition and innovation. Competition is a key element of a market economy with consumers able to select their purchases from a range of suppliers. Price, quality, and terms of trade may vary between suppliers and there is an incentive for consumers to choose the best quality goods at a reasonable price. Human services that are subsidised by governments have long been considered as the antithesis of the free market. However, many developed countries including Australia are examining which human services are most amenable to the introduction of competition (PC, 2016) or have introduced quasi-markets in health, education, job services, social housing or aged care (Newman, Glendinning, & Hughes, 2008).

Competition is expected to increase the focus on the individual needs of the consumer and lead to innovation in the way services are delivered as providers compete for income.

#### **3.3.5.2 Deregulation**

In many welfare states like Australia, the introduction of quasi-market competition first requires de-regulation. In aged care, this includes the removal of the cap on the number of

aged care places to allow new service providers to enter the market. As governments require a way to limit expenditure, eligibility for home and RAC services remains linked to a comprehensive assessment of the needs of older persons. The subsidy that the government formerly directed to the service provider is rerouted to the eligible older person.

### ***3.3.5.3 Co-contribution***

Proponents of CDC believe that transparency regarding the cost of care as well as greater cost sharing, will motivate consumers to compare service price and quality and enlist them in the overall drive to contain costs (Axtell-Thompson, 2005). Some older Australians are already 'saving' a portion of their home care subsidy to enable future purchases of one-off capital items or services. In 2014-15, unspent funds were on average over 10 per cent of the value of the home care package (ACFA, 2016).

### ***3.3.5.4 Discounting***

Removal of caps on the number of Level 3 or 4 (moderate and high level care) home care packages for example, is likely to reduce waiting lists and increase government expenditure. However, the aged care subsidy allocated to the individual is likely to be less than the amount presently paid to the provider and will not fully cover case management and administrative costs. Providers reported these costs to average 27% of the value of home care packages when CDC was trialled in Australia (KPMG, 2015a). Further, the subsidy allocated to the individual may not be fully indexed to the Consumer Price Index (CPI) or the cost of providing care under an agency directed model, thus decreasing in value over time. In Australia, payments for carers and unemployed persons are examples of decreases in real value since their introduction. When the Domiciliary Nursing Care Benefit (DNCB; presently known as the Carer Allowance) was introduced in 1974, the payment was 56% of the nursing home benefit. In 2003, the payment was about 10% of RAC costs (Howe, 2003).

### ***3.3.6 Summary of the conceptual framework***

An historical perspective on aged care in Australia (Chapter 2) has highlighted key changes in the way that care for older people has been constructed over time and the role of government policy and financing in driving such change. The conceptual model in Figure 3.1 reflects an awareness of the broader reform of aged care in Australia that continues to shape the evolutionary model of CDC that is being implemented in home care in Australia.

## ***3.4 A methodological framework***

### ***3.4.1 Health services research***

Health services research (HSR) provides an appropriate framework in which to consider the body of work presented in this thesis by examining access to health care as well as the cost and outcomes of care, both intended and unintended (Agency for Healthcare Research and Quality [AHRQ], 2002). HSR is a multidisciplinary field incorporating research methods from sociology, policy and economic analysis, epidemiology and pharmacology as well as evidence based medicine, clinical informatics and quality improvement (Scott & Campbell, 2002). The aim is to perform research that can influence policy and also be applied in practice to deliver high quality care (Health Services Research Association of Australia & New Zealand [HSRAANZ], 2015).

Most HSR funding comes from government and is directed to a wide range of qualitative, quantitative, descriptive and analytical research methods, each with their own limitations (Bowling, 2014). The studies described in Chapters 4 and 5 were funded by DoHA as part of the NETCP while the COACH study (Chapters 8 and 9) was funded by NHMRC through the Health Services Research Program. There are important differences between health services evaluation and research funding in Australia. Research tends to be investigator driven, with a focus on generating new knowledge for peer review and dissemination. In contrast, health

service evaluation outputs are generally specified by the funding body, with strict timelines for deliverables and potential restrictions on the use of any intellectual property created, and the dissemination of findings. While the NETCP afforded opportunities to participate in the collection and analysis of national data and to develop and test a measure of patient experience of TC, the researcher did not participate in the design of the overall evaluation.

### 3.4.2 Research methods

Figure 3.2 illustrates the research methods selected for the studies comprising the thesis. Each of the methods are described in Chapters 4-9 and the following section is limited to a consideration of the contribution of each method to the overall program of research.

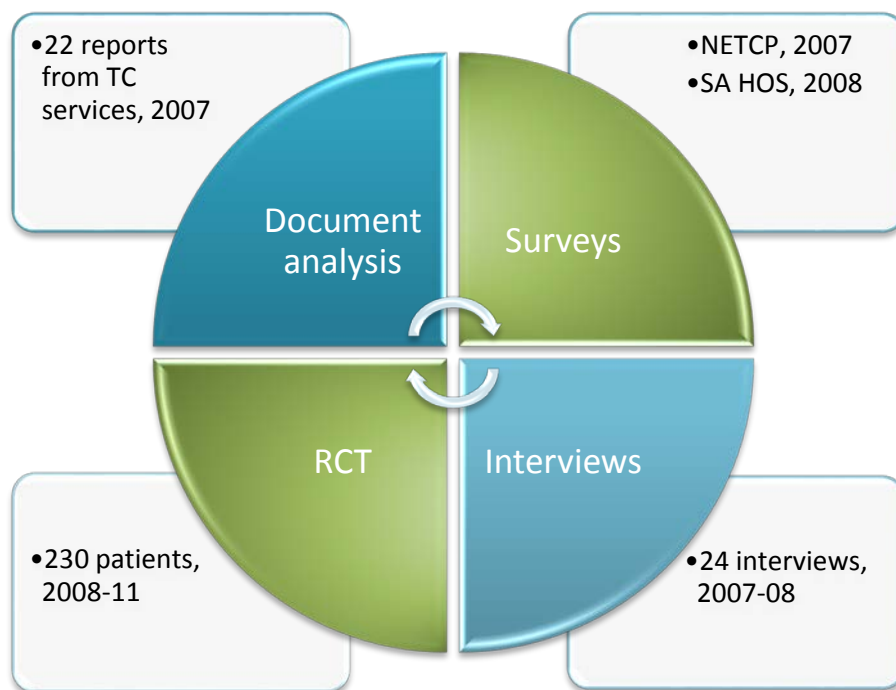


Figure 3.2 Methodological framework

#### 3.4.2.1 Document analysis

Documents can serve several functions in research, including the provision of data about the context in which research participants receive care (Bowen, 2009). However documents provide ‘social facts’ rather than evidence and their purpose is to accomplish specific goals

(Atkinson & Coffey, 2004). For this reason, documents provide fertile ground for discourse analysis (Greenhalgh, Procter, Wherton, Sugarhood, & Shaw, 2012).

In the present thesis, *quality reports* provided insight into TC from the perspective of managers and staff charged with the responsibility of implementing a new program of restorative care in accord with operational guidelines and relevant legislation. The information derived from the study prompted questions about residential vis-à-vis community models of TC, medical needs and medication reconciliation that influenced the intervention study described in Chapter 8.

#### **3.4.2.2 Survey research**

Survey research provides an opportunity to collect standardised information from individuals within a population or subgroup and is frequently employed by health services researchers (Bowling, 2002). The sampling strategy as well as the response rate may influence the extent to which the results from a sample can be generalised to the population from which the sample is drawn (Halbesleben & Whitman, 2013). Specific guidance in developing and assessing the validity and reliability of measures is available (e.g., Streiner, Norman, & Cairney, 2014).

Survey data contributed to the program of research through validation of a measure of patient experience of TC that would enable recipients to express their views about the care they received and aligned with the document analysis (3.4.2.1). A second survey recorded community perceptions of the reasons that older adults enter RAC to complement findings from the interviews with patients entering RAC from a hospital bed and their carers.

#### **3.4.2.3 Interviews**

Semi-structured interviews enable a researcher to seek specific information while retaining flexibility to explore issues or themes that arise in participants' responses to specific



questions or prompts (Patton, 2002). Interviews generally yield richly textured data that provide insight into the experience of illness, ageing, trauma and other health states as well as the experience of care. However, the analysis of qualitative data is resource intensive and skills are acquired through experience as well as supervision.

Trust is a critical element in undertaking research with vulnerable people, including those of advanced aged or with cognitive impairment and the involvement of family members and health professionals adds further layers of complexity in managing relationships and expectations. Engagement with research participants provides personal satisfaction that is unmatched by document analysis and survey research.

#### ***3.4.2.4 Pragmatic RCT***

A pragmatic RCT refers to an intervention study that is undertaken in a clinical setting rather than a laboratory or other controlled environment (Tosh, Soares-Weiser, & Adams, 2011). To enhance policy relevance and decision-making, RCT protocols commonly include outcomes relating to utilisation of health and aged care services and assess health service gains relative to the cost of the intervention (Scott & Campbell, 2002).

#### ***3.4.2.5 Research methods summary***

Within the limitations of funding, the methods described in Section 3.4.2 are complementary and provide a range of perspectives on post hospital transitions for older adults. There was sufficient flexibility in the NETCP to enable the researcher to develop a subset of questions to link with the document analysis. Interviews afforded a unique opportunity to examine decision-making about entry to RAC in patients who were generally ineligible for TC while a SA survey explored community perceptions of entry to RAC. The SA HOS also provided insight into preferences for an aged care subsidy that would allow people to choose RAC or

high level home care. Finally, a pragmatic RCT examined the effectiveness of an intervention to increase patient and family involvement in residential TC.

### **3.5 Summary**

Chapter 3 has examined historical and international perspectives on CDC and the implementation of CDC in home care in Australia. Following a review of relevant literature, a conceptual framework was proposed. The chapter concluded with a discussion of HSR as an appropriate methodological framework for the studies comprising the thesis. Chapter 4 reports on the first empirical study, an analysis of documentation submitted by TC services as part of the quality improvement framework for the TCP.

## CHAPTER 4

### *ASSESSING QUALITY IN THE TCP*

#### **4.1 Introduction**

As discussed in 2.5, TC targets those older Australians at the conclusion of an acute hospital episode who require more time and support in a non-acute setting to complete their restorative process and optimise their functional capacity. A particular objective is to prevent inappropriate admission to RAC by delaying the decision regarding entry until the care recipient's functional capacity has been optimised. The study described in this chapter was undertaken in 2007 and the operational guidelines for TCP have been revised twice since then, first in 2011 and again in 2014. To assist the reader, the policy context and operational guidelines that were in place in 2007, are briefly described. At 30 June 2007, 2,000 TC places had been allocated and 1,594 were operational around Australia.

The key objective of TC is to optimise client independence. The TCP guidelines (DoHA, 2005) state that this is to be achieved through the provision of goal oriented, individualised, time limited care and low intensity therapies and services delivered in an appropriate setting. TC services are characterised by multidisciplinary teams that apply age-friendly principles and practices (COAWG, 2005) and engage in collaborative service delivery and learning. Care is expected to be timely, flexible and reliable, providing support linked seamlessly to other services. The TCP objectives, strategies and service characteristics provide the conceptual framework for a set of 'key requirements' against which services self-assess in their first year of operation. An abridged description of program requirements is provided in Table 4.1 and a copy of the form that is completed by TC service providers (referred to as the 'quality report') is available in Appendix A.

Self-assessment against the key requirements is part of a broader approach to quality improvement and monitoring which also involves the selection of TC service providers, a Plan-Do-Check-Act cycle of continuous quality improvement, and an external complaints mechanism. The *Transition Care Quality Improvement and Monitoring Framework* (DoHA, 2005) proposes external assessment and stakeholder feedback as additional checks of compliance with the requirements. These elements had not been implemented when the current study was undertaken.

The key requirements focus on those aspects of care specific to TCP. TC services are provided by health and aged care organisations and subject to various accreditation and external regulatory processes. Although most quality reports have two or more signatories and are reviewed by *Approved Providers* (individual state and territory governments) before submission to the Commonwealth Department of Health and Ageing, there is currently no mechanism for direct external peer assessment.

The aim of the study reported here was to summarise the contents of the first set of quality reports submitted to the Australian government by TC services. This review was undertaken as part of the NETCP.

## **4.2 Methods**

Ethics approval was obtained from the Australian Department of Health and Ageing and the Flinders Clinical Research Ethics Committee. Content analysis of the first 23 self-reports (the total number available at the time of the study) was undertaken to elicit information regarding compliance with each of the key requirements and to identify gaps in the evidence provided. Content analysis focuses on the characteristics of language as communication and pays close attention to contextual meaning as well as text content (Hsieh & Shannon, 2005).

Responses to each key requirement were extracted from the individual reports and entered into word processing software. Content relating to each key requirement was copied to a separate table. A systematic process of coding, sorting and review was applied to the text. First, complex and multi-faceted responses were broken down into discrete pieces of text and coded according to their content. These were allocated to rows and a column was added to record initial coding (column 1). The second step involved sorting the codes alphabetically as a way of grouping similarly coded text. The third step was to review similarly coded text as a check of consistency and to assist in further refinement of the coding. Steps 2 and 3 were repeated until no new codes emerged; this process revealed subtle patterns and differences among responses and contributed to an assessment of the quality of evidence to support compliance with the key requirements. In step four, relevant codes were collapsed into categories identified as enablers or barriers to compliance. In step five, a matrix approach (Miles & Huberman, 1994) was used to display a summary of results (Table 4.1).

### ***4.3 Results***

The 23 reports that comprise the evaluation sample were received between 15 March and 7 June 2007, having been completed an average of 42.8 (SD = 9.4) weeks following service commencement. The majority of the 23 services (n = 15) were located in New South Wales (NSW). TC services in NSW and Queensland (QLD) provided residential or community TC places, but not both. Those in Victoria (VIC) and Western Australia (WA) provided both residential and community places. The South Australian (SA) sample comprised one residential service and one service with flexible places that could be residential or community as required. NSW and QLD services ranged in size from four to 51 places whereas the SA, VIC and WA services were generally larger, ranging from 20 to 50 places. Tasmania submitted two quality reports but these were not available in time for inclusion in the study.

Table 4.1 Summary of key requirements and evidence of quality

<b>Requirement</b>	<b>Quality of evidence</b>	<b>Enablers</b>	<b>Barriers</b>
TC is linked to the agreed goals of clients, carers, families & to the promotion of self-sufficiency & self-management	Well demonstrated. All services described individual initiatives to ensure goal attainment.	Service specific activities and strategies were described to ensure family/ carer inclusion in goal setting	Nil identified
Selection & use of therapies is informed by evidence based research & leading practice information	Implementation of evidence based research was difficult to identify. Leading practice examples cited.	Nil identified	Some ambiguity noted in the key requirement i.e., the difference between leading practice and evidence based research
Service delivery is designed to optimise independent functioning following discharge	Well evidenced	Recognition of the rehabilitative/restorative focus/training required for TC workers; co-location with a rehabilitation facility helpful	No formal training modules were identified for personal care staff
Clients receive timely & appropriate access to care & equipment	Evidence of established networks with services that provide care and equipment, organisation specific policies and documentation.	Early discharge planning essential.  Some services itemised strategies to nurture and promote ongoing linkage	Waiting lists for HACC, CACP and equipment

Table 4.1 Summary of key requirements and quality of evidence (cont ...)

<b>Requirement</b>	<b>Quality of evidence</b>	<b>Enablers</b>	<b>Barriers</b>
Care plan informed by hospital assessment & discharge planning	Variable	Protocols for transfer of allied health assessments and discharge summary; TC staff visit client in hospital	Delay in receipt of discharge summary; lack of protocol re notification of client discharge
Documentation includes: assessment of function using validated instrument, desired discharge destination, Quality of Life expectations, low intensity therapies, support, counselling & goal review	Functional assessment well evidenced Individualised care planning well evidenced.	Comprehensive assessment developed which incorporates all of the criteria listed	Format of question. Not all services systematically responded to the requirements (n=10); limited access to community-based social workers.
Care plan informs service delivery; periodic review	Evidenced		
Care plan & hospital discharge summary to GP & involved services	GP routinely informed of client admission; Provision of initial care plan not well evidenced		
Residential services provided in a home-like setting	Evidenced	Purpose-built facility	Limitations of existing or temporary buildings

Table 4.1 Summary of key requirements and quality of evidence (cont ...)

Requirement	Quality of evidence	Enablers	Barriers
Client leaves TC with refined care plan; d/c summary includes details of ongoing services; list of pharmacist checked medications ...	Evidence of discharge information including contact details for services involved in ongoing care Provision of discharge care plan not well evidenced.		
Documentation requirements at discharge from TC	Lack of information about documentation of reasons for non-achievement of client goals		Brokerage of TC places requires monitoring of d/c practices
Transport	Stated compliance		Responsibility not clearly assigned to TC <i>or</i> family
Multi-disciplinary assessment in hospital with geriatrician involvement	Well evidenced; intrinsic to ACAT assessment; the composition of the assessment team was documented on the ACCR – geriatrician involvement variable	Routine interRAI assessment for patients >70yrs facilitates access to geriatrician consult	Limited access to geriatricians in regional areas
Skilled MDT staff assess each client & support care plan review	Evidenced. Composition of MDT's was variable in TC	Skilled case management Co-location within health setting	



Table 4.1 Summary of key requirements and quality of evidence (cont ...)

<b>Requirement</b>	<b>Quality of evidence</b>	<b>Enablers</b>	<b>Barriers</b>
Care informed by discussion with & between the relevant geriatrician & GP	Variable	Small number of TC services have medical staff as part of team Case manager has key role in GP involvement	Lack of geriatrician in region or Tele-health access only; variable engagement by GPs
Staff have relevant professional standing	Well evidenced		
Staff work collaboratively with all involved services	Well evidenced	Planned, regular forums	
Annual opportunity for staff to be informed of leading practice in TC	Variable Well evidenced in some states and regions.	Approved Provider &/or TC service provider approval or funding; local initiatives	
Staff utilise other opportunities to be informed of leading practice	Evidence of networking between TC services	Progressive rollout Maturity of TCP and services	Time since inception of TCP
Joint or cross sector training	Developing Some local initiatives	Co-location Community service provider networks	

Table 4.1 Summary of key requirements and quality of evidence (cont ...)

Requirement	Quality of evidence	Enablers	Barriers
Transfer to TC within 4 weeks of ACAT approval	Well evidenced	Delay ACAT until discharge date is known	High demand for residential TC
Hospital assessment & care plan transferred with client	Not well evidenced	Co-location with acute/ sub-acute health service TC provider visits client in hospital Protocol re minimum d/c information to be provided by referring hospital	Hospital medical records not transferable to community providers
Effective links with all services to optimise goal achievement	Well evidenced		
Equipment & support services arranged for discharge	Well evidenced	Business agreements with community service providers to facilitate access Effective links with ACAT staff	Waiting lists for HACC, CACP, EACH and subsidised equipment
Collaboration reflected in protocols & agreements [Appendix 1 Age-Friendly Principles & Practice]	Ambiguity associated with differentiating the age friendly principles from the guidelines relating to robust service agreements		Service promotion and networking mechanisms used extensively

The relative numbers of quality reports submitted from each state, in part, reflected the length of time that services had been in operation. Table 4.2 provides a summary of the characteristics of the 23 TC services that submitted reports. The description of TC providers' self-reports against the key requirements is organised under the following headings, derived from the TCP requirements: (i) timely, seamless care (entry); (ii) client independence is optimised; (iii) collaborative learning; and (iv) timely, seamless care (discharge). These headings encapsulate the critical transition points for continuity of care (admission and discharge), the primary restorative goal of TC (to optimise independence) and collaborative learning as a key strategy for successful implementation of a new model of service delivery at the interface of acute, community and aged care programs.

#### **4.3.1 *Timely, seamless care (entry)***

The key requirement related to the period between ACAT assessment and admission to TC was stated as "Transfer and admission to TC is at the very latest within 4 weeks of ACAT approval for TC, but preferably much less" (DoHA, 2005, p. 48). TC services reported a high level of compliance with this requirement, with only one service reporting that transfer times had exceeded the guidelines on one or more occasion. Several TC services reported transfer times of around 48 hours. In QLD, the integration of community and aged care services enabled a coordinated approach to ACAT assessment and entry to TC. Co-location, common reporting and organisational structures and funding of ACAT assessors as part of the TC team were factors that appeared to expedite transfer.

There was evidence that the new TC services were struggling to set up effective communication systems with hospitals. The key requirements state "Each TC client has a current care plan, which is informed by hospital and discharge assessment and planning" (DoHA, 2005, p. 46). Excerpts from the TCP guidelines suggest that responsibility for the

Table 4.2 Characteristics of Transition Care services that provided quality reports

<b>State</b>	<b>Service</b>	<b>TC places</b>	<b>Provider</b>	<b>Distinguishing features</b>
NSW	Albury	10 R	HS	Visiting pharmacist
NSW	Bathurst	4 R	HS	Rehabilitation Unit
NSW	Junee	4 R	HS	Aged Care ward
NSW	Wyong	20 R	HS	Residential TC setting; P/T medical officer
NSW	Calvary	15 C	HS	broker personal and home care
NSW	Clarence Valley	15 C	HS	
NSW	Richmond Valley	18 C	HS	broker personal and home care
NSW	Shoalhaven	14 C	HS	HS & NGO partnership
NSW	Prince of Wales	8 C	HS	
NSW	LMNorth Coast	19 C	HS	
NSW	Port Kembla	10 C	HS	Area HS & NGO partnership
NSW	Central Coast	20 C	NGO	Area HS & NGO partnership
NSW	Northern Sydney	40 C	HS	Broker community packages; service agreement with Rehabilitation Services

Table 4.2 Characteristics of Transition Care services that provided quality reports (cont ...)

<b>State</b>	<b>Service</b>	<b>TC places</b>	<b>Provider</b>	<b>Distinguishing features</b>
NSW	Tweed	15 C	HS	
NSW	Westmead	44 C	HS	Geriatrician is part of team
QLD	Brisbane South	51 C	HS	brokerage model; P/T geriatrician
QLD	Logan-Beaudesert	5 C	HS	
QLD	West Moreton	6 C	HS	
SA	ATA – HRSS	50 F	NGO	Broker community & residential packages
SA	City Views	40 R	NGO	Residential TC setting; broker allied health, medical & geriatrician services
VIC	Austin Health	17 R 25 C	HS	Co-located with Aged Care Assessment Service; P/T pharmacist, geriatrician
VIC	Barwon Health	14 R 6 C	HS	P/T salaried medical staff
WA	North	20 R 30 C	NGO	Co-located with Residential Aged Care

R = residential; C = community; F = flexible; HS = health service; NGO = non-government organisation; P/T = part-time.

development of the care plan is shared between the referring hospital and the TC provider. Case management is one of the services that must be provided, when required, to all TC recipients and includes ensuring that a comprehensive care plan is available at the time of discharge from hospital (DoHA, 2005). The TCP guidelines also articulate a clear role for hospitals, with specific attention to planning for the client's rehabilitation needs. The guidelines state "the hospital geriatric rehabilitation service or equivalent will also need to play a key role in developing the care plan that will apply for the therapy services delivered through TC" (DoHA, 2005, p. 19). Although TC services reported having access to the Aged Care Client Record (ACCR)<sup>1</sup> and other documentation to inform care planning, only one service reported that the hospital discharge summary included a basic care plan.

Several TC services described routine hospital visits and consultation with patients and clinicians prior to the patient's admission to TC. In this way, TC staff took the lead to ensure that the service had access to relevant information for care planning. This strategy enabled personal contact with the prospective TC recipient and an opportunity to seek clarification regarding health and personal care needs. Other services reported ongoing challenges, including inconsistent provision of discharge documentation as well as system barriers such as the provision of generic discharge letters with little information concerning the recent episode of care. Strategies that aimed to facilitate information flow from the acute/sub-acute sector to TC, such as attendance at hospital discharge planning meetings, were associated with variable levels of success. TC services that had established formal protocols or agreements with hospitals (n = 3) reported fewer problems associated with the timeliness and adequacy of information provision.

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<sup>1</sup> The ACCR is the authorised form for applications for Australian Government funded aged care services under the Aged Care Act 1997 (DoHA, 2005).

### **4.3.2 *Client independence is optimised***

A high level of commitment to the goals of optimising clients' functional capacity and independence was evidenced. However, there was recognition that personal care staff who had worked in RAC settings were less familiar with the restorative and rehabilitation focus of TC. Several services reported on initiatives to enhance the educational preparation and development of personal care staff for TC settings. Service initiatives included discussions with Technical and Further Education (TAFE) institutions regarding the development of an additional module as part of Certificates III and IV in Community Services, and supernumerary placement of TC staff in acute rehabilitation wards for experience and training in the rehabilitation model of care.

### **4.3.3 *Collaborative learning***

Collaborative learning was evident at local, regional and state/territory levels. TC providers highlighted their efforts to network, share practice, provide joint or cross sector training opportunities and advance leading practice. Local and regional initiatives were most often described, although the extent of linkage was reported to vary across regions. Two state-level initiatives were described. At a service level, multi-disciplinary forums were identified as contributing to staff learning as well as ensuring optimal client care and outcomes. Learning opportunities were enhanced by the integration of a range of acute, sub-acute and community based services, enabling staff to work across clinical and community areas or in close proximity to ACAT, rehabilitation, aged care or other expertise.

Services were asked to describe how the selection and use of therapies were informed by evidence based research and leading practice information. The clearest response was that therapies were provided by registered professionals (or under the supervision of registered professionals) who were expected to maintain professional learning. Membership of professional bodies, registration and certification requirements and professional development

opportunities were described. Use of validated assessment tools, subscription to industry journals and access to reliable information via government health information portals were also cited as demonstrating compliance with this requirement.

Difficulties were reported with the requirement that “Each client leaves TC with a refined care plan and discharge summary ... which records: a list of pharmacist-checked discharge medications” (DoHA, 2005, p. 47). Only two services described processes for pharmacist review of medications as part of discharge from TC. Both of these services provided TC in a residential setting and identified hospital and visiting pharmacists as the providers of this service. In a residential TC setting, medical care may be provided by the recipient’s General Practitioner (GP) and/or medical staff employed by provider or partner organisations. In this context, one or more doctors may initiate medication changes and the TC provider has additional responsibilities regarding the supply, storage and administration of medications. For recipients of community based TC, medical care and medications are the responsibility of the GP. Moreover, access to a Home Medication Management Review (HMMR) funded under the Medicare Enhanced Primary Care (EPC) program requires a referral from a GP. The requirement for pharmacist review of discharge medications for recipients of community based TC would benefit from strategies to meet the requirement.

Two of the key requirements included a reference to the involvement of geriatricians or other geriatric specialists in assessment and care planning. The first requirement was that “Each TC client has received in hospital a multi-disciplinary assessment, preferably involving a geriatrician or another geriatric specialist” (DoHA, 2005, p. 47). Responses highlighted regional variations in access to specialist input, with a few services reporting that geriatrician involvement was restricted to clients with complex health needs. In one jurisdiction, routine assessment for hospital inpatients aged 70 years or older using the international Resident



Assessment Instrument (interRAI) was noted to facilitate geriatrician input but generally this did not occur.

The second requirement was that “Care is informed by discussions with and between the relevant Geriatrician and the client’s GP, where possible, and/or other appropriate medical input” (DoHA, 2005, p. 47). Only five of the 23 TC services included a geriatrician in the description of their staffing profile (21.7%) and a further three services reported that a geriatrician consult was available on referral from the client’s GP. Geriatrician input was most often reported in terms of participation at regular case conferences. Most respondents reported difficulty in engaging GPs and some services described plans to develop links with Divisions of General Practice and nurses working in general practice. EPC items were recognised as providing support for GP involvement in multi-disciplinary care planning but there was little evidence of usage in the TC setting.

#### **4.3.4 *Timely, seamless care (discharge)***

Discharge from the program required careful management. Case management and early discharge planning were identified as critical factors in ensuring clients had access to care and equipment at the conclusion of TC. Waiting times for HACC, CACP and EACH and financial subsidies for long-term equipment needs were reported as presenting challenges, both for timely discharge from TC and the provision of optimal services to meet ongoing client needs. Methods for managing this challenge included early referral and maintenance of close links with ACAT staff. One service described the development of *business agreements* with providers of community aged care services. A small number of TC services purchased and maintained their own aids and equipment. For these services, the development of an equipment policy and acquisition of business software were identified as contributing to efficient and equitable access to equipment. Other services described brokerage and joint care agreements for the provision of equipment.

A key requirement related to timely and seamless care was that “Collaboration between acute/sub-acute care, aged, community and primary care is reflected in protocols and agreements, such as those areas covered by Appendix 1 of the Age-Friendly Principles and Practices” (DoHA, 2005, p. 48). Only three responses referred to the Age-Friendly Principles and Practices and there was little evidence that Appendix 1 (sic) was used to inform the development of protocols and service agreements. Nine of the 23 TC services described having service agreements with partner or brokered organisations. Less commonly reported were formal agreements between the TC service and acute or sub-acute services. Services which reported having negotiated minimal hospital discharge documentation requirements and timeframes, for example, reported less difficulties in obtaining relevant and timely information compared to their counterparts. Table 4.1 provides a summary of responses and identifies some of the barriers and enablers to compliance with the key requirements that were identified through analysis of the quality reports.

#### **4.4 Discussion**

Internationally, the risks associated with transfers between institutions and systems of care (health and aged care; primary, secondary and tertiary care) are high enough and occur frequently enough for the terms ‘falling through the cracks’ and ‘transfer trauma’ to have entered the literature (Coleman, 2003; Sherman, 2006). A 2003 Position Statement from the American Geriatrics Society on *Care Transitions* called for patient centred systems of care to optimise transfers (Coleman & Boulton, 2003), monitor adverse outcomes, and the introduction of standards for documenting transfer information. More recently in the US a ‘pay for performance’ strategy for managing transfer information has been suggested (Snow et al., 2009). Nevertheless, work from the US suggests that the most promising strategies are those that focus on the patient and carer who are moving across systems, rather than institutions (Coleman et al., 2004).

The data presented in this chapter confirm that timely transfer of client information is a key challenge that requires the concerted efforts of hospitals, TC and aged care services. TC supports older adults to transition from hospital to home (or RAC) but increases the number of handovers as most clients will transfer to other service providers when the period of TC is completed. When the high rate of readmission to hospital from TC is also considered (Giles et al., 2008), a picture of multiple transfers emerges, each accompanied by the risk of disruption to care or adverse events.

This review found evidence that service delivery was goal oriented, time limited and incorporated low intensity therapies aimed at maximising client independence. Individualised care planning inclusive of the client, family members and other stakeholders involved in the client's longer term care was evidenced. It was apparent that the requirements of TC, which centre on teamwork, case management, a restorative model of care and efficient management of allocated TC places, require adjustment for staff trained in clinical and RAC models.

Less well evidenced were GP, geriatrician and pharmacist involvement in care planning and review, although this varied across services and regions. Case managers were identified as having a key role in facilitating GP involvement in care planning and review. The barriers to GP involvement in care planning and case conferencing are well documented (Preen, Bailey, & Wright, 2006; Shortus et al., 2005), although Commonwealth initiatives to enhance GP involvement in residential care have had some success (Gadzhanova & Reed, 2007; O'Halloran, Britt, & Valenti, 2007). Use of HMMR (Pit et al., 2007; Rigby, 2006) was not reported in the 23 quality reports assessed as part of this study. Very few services were systematically involving a geriatrician in TC.

It was reported that personal care staff were less familiar with the restorative focus of TC and additional training opportunities were sought. Timely transfer of information from the acute

or sub-acute setting was not always achieved. Similarly, waiting lists for HACC, CACP and EACH packages sometimes resulted in less than optimal care at the conclusion of the TC episode.

This study examined the first 23 quality reports submitted to State/Territory *Approved Providers* and the Australian Government. The reports were completed on average 9 months after commencement of the service and, with the exception of the pilot sites for the ICRS program, reflect the early development of service teams and partnership or brokerage models of service delivery.

The key requirements specify the expectations of TC services but do not prescribe how the requirements are to be met. This approach allows for flexibility, innovation and the tailoring of strategies to meet local needs. On the flipside, this lack of prescription contributes to ambiguity in the interpretation of the key requirements, as do subtle differences in the wording of the requirements and relevant sections of the TCP guidelines. Some of the key requirements comprised numerous criteria which presented an additional challenge. Few services responded to the criteria in a systematic way and this detracted from the confidence with which performance against a specific criterion could be reported.

The quality reports comprised the single data source for this study. Additional sources of information such as site visits and discussions with stakeholders are required to expand on the evidence cited in the quality reports, particularly those areas where compliance is currently not well evidenced. Site visits, or an alternative mechanism for external peer assessment would also benefit the program more broadly.

#### ***4.4.1 Implications for policy and practice***

TC is a new program in Australia. Service providers include state funded health services and aged care organisations. There is heterogeneity in the number and mix of TCP places

allocated (residential and community), time since the service became operational, model of service delivery and extent of brokerage arrangements. Some services had been pilot sites for the ICRS program implemented in 2001-02. This experience was reflected in the maturity of service delivery processes and partnerships apparent in responses.

Quality in the TCP is inextricably concerned with care processes to support transfer between locations (hospital to home), sectors (health to aged care), and individual states (illness, frailty, disability to more optimal functioning) (Godfrey et al., 2005). Responses to the quality report highlight emerging best practice in TC with respect to service agreements with referring hospitals that include protocols for the transfer of client information and agreed processes concerning referral and response times. The review has also noted difficulties in providing for clients' ongoing needs once TC has finished and suggestions of less than optimal ongoing care arrangements in some instances. Early attention to discharge planning and partnerships with other service providers are identified as enablers of a smooth transition between services and could be further promoted across TC services. Some of the challenges identified in this review<sup>2</sup> are likely to resolve as TC is embedded as part of the service landscape in Australia.

#### **4.5 Summary**

This chapter has reviewed TC providers' reports of performance against key program requirements. In Chapter 5 the description of a tool to measure patient experience of the TCP is presented. The aim was to attempt to link patient experience with TC requirements. This would provide another perspective on performance against program aims.

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<sup>2</sup>Amendments to the TCP guidelines that address some of the shortfalls noted in this study are discussed in Chapter 10.

## CHAPTER 5

### *ASSESSING PATIENT EXPERIENCE OF THE TCP*

#### **5.1 Introduction**

As described in Chapter 4, TC services are asked to complete 'quality reports' and describe the steps taken to ensure that care is personalised, timely and goal oriented and achieves a smooth transition for the person entering and leaving TC. Although TC recipients and family members are provided with information about aged care complaints mechanisms, their views are not currently incorporated in the reporting arrangements.

Patient experience is an important component of quality measurement (AIHW, 2009; Coulter & Ellins, 2006) but few measures have been rigorously tested. In 2006, the National Quality Forum (NQF) in the US endorsed the CTM-3<sup>®</sup> as an additional priority area for comparative public reporting of hospital care (NQF, 2006).

This study aimed to develop a measure of patient experience that could be used as part of the quality assurance processes for TC. As described in Chapter 4, the key requirements provide the conceptual framework for assessing quality in the TCP although not all of these requirements are able to be assessed through patient experience. Domains that can be assessed in this way include: a restorative model of care that optimises independence (Table 5.1, Requirements 1.1-1.4); accountability for care transitions (1.4, 4.1-4.5); and patient preferences (1.1, 2.2). International research has highlighted involvement in decisions, respect for preferences and continuity of care as aspects of health care that are highly valued by patients (Coulter, 2005). Asking standardised questions about these aspects of care is thus consistent with TCP expectations and patient aspirations and should help to identify where care processes can be improved.

## **5.2 Method**

### **5.2.1 Design**

As part of the NETCP, individual outcomes were assessed through an Australia wide telephone survey of TC recipients three months after completion of their episode of care.

### **5.2.2 Study participants**

All TC recipients discharged from the TCP between 1 February and 30 June 2007 were eligible to take part in the study, including those admitted to RAC (Giles et al., 2008).

## **5.3 Procedures**

### **5.3.1 Ethics and privacy considerations**

The study protocol was approved by Flinders Clinical Research Ethics Committee, DoHA Departmental Ethics Committee and 30 state and regional ethics committees (see Appendix B for a listing of these committees).

### **5.3.2 Recruitment**

Due to privacy legislation, the evaluation relied on TC providers obtaining written consent from TC recipients, or their proxies, for contact by the evaluation team. TC providers in Western Australia were not approached at the request of the DoHA. Consent to contact forms included an address and telephone number(s) for the TC recipient and next of kin and the date of discharge from TC. A letter of introduction, participant information sheet and consent form were mailed to each TC recipient two weeks prior to a scheduled telephone call. The introductory letter included a free-call telephone number for TC recipients who wished to withdraw their consent.

Up to seven attempts were made to contact each TC recipient over different times and days of the week. Searches of an electronic telephone directory (Telstra Corporation Ltd., 2007) and obituary websites (Australian Obituaries, 2007; Obits Pty Ltd, 2007; Ryerson Index Inc.,

2007) were used to trace participants who had changed address, had incorrect contact details recorded or had died. Proxy interviews were conducted when the TC recipient or their carer advised that a self-responding interview was not appropriate. To assess test-retest reliability of the patient experience measure, a consecutive sample of TC recipients were approached regarding consent to recontact 14 days after the initial telephone interview.

### ***5.3.3 Drafting the questions***

The measure of patient experience was developed from the TCP guidelines and sought to elicit older adults' experience across the three domains described above: (i) restoration; (ii) care transitions; and (iii) preferences. The first question assessed how well older adults were prepared to receive TC (Coleman, Mahoney, & Parry, 2005). TC services identified equipment and continuity of care as challenges (Chapter 4) and this was assessed through Q7-8 (Table 5.1). Questions were coded using a 5-point Likert scale (strongly disagree =1, disagree =2, agree =3, strongly agree =4, don't know/not applicable =5). Administration of the patient experience questions as part of a broader survey of individual outcomes of TC limited the number of items that could be included. In total, there were eleven items.

### ***5.3.4 Other measures***

The number of outcome measures was kept low to minimise respondent burden (Giles et al., 2008). In addition to patient experience, demographic measures (age, state of residence), living arrangements before and after TC (community or RAC), setting in which TC was received (residential, community or both), length of stay, overall satisfaction with TC (very satisfied, satisfied, dissatisfied, very dissatisfied) and the number of hospital admissions in the three months following discharge from TC, were collected. Validated measures included the CTM-3<sup>®</sup> which assesses the quality of preparation for discharge (Coleman et al., 2002) and the Modified Barthel Index (MBI; Shah, Vanclay, & Cooper, 1989), described below.



Table 5.1 Summary of key requirements and corresponding survey questions

Requirement	Question(s)
<i>Objective: Client Independence is Optimised</i>	
1.1 TC is linked to the agreed goals of clients, carers, families & to the promotion of self-sufficiency & self-management	1, 2
1.2 Selection & use of therapies is informed by evidence-based research & leading practice	
1.3 Service delivery is designed to optimise independent functioning following discharge	3, 4, 5
1.4 Clients receive timely & appropriate access to care & equipment	7, 8
<i>Strategies: Goal Oriented, Individualised Care; Low Intensity Therapies</i>	
2.1 Care plan informed by hospital assessment & discharge planning	
2.2 Care plan/client file includes: functional assessment, desired discharge destination, expectations and goals concerning lifestyle, community participation, relationships, emotional well-being and activities; therapy and clinical goals, support and counselling appropriate to each client's reaction to anticipated changes in his/her life...	2, 6, 9, 11
2.3 Care plan informs service delivery; periodic review	
2.4 Care plan & hospital discharge summary to GP & involved services	
2.5 Residential services provided in a home-like setting	10

Table 5.1 Summary of key requirements and corresponding survey questions (cont ...)

Requirement	Question(s)
2.6 Client leaves TC with refined care plan; discharge summary includes details of ongoing services; list of pharmacist checked medications...	
2.7 Discharge documentation includes agreed goals and goal attainment...	
2.8 Transport for discharge where required	
<i>Characteristics: Aged Friendly Principles; Collaborative Learning Model</i>	
3.1 Multi-disciplinary assessment in hospital with geriatrician involvement	
3.2 Skilled multidisciplinary staff assess each client & support care planning and review	4
3.3 Care informed by discussion with & between the relevant geriatrician & GP	
3.4 Staff have relevant professional standing	
3.5 Staff work collaboratively with all involved services	
3.6 Annual opportunity for staff to be informed of leading practice in TC	
3.7 Staff utilise other opportunities to be informed of leading practice	
3.8 Joint or cross sector training	

Table 5.1 Summary of key requirements and corresponding survey questions (cont ...)

Requirement	Question(s)
<i>Characteristic: Timely, Seamless Care</i>	
4.1 Transfer to TC within 4 weeks of ACAT approval	
4.2 Hospital assessment & care plan transferred with client	
4.3 Effective links with all services to optimise goal achievement	
4.4 Equipment & support services arranged for discharge	7, 8
4.5 Collaboration reflected in protocols & agreements	

#### **5.3.4.1 CTM-3<sup>®</sup>**

The CTM-3<sup>®</sup> comprises: (i) patients' understanding of their medications; (ii) the extent to which patient preferences are taken into account in deciding what the patient's health care needs will be on discharge; and (iii) patient understanding of their responsibilities in managing their health. These three items have been shown to identify care deficiencies and predict post-hospital return to the emergency department within the first 30 days after discharge (Coleman, Parry, Chalmers, Chugh, & Mahoney, 2007). Each item has a 4-point response scale: 'strongly disagree' = 1, 'disagree' = 2, 'agree' = 3 and 'strongly agree' = 4. Scores are summed and divided by the number of completed items. A linear transformation is then used to provide a final score between 0 and 100, with higher scores indicating a better transition.

#### **5.3.4.2 Modified Barthel Index**

The MBI is a simple and rapid measure of functional independence with high reliability (0.90; Shah et al., 1989). The MBI has 10 items, each scored on a 5-point scale from 'unable to perform task' to 'fully independent'. The modified version was developed to enhance measurement sensitivity with scoring varying from item to item (e.g., 0, 1, 3, 4, 5 for personal hygiene and bathing; 0, 3, 8, 12, 15 for ambulation and chair/bed transfer). The MBI evaluates the degree of independence of a client from any assistance (regardless of how minor, and for what purpose) to complete independence. A score of less than 75 indicates moderate to severe dependency, while a score of 75 to 100 is classified as mild to minimal dependency. TC service providers are required to report MBI scores on entry and discharge in order to claim payment for care provided to recipients. Full instructions for administration and scoring of the MBI are provided by DoHA (2006).

### 5.3.5 *Statistical analysis*

Cronbach's alpha was calculated to assess internal reliability of the first nine items in the questionnaire (Bland & Altman, 1997). Questions 10-11 were excluded as they were asked of a subset of participants only. The internal reliability of self and proxy respondent groups was also determined. Kappa was used to measure agreement between the initial and retest interviews. A value of 1 indicates perfect agreement between the two observations. A value of 0 indicates that agreement is no better than chance (Cohen, 1960).

Exploratory factor analysis was undertaken using responses from 630 telephone interviews (consent to use data from a further 5 interviews was withdrawn). The factor solution was based on the correlation matrix of all available data. A Varimax rotation with Kaiser Normalisation was used in the solution. A scree plot was generated and factors with an eigenvalue of  $\geq 1$  were retained. The regression method was used to derive uncorrelated factor scores that have a mean of 0 and a standard deviation of 1 (Tabachnick & Fidell, 2007). To assess criterion validity, correlations between factor scores and a global measure of satisfaction as well as correlations between factor scores and the CTM-3<sup>®</sup>, were calculated.

Construct validity was evaluated through the ability of the questionnaire to discriminate between recipients hypothesised to differ in their experience of care. Independent samples t-tests were used to compare the derived factor scores between groups of respondents classified by: (i) TC setting (community/residential); (ii) respondent (self/proxy); (iii) dependency (MBI  $\geq 75$ / $<75$ , ); (iv) overall satisfaction with TC (yes/no); (v) hospital admission since leaving TC (0/ $\geq 1$ ); and (vi) living arrangements at 3 months post discharge (home/RAC). All statistical analyses were undertaken using SPSS Statistics Version 17.0.

## **5.4 Results**

A total of 635 recipient interviews were conducted (374 self-respondent and 261 proxy respondent), with an overall response rate of 86.1%. The evaluators were unable to obtain a random sample. One state department of health declined to participate in this aspect of the evaluation and, in another state, no participants were recruited from a TC service which had only commenced operation in February 2007 (Giles et al., 2008). Five recipients withdrew their data after their proxy had completed the interview, reducing total interviews to 630.

Thirty-five proxies (13.7%) had limited involvement in the TC episode and were unable to respond to questions about the older person's experience of care, while a further four proxy respondents (1.6%) had missing responses for all but one of the nine questions. Problems with recall and comprehension resulted in exclusion of seven self-respondents (1.9%), and two self-respondents (0.5%) attempted only one question. Construct validity was therefore assessed with a final sample of 582 (365 self-respondents and 217 proxy respondents).

### **5.4.1 Sample profile**

Tables 5.2a and 5.2b provide descriptive summaries of the valid sample. Respondents were aged between 57 and 106 years, with an average age of 82 years, and half were from NSW. Most received TC in the community for a period of about nine weeks. Prior to hospitalisation, a large majority of respondents were living in the community. About 12% of respondents moved directly from TC to RAC and at three months after discharge from TC, 15% of respondents were in RAC. One in five respondents (22.5%) was readmitted to hospital in the three months following discharge from TC.

### **5.4.2 Test-retest reliability**

Test-retest reliability was assessed in a consecutive sample of 27 TC recipients (or proxies). Twenty two respondents consented to participate in the reliability study. One recipient and

four proxies were unable to complete the quality questions in the initial interview or were unavailable for a retest interview in 14 days, and were not eligible to participate. One participant was subsequently unavailable and a total of 21 interviews were therefore completed (8 interviews with a TC recipient and 13 with a proxy respondent). Recipients or their proxy completed the initial interview an average of 112.3 days (SD 9.4) after discharge from TC and the retest interview an average of 14.8 days (SD 2.3) after the initial interview.

Table 5.2a Sample characteristics

<b>Characteristic</b>	<b>Mean</b>	<b>SD</b>
Age (years)	81.6	7.9
Modified Barthel Index	85.8	20.7
Days since discharge	89.7	7.4
Length of Stay by TC setting (weeks)		
Residential	6.9	3.7
Community	8.7	3.5
Both	10.1	3.2

Kappa coefficients were calculated for each item as a measure of test-retest reliability (Table 5.3). Responses were collapsed from the original 5-point scale to 'disagree' and 'agree', with a third category of 'don't know/not applicable'. The percentage observed total agreement (Feinstein & Cicchetti, 1990) is also reported. Test-retest reliability ranged from fair (0.35) to very good (1.00) according to the classification by Landis and Koch (1977).

Table 5.2b Sample characteristics

Characteristic	N	%
Respondent		
Self	365	62.7
Proxy	217	37.3
TC setting		
Residential	157	27.0
Community	401	68.9
Both	22	3.8
Missing	2	0.3
State		
ACT	35	6.0
NSW	292	50.2
QLD	107	18.4
SA	39	6.7
TAS	36	6.2
VIC	73	12.5
Residence prior to TC		
Community	563	96.7
Residential Care	13	2.2
Missing	6	1.0
Residence at discharge from TC		
Community	489	84.0
Residential Care	69	11.9
Hospital	16	2.7
Missing	8	1.4
Residence 3 months post discharge		
Community	475	81.6
Residential Care	89	15.3
Hospital	16	2.7
Missing	2	0.3



Table 5.3 Test–retest reliability

Question	Observed %	Kappa	Agreement	p
1. Prior to TC I had a good idea of what to expect from TC.	71	0.47	Moderate	0.015
2. TC staff and I agreed about my health goals and how to achieve them.	90	0.57	Moderate	<0.001
3. TC helped me to achieve my goals.	95	0.78	Good	<0.001
4. I felt confident in the skills and knowledge of the therapy staff.	95	0.85	Very good	<0.001
5. Nursing and personal care staff assisted me to become more independent.	76	0.35	Fair	0.028
6. I had the opportunity to participate in social and recreational activities.	76	0.56	Moderate	<0.001
7. When I left TC I had the equipment and community services I required.	100	1.00	Very good	<0.001
8. When I left TC I had contact details for agencies involved in meeting my ongoing needs.	81	0.63	Good	0.001
9. I had to accept that I couldn't do all the things I used to. TC staff helped me deal with feelings of loss.	76	0.56	Moderate	0.003
10. It wasn't like hospital (home-like environment)	100	1.00	Very good	<0.001
11. I was moving into residential care and the TC staff realised it was a difficult time emotionally.	100	1.00	Very good	<0.001

TC, Transition Care; Observed, percentage observed total agreement

### 5.4.3 *Internal reliability*

Overall reliability for the first nine questions in the scale was only moderate (Cronbach's alpha 0.65) and changed little from self-respondents (0.67) to proxy respondents (0.63). The factor solution revealed three factors (Table 5.4) that accounted for 59% of the overall variance in these data. Factor 1 ('restoration') was represented by items Q3, Q5 and Q9 that ask about goal achievement, independence and adaptation. Factor 2 ('continuity') was illustrated by items Q7 and Q8 that ask if services and equipment were in place at discharge from TC. Factor 3 ('involvement') was represented by questions about preparation to enter TC (Q1) and the opportunity for social interactions (Q6). The factor analysis did not yield any redundant questions.

The correlation between scores on each factor and a global measure of satisfaction (*overall, how satisfied were you with the care you received?*) was poor for two of the three factors. Pearson's correlation coefficient was moderate at 0.57 for 'restoration' and overall satisfaction, but poor at 0.18 for 'continuity' and satisfaction, and 0.11 for 'involvement' and satisfaction. Correlations between scores on each factor and scores on the CTM-3<sup>®</sup> were small but significant at the 0.01 level ( $r = 0.31$  for 'restoration',  $0.29$  for 'continuity', and  $0.23$  for 'involvement').

### 5.4.4 *Construct validity*

Mean scores for the three patient experience factors are presented in Table 5.5. They are displayed according to subgroups based on TC setting, respondent, satisfaction, dependency, hospital admissions since leaving TC and living arrangements at 3 months.

Table 5.4 Principal component analysis of questionnaire items

Question	Factor 1 Restoration	Factor 2 Continuity	Factor 3 Involvement
1. Prior to TC I had a good idea of what to expect from TC.	0.07	-0.16	<b>0.77</b>
2. TC staff and I agreed about my health goals and how to achieve them.	0.50	0.27	0.49
3. TC helped me to achieve my goals.	<b>0.79</b>	0.08	0.01
4. I felt confident in the skills and knowledge of the therapy staff.	0.66	0.27	-0.05
5. Nursing and personal care staff assisted me to become more independent.	<b>0.77</b>	-0.03	0.08
6. I had the opportunity to participate in social and recreational activities.	0.01	0.17	<b>0.57</b>
7. When I left TC I had the equipment and community services I required.	-0.01	<b>0.85</b>	-0.10
8. When I left TC I had contact details for agencies involved in meeting my ongoing needs.	0.16	<b>0.77</b>	0.27
9. I had to accept that I couldn't do all the things I used to. TC staff helped me deal with feelings of loss.	<b>0.73</b>	-0.08	0.18

Within each column, **bolded** numbers indicate the items that are most representative of the factor

Table 5.5 Comparison of factor scores by TC setting and respondent characteristics

	<b>n</b>	<b>Restoration</b>		<b>p</b>	<b>Continuity</b>		<b>p</b>	<b>Involvement</b>		<b>p</b>
		<b>Mean (SD)</b>			<b>Mean (SD)</b>			<b>Mean (SD)</b>		
TC setting										
Residential	157	-0.42	(1.49)	< 0.001	0.01	(1.14)	0.849	-0.03	(1.24)	0.787
Community	401	0.19	(1.06)		-0.01	(1.28)		0.00	(1.23)	
Respondent										
Self	365	0.18	(1.16)	< 0.001	-0.01	(1.21)	0.794	-0.04	(1.17)	0.304
Proxy	217	-0.30	(1.28)		0.18	(1.25)		0.07	(1.31)	
Satisfaction										
Dissatisfied	32	-2.35	(1.58)	< 0.001	-0.29	(1.34)	0.167	-0.54	(1.03)	0.012
Satisfied	534	0.15	(1.06)		0.02	(1.23)		0.03	(1.24)	
Function										
MBI < 75	101	-0.38	(1.47)	0.001	0.05	(1.13)	0.673	0.10	(1.32)	0.342
MBI ≥ 75	480	0.08	(1.15)		-0.01	(1.25)		-0.03	(1.21)	

Table 5.5 Comparison of factor scores by TC setting and respondent characteristics (cont...)

	<b>n</b>	<b>Restoration</b>		<b>p</b>	<b>Continuity</b>		<b>p</b>	<b>Involvement</b>		<b>p</b>
		<b>Mean (SD)</b>			<b>Mean (SD)</b>			<b>Mean (SD)</b>		
Living at 3months										
Community	475	0.10 (1.17)		< 0.001	-0.02 (1.25)		0.404	-0.02 (1.22)		0.755
Residential care	89	-0.49 (1.41)			0.10 (1.06)			0.03 (1.30)		
Hospital										
≥1 admission	128	0.02 (1.26)		0.883	-0.24 (1.10)		0.010	-0.06 (1.06)		0.563
0 admissions	449	0.00 (1.22)			0.07 (1.26)			0.02 (1.27)		

#### **5.4.5 Factor 1: 'restoration'**

Restoration scores differed by TC setting, respondent, overall satisfaction with care, functional status and living arrangements at 3 months. Recipients of TC in a residential setting had lower scores compared to those who received TC in the community. The mean score obtained from proxy respondents was lower than from self-respondents. Satisfaction with care resulted in a higher mean than that reported by those who were dissatisfied.

Respondents who reported better functional ability ( $MBI \geq 75$ ) had higher mean restoration scores (mean 0.08, SD 1.15) than those whose MBI was less than 75. Finally, restoration scores were higher for respondents living in the community at 3 months compared to those who were living in RAC.

##### **5.4.5.1 Factor 2: 'continuity'**

Respondents with one or more hospital admissions in the three months since discharge from TC had lower mean continuity scores than those who reported no hospital admissions in this period. No other significant differences were noted for continuity.

##### **5.4.5.2 Factor 3: 'involvement'**

Again, only a single statistical difference was noted for involvement, with satisfied respondents reporting higher scores than those who were dissatisfied with care.

### **5.5 Discussion**

The aim was to develop a questionnaire to assess TC recipients' experiences of key aspects of program quality as defined in the TCP guidelines. The questionnaire has been shown to be feasible to administer by telephone interview and to discriminate between various aspects of care. Test-retest reliability was also demonstrated.

This study was the first to ask an Australia wide sample of TC recipients about their experience of TC. First, analysis of all valid responses revealed three factors (latent variables)

that contribute to patient experience of TC: restoration, continuity and involvement. Second, scores on each factor were found to differ across subgroups in ways that are consistent with the available evidence. For example, older adults who receive TC in a residential setting have poorer functional status on admission, make fewer gains compared to recipients of community-based TC and are more likely to transfer to a RAC facility on completion of the TC episode (Giles et al., 2008). Differences in scores on the restoration factor by TC setting, respondent, functional status and living arrangements at 3 month follow-up are consistent with the literature and support construct validity.

Similarly, the finding that dissatisfied respondents had lower scores on the restoration and involvement factors is consistent with previous research that identified self-care (Johnson et al., 2006; Quine & Morrell, 2007), participation in decisions and respect for preferences (Coulter, 2005) as highly valued attributes of health care.

Those who reported one or more hospital admissions in the 3 months since leaving TC had lower mean scores on the continuity of care factor than respondents who were not readmitted. Continuity of the care plan requires access to services that best meet the needs of the older person (Boling, 2009) and some TC services have reported difficulties in securing an appropriate level of ongoing care for patients who are discharged from TC (Chapter 4).

It is important that the findings reported here be interpreted in the light of several limitations. While the TCP requirements provided the conceptual framework for the questionnaire, not all requirements could be assessed through patient experience. Question development occurred as part of the NETCP and precluded initial testing of a larger set of questions. The sample of 630 respondents represented less than one fifth of the population of TC recipients discharged between February and June 2007. Of note is that the interviewed sample reported higher

functional status on the MBI and were discharged to the community at a higher rate than the total population of TC recipients over this period (Giles et al., 2008).

### ***5.5.1 Implications for policy and practice***

The present study has implications for the participation of older adults in the evaluation of TC. Specifically, the study has demonstrated that it is feasible to administer the questionnaire by telephone three months after discharge from TC. The majority of older adults were able to respond to questions about their understanding of TC and participation in goal setting as well as their experience of care. Understanding the purpose and potential benefits of TC can improve older persons' engagement with the program (Benten & Spalding, 2008) while attention to individual goals and preferences is a key factor in satisfaction with the outcomes of TC (Wilde & Glendinning, 2012). Feedback from older adults and carers about their experience of discharge from TC may also assist policy makers to identify and respond to gaps in community services due to geographical or other factors.

Structured and uniform collection of information from TC recipients about their experience of care would enable public reporting of service quality and assist consumers to make informed choices. Consumer access to information about the quality of services will become increasingly important as the government moves towards an aged care entitlement, deregulation of the number of aged care places and greater competition between providers (PC, 2011). In the interim, governments could consider financial incentives for providers that involve users in the evaluation of TC and meet specific quality criteria.

Older adults with moderate to severe cognitive impairment may be unable to participate in a structured evaluation of TC. Nevertheless, the present study has found that it is feasible to administer a standardised measure of experience of care to older adults and fill a gap in quality assurance activities undertaken by TC services in Australia.



## **5.6 Summary**

Providers' self-reports of performance against the key requirements of the TCP have highlighted several areas for targeted quality improvement activities, including pharmacist review of medications<sup>1</sup> and provisions for clients' ongoing needs once TC care has finished (Chapter 4). Quality reports are completed in the first year and may reflect the early developmental phase of many services. As the TCP matures, its quality assurance systems need to evolve.

Patient experience is an important component of quality assurance. A shift has occurred from measuring satisfaction with care towards asking whether or not certain processes or events occurred during an episode of care. In this way, patients' experiences can be aggregated and become part of a broader set of indicators of quality and safety, rather than an add-on.

This study represents an initial attempt to measure patient experience of TC against program requirements. Preliminary testing indicates that the questionnaire is reliable and has satisfactory construct validity. It has proven to be appropriate for TC recipients and could fill an important gap in the information available to program and policy staff.

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<sup>1</sup> Changes to the TCP Guidelines 2011 in relation to this requirement are discussed in Chapter 10.

## CHAPTER 6

### *DECISION MAKING ABOUT ENTRY TO RAC FROM A HOSPITAL BED*

*Since it is the Other within us who is old, it is natural that the revelation of our age should come to us from outside - from others.*

Simone de Beauvoir

#### **6.1 Introduction**

For many older Australians the decision to enter RAC is made from a hospital bed. Indeed, having a formal aged care assessment conducted in the hospital setting greatly increases the odds of a recommendation for RAC compared with being assessed in the community (NDR, 2009). Data from the Aged Care Assessment Program in Australia 2007-08 identifies the following factors as increasing the likelihood of an ACAT recommendation for RAC: advanced age (80 years or over), having a severe or profound core activity restriction, living alone or with non-kin, having a diagnosis of dementia, stroke, chronic lung disease, anxiety, depression or other psychiatric disorder (or experiencing confusion or disorientation), bowel incontinence, and use of residential respite. Protective factors include being female, having a co-resident or non-resident carer, informal assistance, use of formal services, carer respite and day therapy (NDR, 2009).

As discussed in Chapter 2, the provision of RAC in Australia is tightly regulated. Further, there is currently limited choice of provider because of high occupancy (Flicker, 2011).

Therefore older Australians often have to take the first bed available rather than being able to choose their future living arrangements. The introduction of the TCP in 2005 is likely to have alleviated the pressure for some older Australians who may otherwise enter RAC directly from hospital and specifically those who are assessed as having a potential to make functional gains that may enable them to enter RAC at a lower level of dependency as well as those who

require more time to determine the most appropriate long term living arrangements (DoHA, 2011).

The experience of searching for and selecting a RAC facility following a hospital admission has been described previously (Cheek & Ballantyne, 2001; McAuley, Travis, & Safewright, 1997) and decision-making about entry to RAC has also been explored (Davies & Nolan, 2003; Lundh, Sandberg, & Nolan, 2000; Nolan et al., 1996). Although some studies include older adults as research participants (Atkinson, Tilse, & Schlecht, 2000; Espejo, Goudie, & Turpin, 1999; Heppenstall, Keeling, Hanger, & Wilkinson, 2014; Johnson, Popejoy, & Radina, 2010; Jordan & Lindsay, 1998), eligibility criteria generally exclude those with cognitive impairment. In the studies cited above, cognitive impairment was most commonly defined with reference to validated assessment tools (Atkinson et al., 2000; Johnson et al., 2010), capacity to consent (Heppenstall et al., 2014) or participate (Jordan & Lindsay, 1998), mental state or diagnosis of dementia (Cheek & Ballantyne, 2001).

More than 50% of older adults in RAC in Australia have a diagnosis of dementia (AIHW, 2012) and little is known about their experience of entering RAC from a hospital bed, nor of their opportunities to participate in the decision making process. Concerns about the limited extent to which people with dementia are involved in important decisions about their lives have led to the development of more inclusive (National Health and Medical Research Council, Australian Research Council, & Australian Vice-Chancellors' Committee, 2007) and relationship-centred approaches to consent and research participation (Dewing, 2002; Hellstrom, Nolan, Nordenfelt, & Lundh, 2007).

Only a small number of the above studies describing the move to RAC have included social workers as research participants (Hicks, Sims-Gould, Byrne, Khan, & Stolee, 2012; Taylor & Donnelly, 2006; Thetford & Robinson, 2006; Wilson, Setterlund, & Tilse, 2003). This

precludes the views of a key professional group often responsible for negotiations around post-hospital placement, including those between the patient and family members.

In the hospital setting social workers have specific responsibilities with regard to older patients who are flagged as potentially requiring admission to RAC. These responsibilities include facilitating ACAT assessment, assisting families to secure a RAC place and monitoring progress towards placement for those patients assessed as eligible for RAC.

Social workers are tasked with finding efficient solutions to post-hospital placement (Efrainsson, Sandman, Hydén, & Rasmussen, 2004) and work within a traditional hierarchy in which medical staff decides when the patient is clinically stable and social workers are responsible for arranging post-hospital care. Other health professionals such as physiotherapists, occupational therapists and nurses have complementary roles in assessing physical function and the ability to plan and manage activities of daily living but social workers have primary responsibility for negotiating and enacting the decision to move to RAC.

### ***6.1.1 Approaches to patient autonomy***

Social work practice in Australia is underpinned by a traditional approach to bioethics with an emphasis on individual autonomy. This approach is encapsulated in the Australian Association of Social Workers (AASW) Code of Practice (2010, p. 25) which states:

*Social workers will promote the self-determination and autonomy of clients, actively seeking to enable them to make informed decisions on their own behalf [and] will act to reduce barriers to self-determination for those who are unable to act for themselves, because of factors such as vulnerability, disability, age, dependence, language, religion and/or culture.*

An alternative approach views decision-making in health care from a social constructionist perspective and examines how professional discourse and practice limit patient autonomy.

Drawing upon Foucault's theory of governmentality (1991), Hicks and colleagues (2012) conceptualise decisions about post-hospital care for frail older persons as dispersed through networks of health professionals who guide individuals to make decisions that are 'rational' and conform to what is in their best interest. Hicks argues that the options available to older persons are bound by existing service configurations and describes how resistance on the part of the older person is reinterpreted as the person being 'unrealistic' (Hicks et al., 2012).

### ***6.1.2 Study aims***

The study described in this chapter sought to address gaps in the literature through the inclusion of older adults with cognitive impairment as well as social workers. The study aims were: (i) to examine pathways that lead to hospital admission; (ii) to explore the decision-making surrounding the move from hospital to RAC; (iii) to identify ways in which transitions could be improved.

## ***6.2 Methods***

### ***6.2.1 Design and setting***

Semi-structured interviews were conducted with a purposeful random sample of older inpatients at the Repatriation General Hospital (RGH) in Adelaide, South Australia and their informal carers and relevant social workers. The Aged Care Client Record for each participant was also examined.

### ***6.2.2 Rationale for a purposeful sampling methodology***

The sampling framework was the list of inpatients approved for low or high level RAC and awaiting placement. The number of patients awaiting placement on any one day varied between 21 and 27 and as this number of interviews could not be accommodated by the researcher prior to patient transfer to RAC, a decision was taken to employ a purposeful random sampling strategy. The purpose of a small random sample is credibility (Patton,

2002) and, in the context of the study described here, credibility was enhanced through the selection of potential participants from the pool of all patients awaiting admission to RAC, including those with cognitive impairment. In examining factors important in the move from hospital to RAC, the experience of older adults as participants in decision-making as well as the meaning that older adults gave to their situation (Liamputtong, 2013), were of interest. For this reason, sampling was not limited to cognitively intact adults.

Permission to undertake qualitative interviews with older adults moving from hospital to RAC was first sought from the head of the social work department at the RGH and was granted with the proviso that the researcher consult with the relevant social worker prior to approaching individual patients and carers. The social worker could request that an individual or family not be approached to participate if they were aware of a heightened level of distress surrounding the decision. The acceptability of an audio-recording device was also questioned.

### ***6.2.3 Eligibility for inclusion in the study***

Inclusion criteria were: ACAT approval for permanent RAC (low care or high care), the ability to provide informed consent (or family member available to provide proxy consent), informal carer willing to be interviewed, and social worker approval to approach the patient and family. Inpatients of palliative care, rehabilitation and psycho-geriatric wards were excluded, as were patients who were admitted to hospital from RAC and those scheduled to transfer to RAC within 24 hours. Patients who did not have an informal carer, or where the carer was unwilling to participate in the study or did not have basic proficiency in English, were excluded.

### ***6.2.4 Development of the interview schedule***

Question development was informed by a review of the literature as well as discussions with the heads of the social work department and a geriatrician with extensive experience in

conducting ACAT assessments in both hospital and community settings. In addition, social workers from relevant wards were invited to attend a presentation of the research proposal and to provide feedback. Social workers were interested in eliciting feedback from study participants about ways in which transitions from hospital to RAC could be improved and a question was added to the interview schedule to accommodate this request.

There were five key questions about the experience of moving from hospital to RAC and the factors that were important in the decision-making process (Table 6.1). Patients and carers were asked the same questions, with minor changes to accommodate the relationship between the patient and carer (e.g., from “your ...” to “your husband’s ...”).

Table 6.1 Questions posed about the experience of moving to RAC

- 
1. What has changed as a result of the illness or injury that led to your hospitalisation? Prompt: how were you managing before the illness or injury that led to your hospitalization?
  2. Had you thought about the possibility of moving to residential care before being admitted to hospital?
  3. Do you know what level of care you have been approved for?
  4. What factors did you weigh up in making the decision to move into residential care?
  5. Would different or further information about moving into residential care have assisted you in making the decision?
- 

Social workers were asked what prompted the ACAT assessment, whether the patient and carer had arrived at a decision about residential care, the main factors in the decision and their thoughts about how the process could have been improved for the patient and family.

The questions for social workers are shown in Table 6.2.

Table 6.2 Questions for social workers about the decision to move to RAC

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1.	What prompted the ACAT assessment?
2.	What was the outcome of the ACAT assessment?
3.	Have the patient and carer arrived at a decision about residential care?
4.	What are the key factors in this decision?  For the patient...  For the carer...
5.	How could we improve the process for this patient/ family?

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### **6.2.5 *Supplementary data***

As part of formal consent, permission was sought from the patient (or their proxy) to access the Aged Care Client Record (ACCR). The ACCR included socio-demographic information (age, gender, usual living arrangements) and detailed the older participant's pre-morbid and current activity limitations as well as the provision of formal and informal assistance. The ACCR also identified the primary health condition that had the greatest impact on the need for assistance with activities of daily living and social participation (from the perspective of the ACAT assessment team) and made recommendations regarding the most appropriate living environment for the person's long term care needs. The use of multiple evidentiary sources (i.e., documents and interviews) allows the development of a comprehensive understanding of the phenomena, reduces the potential bias associated with using a single method and can enhance interpretative rigour (Mays & Pope, 2000).

### **6.2.6 *Ethical considerations***

The study was approved by the RGH Research and Ethics Committee (Protocol 35/06) and registered with the Australian New Zealand Clinical Trials Registry ANZCTR, registration



number ACTRN12606000302550. All participants gave informed consent, and proxy consent was also obtained for patients with cognitive impairment, as reported by the social worker.

### **6.2.7 Procedure**

Patients and family members were interviewed separately and in a private area of the ward, most often a treatment room or sunroom. The aim of the interviews was to enable participants to relate their experience of hospital admission and the decision to move to RAC, in their own narrative (Patton, 2002). An advanced practice nurse (aged care) was available to assist with the interviews, which enabled the researcher to focus on the interview process. A transcript was prepared immediately following the interview and a copy provided to participants for review. This was read aloud to patients with failing vision and those who expressed a preference for this procedure. The purpose of the transcript was to reduce error through respondent validation (Mays & Pope, 2000), provided a written record of participation, the opportunity to reflect on and clarify responses, and validate participants' ownership of how their experiences and views were portrayed. The way that people interpret their experience can change over time (Kitto, Chesters, & Grbich, 2008) and rapid dissemination of the transcripts aimed to reduce this effect.

### **6.2.8 Analysis**

Descriptive statistics were used to summarise respondent characteristics such as age, gender and number of days from ACAT assessment to interview and transfer to RAC. Interviews with participants, carers in particular, yielded rich accounts of events that led to hospital admission and a recommendation for RAC. The temporal aspects of the data, significance accorded to particular events and deeply contextualized accounts led the researcher to consider a narrative approach to analysis. A narrative approach also provided a way forward

with respect to the complex, multilayered and contested ‘truths’ about moving from hospital to RAC as revealed by the central characters in the plot (patients, carers and social workers).

### **6.2.9 Narrative inquiry**

The proposition of narrative inquiry is that people use stories to accomplish specific purposes. These purposes include assigning meaning to personal experience, conveying that meaning to others, constructing and reconstructing identity, and to persuade others. In everyday stories “a speaker connects events into a sequence that is consequential for later action and for the meanings that the speaker wants listeners to take away from the story” (Riessman, 2008, p. 3). ‘Sequence’ and ‘consequence’ are integral aspects of narrative as well as approaches to the analysis of narrative.

A narrative has a plot, episodes or events central to the story, themes, characters and a point of view from which the story is told. Narratives are shaped and re-shaped through telling and are performative (Riessman & Quinney, 2005). Narratives can be functional, for example enabling individuals to re-cast chaotic experiences into causal stories in order to make sense of them and to render them safe (Bruner, 1990). In the same way that individuals construct stories of self “so too do nations, governments, and organizations construct preferred narratives about themselves” (Riessman & Quinney, 2005, p. 393).

The ability to narrate experience relies upon pervasive, culturally shared, and often unquestioned ‘truths’. Cultural and interactional contexts determine what can be said and taken for granted, and personal narratives convey as much information about ‘public’ issues as they do about the narrator. Personal narratives about the decision to move from hospital to RAC are embedded in social tensions concerning care for dependent elders, women’s work and the nuclear family as well as the economic and social conditions that shape participation in the labour market and attitudes to older adults. Moreover, authority over meaning is

dispersed between narrator and audience and certain forms of storytelling are privileged in hospitals and other powerful institutions (Riessman, 2008). The ways in which professionals talk about patients (in team meetings, for example) serves to construct particular case formulations, marginalizing other ways of thinking (Riessman & Quinney, 2005) and this has profound consequences for older people who are seen to be ‘unrealistic’ about their future living arrangements (Hicks et al., 2012).

### **6.2.10 Narrative methods**

Riessman (2008) describes four analytical methods: thematic, structural, dialogic/performance and visual, as well as various approaches that fit within each of these. Each method preserves the sequence and structure of personal accounts (Riessman, 2008); that is, they keep the story intact rather than disaggregating text in categories in the way that grounded theory and most other qualitative methods do. Narrative analysis is concerned with sequence, audience (for whom was *this* story constructed?), taken for granted knowledge, purpose (what does this story *accomplish*), as well as gaps and inconsistencies that might suggest a counter-narrative (Riessman & Quinney, 2005). Of the four methods described by Riessman, structural analysis directs attention to a ‘unit of discourse’ rather than a complete narrative and is congruent with the semi-structured interview format used to collect the qualitative data for the current study.

### **6.2.11 Gee’s approach to structural narrative analysis**

William Labov (Labov, 1982; Labov & Waletzky, 1967) and James Gee (Gee, 1985, 1991) are key figures in the development of structural approaches to narrative analysis. Despite a common focus on narrative structure, each has a distinctive analytic strategy. Labov uses structural coding to identify elements of a narrative such as ‘orientation’, as well as to examine relationships between plot units. Conversely, Gee works with units of speech known as ‘stanzas’. Stanzas attend to narrative sequence, as well as reproducing breaks and pauses in

the flow of speech that 'key' how a story is interpreted (Gee & Grosjean, 1984). In the present study, stanzas assist the reader to engage with the flow of thoughts and emotion as experienced by older persons when asked about the impending move to RAC.

### **6.3 Results**

Of 21 patients randomly selected, 11 did not meet eligibility criteria. Four were in palliative care, rehabilitation or psycho-geriatric wards, one was living in RAC prior to hospitalisation, another was for imminent transfer to RAC, and two did not have a carer available for interview. In three cases social workers requested that the patient and family not be approached. Of these, one was medically unstable and had a poor prognosis. The Guardianship Board was involved in the second case (as the patient was assessed as not having capacity to make the decision about long-term accommodation needs) and in the third case, the patient had dementia and was adamant that she could return home to live independently. The social worker expressed concern that the patient would become very distressed if asked about the impending transfer to RAC.

Permission was therefore gained to approach ten families, of which two patients were unable to be interviewed. One had suffered a stroke and had difficulties with receptive and expressive language and the second had severe cognitive impairment secondary to alcohol abuse. Of the eight remaining patients, six had a diagnosis of dementia and proxy consent was obtained to interview three of these. The two patients without dementia were approached regarding study participation and one consented to interview. Both patients nominated a family member who could be approached about the study. Consent was also obtained from each of the social workers who were involved in discussions with the patient and family as part of the decision to move from hospital to RAC.

In summary, there were 24 interviews in total, reflecting ten case studies. These comprised four patients, ten informal carers and ten social workers.

### **6.3.1 *Sample characteristics***

The mean age of patients was 84.1 years (SD = 5.1; range 73-88 years). Seven were male. Five patients lived alone and five had a co-resident carer, most often a spouse ( $n = 4$ ). Reason for hospital admission was recorded as 'increased or intermittent confusion' ( $n = 2$ ), 'severe dementia' ( $n = 2$ ), 'dizziness for investigation', 'post CT head', 'situational crisis', 'congestive cardiac failure', 'bilateral deep vein thrombosis' and 'above knee amputation'.

An ACAT recommendation and approval for RAC occurred during the index<sup>1</sup> hospital admission (five cases), during a previous hospital admission (three cases), or in two cases ACAT approval for RAC was granted while the older person was living at home in the month prior to hospital admission.

Of the five patients who had an ACAT assessment during the index admission, three assessments were completed between Day 8 and Day 10 of admission. Two assessments occurred on Day 22 and 24 post hospital admission. One assessment was delayed due to medical instability and, in the second case, due to a delay in obtaining formal assessment of the older person's decision making capacity. Two patients died prior to transfer to RAC and a third died two weeks after transfer. Participant characteristics are shown in Table 6.3<sup>2</sup>.

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<sup>1</sup> In this chapter, index admission refers to the hospital admission during which consent to participate in the study was obtained.

<sup>2</sup> All names in this chapter are pseudonyms. Names of places have been changed or omitted.

Table 6.3 Participant characteristics

<b>Case</b>	<b>Betty #1</b>	<b>Olga #2</b>	<b>Thomas #3</b>	<b>David #4</b>	<b>Beryl #5</b>	<b>Frank # 6</b>	<b>John #7</b>	<b>William #8</b>	<b>Harold #9</b>	<b>Robert #10</b>
Gender (age)	F (87)	F (79)	M (85)	M (86)	F (88)	M (73)	M (88)	M (89)	M (87)	M (80)
Reason for admission	CCF	Severe dementia	Situational crisis	R) AKA	Bilateral DVT	Post CT Head	Dizziness FI	Intermittent confusion	Increased confusion	Severe dementia
Marital status	Widow	Widow	Widower	Married	Widow	Married	Separated	Widower	Married	Married
Lived alone	✓		✓		✓		✓	✓		
Dementia	✓	✓				✓		✓	✓	✓
Patient interviewed	✓	✓	✓	✓						
Carer interviewed	<b>Mary</b> (daughter)	<b>Philip</b> (son)	<b>Sarah</b> (daughter)	<b>Eunice</b> (wife), <b>Carolyn</b> (daughter)	<b>Julie</b> (daughter)	<b>Evelyn</b> (sister)	<b>Ruth</b> (former partner)	<b>Anne</b> (daughter)	<b>Michael</b> (son)	<b>Joan</b> (wife), & daughters
LOS (days)	73	50	29	62	28	161	58	39	52	67
Discharge destination	LLC	HLC	Died	HLC	HLC	HLC-D	LLC	Daughter's home	Died	HLC

CCF = congestive cardiac failure; CT = computerized tomography; DVT = deep vein thrombosis; ESL = english as a second language; F = female; FI = for investigation; HLC = high level care; HLC-D = high level care, dementia; LLC = low level care; LOS = Length of stay; M = male; R) AKA = right above knee amputation

### 6.3.2 *Patient narratives and interpretation*

Of the four patients interviewed, two had a diagnosis of dementia and a third had difficulty recalling his age. Brockmeier (2000) argued that the process of remembering is a back-and-forth movement between the past and the present whereby “we revise and edit the remembered past to square with our identities in the present” (Riessman, 2008, p.8) thus it is perhaps unsurprising that patients provided a sanguine narrative about how they were managing at home prior to hospital admission. Following Gee’s approach to narrative analysis (1984), units of speech are presented with breaks and pauses that ‘key’ how a story is interpreted.

#### 6.3.2.1 *Case 1 – Betty’s story*

Betty was 87 years old. Prior to hospitalisation, Betty lived alone, injected herself with insulin and monitored her blood sugar levels with Royal District Nursing Service (RDNS) oversight. Betty had ulcers on both legs as a complication of her diabetes and had been diagnosed with Alzheimer’s Dementia and Congestive Cardiac Failure (CCF). Betty was admitted to hospital following a routine appointment with a podiatrist who referred her for urgent GP review. I asked Betty how she was managing at home, before coming to the hospital.

*The RDNS people used to come*

*Matthew would come*

*He would come in and say “how are we today Mrs B”.*

*He liked his biscuits*

*I always kept a packet of those (gestures, appears to be breaking in two)*

*Interviewer: Scotch finger?*

*Yes, I kept those ones in the cupboard for Matthew.*

The simple narrative above had a purpose, which is to defend an identity as a competent person who engaged in reciprocal relationships with others. A subsequent unit of speech

arises from a similar position as a ‘defended self’ (Hollway & Jefferson, 2000), this time in response to the question “Were you involved in the decision to move to a nursing home?”

*No, and I’m not happy about it either.  
I don’t want to be under anyone’s thumb.*

*Do you know which ones?  
Can you give me the names of the nursing homes  
so I can pick for myself?  
and I’d see what the girls would like.*

*I’ve got three daughters  
Deidre, and  
do you know the names of the others?  
I’ll let you know when I think of it*

*I don’t want to go to that one up the road  
what’s it called?*

*What bothers me is that  
they didn’t bother to tell me.  
Even my mother and father  
didn’t bother to talk to me.  
They didn’t bother to tell me and I’d been his only child*

*He was a butcher...  
I worked alongside my father before I went to high school  
I used to make a home delivery to a Mr. Smith.*

The narrative occurred in a flurry of speech and the narrator was unperturbed by the names that she was unable to retrieve. The narrator asserts a desire for involvement in decision making and to choose where she will live. In doing so she recalls another time, being sent to boarding school.



From the vantage point of the researcher, there appears to be a disjunction between the way that Betty sees herself (self-identity) and how others see her (social identity). In moving from home to hospital and waiting for a RAC bed, Betty had also moved from self-determination to substitute decision making, notwithstanding her daughter's (Mary) desire to involve her mother in the decision to enter RAC. The narrative suggests that Betty had yet to accept the 'biographical disruption' that was occurring (Beard, 2004) and was vested in preserving her self-identity.

#### **6.3.2.1.1 Mary (carer)**

Family concerns about the safety of an older person who lives alone are common. These concerns can be exacerbated by distance, health conditions, advancing age and signs of a decreased capacity for self-care.

Mary was separated from her mother by a five hour drive. In 2006, Mary's mother, Betty, stopped taking her medications and was admitted to hospital for several weeks. Betty was subsequently discharged with RDNS visits three times a week to supervise showering and diabetes self-care as well as dressing her leg ulcers. Mary also arranged a meal delivery service.

Less than a year later, Betty was readmitted to hospital with hypoglycaemia. She was found unconscious by RDNS and Mary was told that it took the paramedics about 30 minutes to rouse her mother. Betty was in hospital for about a week before being deemed ready for discharge. Mary felt that the decision to discharge her mother was premature.

*They wanted to discharge her and she was still confused. She wasn't oriented to place. She thought she was at the Adelaide Railway Station and was asking for her father. They sent her home and I knew she wasn't right. I wanted her to have an ACAT. I asked the hospital to arrange an ACAT but she was discharged without one.*

Mary and Betty were fortunate in having family friends who lived close to Betty and were able to 'keep a look out' for her welfare. The couple, aged in their seventies, had expressed concern about Betty's increasing forgetfulness and was alarmed to find Betty in the front yard of her home at midnight with a torch, unsure of where she was. They told Mary they were afraid to go away on holiday in case something happened.

Mary described herself as a 'planner'. She knew that it was difficult to get into RAC; that there were long waits and that her mother needed an ACAT. A couple of months after her mother was discharged from hospital, Mary contacted the regional ACAT service to request an appointment. She was dismayed at being told that the waiting time for an ACAT assessment was 6-8 months and further distressed by the staff member's suggestion that, should something go seriously wrong, her mother would receive the care she required.

Betty had a diagnosis of Alzheimer's Dementia and had been prescribed donepezil in the hope that it would improve her cognitive function. Betty's GP also recommended that her driver's licence not be renewed. Betty was having difficulty using familiar appliances including the microwave that she used to defrost and heat frozen meals on the weekends. Mary was in Sydney on Australia Day when her mother phoned saying there'd been no money on Friday and that she had no food. When Mary returned home her mother asked if one of her children had gone to Sydney and flown in a hot air balloon.

A third hospital admission, resulting in an ACAT recommendation for RAC, was prompted by a routine podiatry visit. Concerned by Betty's leg oedema, the podiatrist recommended review by a GP who subsequently recommended hospitalisation for management of CCF.

Mary found it difficult to talk to her mother about moving into RAC. Several months earlier a friend had suggested to Betty that she consider moving in with Mary. Betty's response had been to 'close down' and Mary thought that her mother's recent complaints of feeling sick

and refusing to eat following the offer of a RAC bed were an attempt to regain some control of her situation.

Stones and Gullifer (2014) suggest that defiance, even when the ‘battle is all but lost’ demonstrates the psychological strategy of ‘secondary control’. Further reading however, reveals considerable divergence in the way the construct of secondary control has been interpreted and tested empirically (Morling & Evered, 2006) as well as some equivocal statements in the original work by Rothbaum, Weisz and Snyder (1982). For the present study, the following assertion invites reflection as further narratives are examined.

*Because control is so valued, the quest for it is rarely abandoned  
(Rothbaum et al., 1982 p.,7)*

#### **6.3.2.1.2 Social work perspective on Betty**

The social worker requested an assessment of Betty’s testamentary capacity so as to provide Mary with additional information about her mother’s insight into her care needs and decision-making capacity. If Betty was assessed as lacking the capacity to make decisions about her future care, her daughter could evoke Power of Guardianship and make the decision about RAC admission on behalf of Betty.

The assessment determined that Betty had (limited) capacity to make the decision and this information provided the context for discussions between Mary and her mother. The social worker noted that although Betty deferred to Mary verbally, Betty’s body language made it clear that she did not want to go to RAC.

*It took a few days and much talking for Betty and her daughter to arrive at a decision for placement.*

As well as navigating relational complexities and differing perspectives, social workers need to consider care needs in the context of available services, formal and informal, public and

private. Like other health professionals, social workers are often working with a fragmented and incomplete patient history, pieced together from interactions with the patient, family and health professionals. Some sources are privileged over others and some pieces of information are accorded greater significance by the recipient than the narrator. The story of Betty wandering in her yard at night, unsure of where she was, became important in framing expectations and intentions regarding RAC. Only private services can manage overnight care needs and this was not an option for Betty due to financial constraints. This information set the scene for an ACAT assessment undertaken with the intention of placement rather than support services to remain at home.

### **6.3.2.2 Case 2 - Olga's story**

Olga was a 79 year old widow who was diagnosed with Alzheimer's Dementia about 12 months prior to being interviewed. Olga had lived alone for many years but in recent months Olga's son Philip and his dog Jed had come to live at the house. Sometimes the trio travelled south to stay at Philip's house. Olga was happy with this arrangement.

Something had changed and Olga found herself sharing a room with three other women. The room opened onto a hospital corridor. Philip visited regularly and sometimes they sat outside in the sunshine. He became uncomfortable whenever Olga asked about going home. There was talk of a nursing home. I asked Olga how she was managing at home before coming to the hospital.

*Well, I think I had gone a bit off, but*

*I knew what I was doing.*

*I had a turn,*

*I forget things*

*I got uptight*

*At the end, I got mixed up*

*– funny in the brain for a while*

*I'm better now.  
We had help with the cleaning, but  
that dropped off  
we don't have it anymore.  
My son is a marvellous cook  
I can manage my own meals  
I did have Meals on Wheels  
Once, a long time ago.*

In the narrative above, Olga attempts to reconcile what others have said with her own (defended) sense of self. The temporal aspects are important as the narrative moves between a remembered past (managing fine, having trialled and foregone various forms of home help), the present (I'm okay now) and acknowledgement of a period of confusion in between. A second excerpt concerns the decision to move to RAC.

*I was angry at first  
That they would  
put me in a nursing home  
I've looked after them all these years  
I'd sooner be in my own place  
I've seen what those places are like  
I wouldn't want to go to one.*

*If he asked me,  
I'd say  
I don't need a nursing home.  
But he knows  
I don't like people over my shoulder.*

*Whatever he comes up with,  
I'll fall into place.  
For a son,  
I couldn't have done better.*

*I don't want to upset him, but  
I like to express my own opinion  
I'm not ready for the loony bin  
What should I do  
...just sit back?  
I have to say something  
I can't just let them put me somewhere.*

*Has a decision been made?  
He could take me out now  
I've said to him  
"just take me home for a day ... half a day"  
I don't understand  
I want to see what the place looks like.  
I want to check on Jed.*

Dementia is often understood as a gradual erosion of identity and loss of what it means to be a person. A study that included interviews with older people at the time of diagnosis of Alzheimer's Disease found that older adults deliberately manage their interactions to make sense of their lives and preserve their self-identity (Beard, 2004). A recent review of both qualitative and quantitative studies that have examined aspects of self, concluded that there is at least some evidence for persistence of self in both the mild and moderate-to-severe stages of dementia (Caddell & Clare, 2010).

Olga's story has a purpose and a plotline. The purpose is to convey an image of a 'reasonable' person who is considerate of the needs of her unmarried son (Philip), whilst also protesting at the silence in response to her requests to return home 'one last time'. Olga describes moving from initial anger towards a position where she will accept the decision that her son makes about her future living arrangements. This is not to suggest that Olga accepts moving to RAC. She despairs at the thought of living in a shared space and the surveillance

that incurs. She says “he knows that I don’t like people over my shoulder”, but the narrative suggests that much is left unsaid between mother and son. The plea to the researcher, captured by the question “what should I do?” suggests that Olga would appreciate an opportunity to talk about how she is feeling and the difficulty of balancing her own desires and respect for her son’s autonomy.

#### **6.3.2.2.1 Philip (carer)**

Olga’s narrative revealed expectations of her unmarried son that Philip wasn’t sure he was comfortable with. The expectation to share a home did not extend to Philip’s brother and sister-in-law. Philip tried to imagine his future. His mother had fallen once while staying with him and Philip had rails installed in the wet areas to reduce the risk of a recurrence. He lived in a semi-rural area and felt ‘walled-in’ while staying at his mother’s home in the city. Philip spoke of his alarm at waking one morning to find that his mother had left the front door open. He also recounted how he’d gone out with friends one evening and returned around midnight to find his mother worrying, even though he’d left her with a list of phone numbers so that she could contact him. At times, the responsibility and the constraints on his personal freedom were overwhelming. On a week when his mother seemed particularly confused, Philip took his mother to see the GP. He talked candidly about the strain he was feeling. The GP referred Olga to the hospital with a letter of referral that detailed a seven day history of delusions and increasing confusion, carer strain and a recommendation for RAC.

Philip found it difficult to discuss RAC with his mother. In fact, a friend of his mother’s had stepped in and taken Olga to visit a RAC facility a week earlier. Despite his mother having been in hospital for more than a month, Philip wasn’t ready to fully broach the subject, or to deal with his mother’s frequent requests to go home.

*For Mum, her home is very important to her. She keeps asking if she can go home, just for half a day ... my concern is how would I get her to come back to the hospital?*

During an initial conversation with the researchers, Philip wavered between expressing an interest in further information about home care services, and tears, as he talked about his own health and concerns that he wasn't up to the task of caring for his mother full-time. One interpretation is that Philip was torn between continuing to care for his mother and his own needs. Another possible interpretation is that Philip had made a decision several weeks earlier but that he was still refining the narratives that he could call upon when discussing his decision with friends and family members, health professionals involved in the decision-making process, as well as researchers whom he had met briefly prior to the interview. Indeed, Rosenthal suggests that narratives are constructed in "the context of the interaction with a listener or imaginary audience" (Rosenthal, 1997, p. 63).

Drawing upon the work of Gubrium and Holstein (2009), Chase describes the interplay between the narrator and the listener whereby narratives have purpose and consequence and may be accepted, or challenged. "In this approach, narration is the practice of constructing meaningful selves, identities and realities" (Chase, 2011, p. 422).

#### **6.3.2.2.2 Social work perspective on Olga**

The social worker described how she had met with Philip and his brother and presented information about the home care options that could be considered as well as RAC. The social worker suggested it would have been easier for Philip if the move to RAC had occurred soon after the decision was made, stating "Every time he visits his mother he is confronted with the decision".



All participants were provided with an advance copy of the interview schedule and social workers generally provided concise and considered responses. When asked about the key factors in the decision for Olga and Philip, the social worker responded as follows;

*[Olga] doesn't have a carer who can provide the 24 hour supervision that she needs. Her son has good insight re his own health problems. He knows he can't commit long term ... that the caring arrangements prior to hospitalisation aren't sustainable.*

The response appears factual and unencumbered by the emotions and expectations of mother and son. Indeed, the GP had 'set the scene' by sending Olga to the hospital with a letter indicating that she was no longer safe to live alone, the caring arrangements were unsustainable and that Olga required permanent RAC. The history of a marked increase in confusion and delusions was transcribed to the ACCR. In a person with dementia, an increase in confusion can often signal that the patient is unwell. In a person with diabetes, illness can lead to high blood sugar levels, drowsiness and confusion. There may have been a simple and reversible reason for the deterioration in Olga's cognitive status but for her son, the increase in stress and responsibility led to a crisis and an authoritative figure (GP) had intervened.

The social worker reported that Olga's cognitive status had improved since admission, indicating that although Olga sometimes had difficulty finding her room, she was easily redirected. In relation to self-care, nursing staff had noted a few episodes of incontinence but reported that Olga was largely 'self-care'.

The ACAT assessment recommended permanent RAC. Alternative ways to support Olga in her home, and her son in his voluntary role as a carer, had not been exhausted. Decisions are made cognisant of available resources. The ACCR noted that Olga required supervision, prompting and direction because of her dementia as well as assistance with diabetes monitoring. The social worker was surprised when the ACAT approval was for HLC as

Olga's needs may have been met in a dementia-specific LLC environment. Demand for dementia-specific LLC places exceeds supply and older persons with dementia may be at risk if they wander outside the grounds of a regular LLC facility. If the care arrangements had been sustainable, Olga could have joined a waiting list.

Philip expressed an interest in learning more about alternatives to RAC but was also visibly distressed. The specialist aged care nurse who conducted the interview proceeded with care. After the interview we reflected on the son's expression of ambivalence and guilt. Social workers navigate this minefield frequently. In conveying the decision about entry to RAC as based on simple truths, perhaps social workers find themselves reproducing the facts that fit the chosen path.

It is easier to move someone from hospital to RAC. Hospital routines reinforce a loss of autonomy and older patients quickly lose confidence in their ability to influence decisions about their long term living arrangements. It can be uncomfortable for older adults to acknowledge their reliance on others, as doing so may threaten their self-identity. Moreover, dependence on family members changes the relationship and older adults frequently express concerns about being a 'burden' on others.

### **6.3.2.3 Case 3 - Thomas' story**

Thomas is 85 years old but when I ask Thomas to tell me his age, he says "I'm 58, I'm the same age as the blokes in the other beds", and gestures to the men in the beds opposite.

Thomas' medical records indicate the reason for admission as 'situational crisis', however that doesn't concur with the account given by his daughter, Sarah. When I speak to Sarah, her eyes well with tears as she recounts the first time her father asked her for help and how she'd taken him to see one doctor, and then a second, about the pain in his back and his desire for

assistance with the tasks of everyday living. I asked Thomas how he was managing at home before being admitted to hospital.

*I wanted to live in a nursing home  
I get a lot of pain.  
I think of it as a red dot here (points to R shoulder)  
a yellow dot here (L collarbone)  
a grey one back here somewhere (L shoulder)  
I class them according to how strong they are  
and how they knock me around*

*I don't know why I get it.  
They tell me "you're getting a bit more than the usual person".  
I ask "am I doing anything wrong?"*

*I couldn't go back to  
- on my own  
It's too hard.  
I have to go to the shops, get food and cook it  
- just for one person, just for myself  
It's not right.*

*I wanted to live in a nursing home  
This was the only way I could get there without breaking any laws  
I remembered I'd been in the Navy  
all those years  
I thought why not take (prompt: advantage?)  
yes, of those things  
But I don't know how I got here.*

The narrative provides a glimpse of the internal world of an elderly man who is struggling to understand what is happening to him. He doesn't know why he is in pain and, although he has asked others about his pain, he says they can't explain it either. Despite putting his best

efforts into answering the researcher's questions, Thomas appears to have difficulty making sense of his experience and admits that he can't recall how he came to be in the room that he shares with three other men. There are also two men in street clothes sitting in chairs by the window. These men are volunteers and part of their role is to alert staff if a patient is in danger of falling. One of the volunteers sees Thomas looking his way and raises his arm to wave. Thomas smiles and returns the wave. His daughter remarks that he enjoys the company of the other men.

Thomas' vivid description of his pain and the transparency of his responses provide additional lessons in understanding human frailty. Within three weeks of first meeting Thomas, he died. I stopped by to see him the evening before he died. He was laying in the hospital bed, peaceful and unaware of my presence, the palliative care specialists having ensured adequate pain relief. I said goodbye to this gentle man with a lovely sense of humour who had touched my heart.

In many ways, Thomas was fortunate. His medical and care needs were clearly evidenced, palliative care clinicians were available to guide care, Thomas remained in the same ward to which he had been admitted three weeks earlier and staff provided a peaceful and respectful environment for his passing.

#### **6.3.2.3.1 Sarah (carer)**

Sarah's narrative revealed a man who had experienced delusional thoughts over several years and described how this had contributed to several changes in living arrangements.

*Dad had been living in an Independent Living Unit. It was 3 or 4 years ago when he started complaining about his neighbour drilling holes through to his unit and threatening him. Dad announced that he was leaving the unit and going to live with my brother. He was 80 then. I remember saying 'Dad, you don't leave [name of aged care housing provider] at the age of 80.' But he was determined, and so*

*he went to live with my brother for about 9 months, until I insisted he come back to the city.*

*There had been some tension. Dad thought my brother was playing loud music at night. He wasn't. ... I found a place for Dad only a few streets from where I live. Dad said 'It's the happiest I've ever been. I'd like to die here.'*

Sarah was grief stricken at the diagnosis of advanced cancer and her father's rapid decline following admission to hospital. She described having taken her father to see a doctor a month before he was admitted to hospital with complaints of back pain and how the GP seemed disinterested and said it was 'all under control'. Sarah was distressed to think that her father may have been suffering more than she, and others, recognised.

*Dad had complained of back pain previously but in the last couple of weeks before he was hospitalised he started talking about major pain. He said he'd fallen over. He has always been a very private person. I made a double appointment with a new doctor on Monday hoping to 'sort out' what was going on with the pain. Doctor Smith was a wonderful and kind doctor. Dad was admitted to hospital the next day.*

#### **6.3.2.3.2 Social work perspective on Thomas**

Thomas was deceased at the time of the interview with the social worker. The staff member described how Sarah had arranged an outpatient appointment with one of the social workers, seeking assistance for her father. The appointment resulted in a referral for an ACAT assessment as well as an application for a personal safety alarm for Thomas to wear at home. Thomas was placed on the waiting list for an ACAT assessment in the community. Two weeks later, he was admitted to hospital with increasing pain and confusion.

An ACAT was arranged ten days after admission. Initially it was thought that Thomas would enjoy a better quality of life in LLC but his health declined rapidly, his prognosis was poor and high level RAC was recommended.

Social workers sometimes despair at the apparent lack of planning for increasing dependency that might necessitate a move to RAC and there are frequent calls to improve older person's participation in end of life care planning. For a subgroup of older persons like Thomas however, the pace at which disease evolves surpasses the plans that are being put in place. An ACAT provides a snapshot of a moment in time and, in circumstances such as those of Thomas, the assessment of needs is outdated even before approval for care is received.

#### **6.3.2.4 Case 4 – David's story**

David had lived with diabetes for many years and experienced the devastating vascular complications of the disease. He was legally blind, had one above knee amputation and, following a period of rehabilitation, required amputation of a second lower leg. David was well-educated and accustomed to being in control of his life and exerting a degree of control over those around him. He did not allow his increasing physical disability to negatively impact his sense of self-worth and was confident that his family would rally around and support his desire to return home. David had connections to senior public servants and past and present government Ministers and was aware that others had set precedents and negotiated to 'cash out' their aged care entitlements and manage their own care arrangements. David was confident that he could manage at home with twice daily care.

These plans were challenged by health professionals in the rehabilitation ward and the TC facility and, ultimately, by David's wife, Eunice and daughter, Carolyn. In David's case, as in similar situations, aged care and rehabilitation professionals supported a home trial so that David and his family could assess for themselves if they could manage at home. For David's family, having him at home for a few hours on Christmas Day confirmed the futility of the situation; they simply could not support their husband and father's desire to return home. I asked David how he was managing at home prior to his first amputation.

*How was I managing before coming to hospital?*

*I was handling all the financial affairs*

*I was managing very well*

*My wife did the running of the home.*

In responding, David asserts his ability to manage the couple's finances despite limited vision, and to maintain valued social roles and relationships. David fights against the threats to his "inner psychological continuity" as well as "outward continuity of social behaviour and circumstances" (Atchley, 1989, p. 183) that he associates with a move to RAC. I also asked David about his involvement in the decision to move to RAC.

*I didn't make the decision.*

*They made it – the doctors, and*

*The physio had a say*

*even though I never saw the guy*

*He had a say.*

*They assessed me, and*

*Without asking me any questions*

*They decided.*

*My response at that time was 'okay'*

*but I didn't know what was involved*

*My family were consulted, and*

*They made a decision.*

*My wife is frail and*

*They thought she couldn't manage*

*I've looked at the possible costs involved*

*because it affects my family,*

*and my family comes first.*

The narrative above reveals the anger, mostly contained so as to reconcile with a preferred self-identity as an articulate and reasonable man. Although other accounts challenge some of the ‘truths’ in the narrative presented here, David doesn’t try to disguise his subjective stance. The juxtaposition of ‘I’ and ‘they’ is stark, as if the narrator believes he has to shout in order to be heard.

Efraimsson and colleagues (2004) suggest that discharge planning conferences (DPC) are a form of ‘institutional talk’. DPCs, the authors claim, aim to solve specific predefined problems, are structured in a formal way and participants have distinct roles, rights and obligations (Drew & Heritage, 1992). Moreover, the interaction between participants becomes routine and predictable, with health professionals reproducing the values and rules of the institution (Hicks et al., 2012). In planning for discharge of older patients, Efraimsson and colleagues (2004) assert that the institutional values are efficiency and rationality. The authors further suggest that, although DPCs aim to enhance patient involvement in care, decisions have often already been made (Efraimsson et al., 2004).

One of the most compelling features of David’s story was how the narrator softened his stance when the transcript of the interview was read back to him a few days later. Riches and Dawson (1996) suggest that the process of telling one’s story contributes to an altered understanding of the story for the narrator while Chase (2011) suggests that the act of narrating may allow the storyteller to reclaim their experience and, by doing so, resist a dominant narrative. Perhaps David simply needed an opportunity to say how he felt without being countered by other’s views? Maybe he simply wanted to “leave behind the best impression” (Johnstone, 2014).



#### 6.3.2.4.1 *Eunice and Carolyn (carers)*

A counter narrative described a man who slept in an electric recliner and, in the morning, liked to sit at the kitchen table with the sun coming through the window. This man had regular visitors, a nurse to dress his leg ulcers daily, a care attendant to help him shower twice a week and someone to read documents and assist with paperwork. His wife helped with toileting and transfers and sponged him on the days between 'shower days'.

David's wife, Eunice and daughter, Carolyn were interviewed together. Carolyn did most of the talking, with liberal use of the pronoun 'we' to indicate a shared narrative. Her mother nodded her agreement. Carolyn described the journey from acute to sub-acute care (rehabilitation) and then TC following the first amputation. In doing so, she also described her father's distress and his fight to retain some control of his future.

*When he was in rehab we were optimistic. He was doing exercises to build his arm strength so that he could transfer. Then they suggested he go to transition care. Things went downhill after that. The bandaging of his second leg was inadequate. That's when he got the idea that maybe he could get full-time care at home.*

*I explained that Mum couldn't cope but he insisted that he was going home anyway. I had to be very blunt with him. I told him he needed to adjust his attitude; that he wasn't able to go home and clearly stated that that was the end of the conversation [tears]. He had to face facts. He needed specialised care.*

*I'd take him outside in the sunshine. I did that a lot. He was angry about the care he received. He wanted to go home ... where he had choices, where he could say 'I've had enough', where it is peaceful. I spent a lot of time talking to Dad. I felt it was my job as his daughter. It's brought us closer.*

David's experience of aged care was out of step with the future he wanted for himself. His anguish was intense because he was powerless to change his future. Carolyn understood that

and was willing to bear the brunt of her father's frustration because she was equally determined to protect her mother's quality of life.

This case provides compelling evidence that a strong will, self-confidence and information isn't sufficient to keep an older person from entering RAC. For older adults with a spouse, offspring or other informal care arrangements, care in dependency almost always involves negotiation with actual (or potential) caregivers. Older adults with an informal carer are better placed to be offered, and able to accept, EACH and EACH-D packages. Older people who do not have someone available or willing to be nominated as an informal carer are vulnerable to placement in RAC. Dependency and informal care intersect to determine living arrangements and David's dependence on informal care meant that he was unable to execute his choice to remain living at home with paid carers visiting twice a day.

#### ***6.3.2.4.2 Social work perspective on David***

The tension between David's care needs and his desire to return home, as well as the tension between David's wishes and those of his wife, were recognised by health professionals at each step of David's journey from home to RAC. An aged care assessment is a prerequisite for TC and, given the purpose of TC is to optimise independence and avoid premature admission to RAC most aged care approvals are limited to TC only. In David's case, however, approval for high level permanent and respite care was given at the initial assessment.

The social worker's account of David's situation was presented with self-assuredness and authority derived from experience and seniority. The social worker stated that David's wife and daughter had come to a decision that he was unable to remain living at home. The simple 'truth' was that David's wife couldn't provide the level of care needed. David required assistance with transfers, bathing and toileting as well as dressings to his sacrum. Limited

vision meant that he also needed assistance to indulge his love of print media and current affairs, although that was outside of the concerns of the aged care assessor. By focusing on activities of daily living as a measure of dependency, health professionals are able to make rational decisions about the most appropriate setting for future care. To the extent that decisions about care can be reduced to a measure of dependency, decisions are simplified and free of moral judgements. It is people's stories that complicate decisions as well as the shared history between key stakeholders. Narrative and emotion increase the complexity of the decision.

The social worker said that David lacked insight concerning his care needs. It seemed problematic - this idea that David was less than fully aware of his limitations and the impact of his disability on his family - however I decided not to question the label. David was a man grappling to find a solution that would keep him out of RAC, a place that he said he had never really thought about because it was "a place where people went to die".

#### ***6.3.2.5 Patient participation in decision-making: what did we learn?***

The previous section set out to describe the circumstances of four older adults in hospital and waiting for a RAC bed. Specifically, the researcher sought to describe older adults' perceptions of involvement in the decision-making process. Three of the older adults believed that the decision to move to RAC was made by others, including David who attended a family meeting in the TC setting. This underscores the significance of the patient's *experience* of participation in decision-making, rather than simply the occurrence of a family meeting once the various health disciplines have reached a consensus about the appropriate setting for future care and accommodation.

A common goal of narrative inquiry is to amplify the voice of marginalised groups (Chase, 2011; Riessman, 2008). The present study provided older adults with an opportunity to talk

about a significant event in their lives. Betty asked for the names of nursing homes so she could choose for herself and Olga asked if she should just ‘sit back’ and accept the decision that had been made, or speak up. It is easy not to hear the voices of older adults in hospital, particularly those who have cognitive or other functional limitations. If we genuinely listen to the voices of older adults, we may need to think about ways to improve systems of care.

The first part of this chapter described the explicit narratives of the research participants and points to broader social and institutional narratives that privilege the views of health professionals and family members over those of older adults. One aspect of this privilege relates to the older adult’s dependence on others for assistance to live in the community. For every dependent person, there is a powerful ‘other’, whether a spouse, family member or institution. Frailty or a decline in cognitive or communicative ability means less power to influence decisions. Older adults experience a loss of self-determination but perceive few options, other than to acquiesce.

Chase proposes that narrative is “meaning making through the shaping or ordering of experience” (2011, p. 121), whereas Gamson (2002) suggests that narrative lends itself to the expression of moral complexity. The next section further examines the meanings that carers attach to their experience of preparing for the move to RAC and highlights the complexity of family interactions with the hospital and aged care systems.

### **6.3.3 *Carer narratives***

The focus of the previous section was on individual narratives within a patient-family-social worker triad. The present study also revealed storylines that were common across carers, as well as common narratives within social work practice and discourse. These ‘shared narratives’ (Jones, Torres, & Arminio, 2014) are drawn from the full set of carer interviews ( $n = 10$ ). Professional narratives are examined in 6.3.4.

Four shared narratives were discernible within the set of interviews with caregivers. These narratives arose from interview questions about anticipation of entry to RAC. Carers were asked if they had considered the possibility of RAC prior to the recent hospital admission and about any discussion that may have taken place involving the older person. These questions flowed into a discussion about the factors that were significant in the decision for RAC. The four narratives are described as ‘early conversations about future care’, ‘drawing a line in the sand’, ‘struggling with expectations of self and others’, and ‘‘til death us do part’. Each of the narratives is discussed below.

### ***6.3.3.1 Early conversations about future care***

Advance or anticipatory planning is posited as a rational response to the risk of losing the capacity to live independently, manage personal finances, and make decisions about future health care and accommodation needs. While messages are primarily directed at individuals to plan for their own future needs, family members may be instrumental in initiating conversations with older adults.

One health event that alerts older persons and families to consider a future they may otherwise not have anticipated is a diagnosis of dementia. While dementia typically has a slow progression, other health events like cancer may be associated with a rapid decline in health status and outpace plans for future care needs.

In the present study, four carers described anticipatory conversations about a move from home to a retirement village or other accommodation designed to provide for increasing support needs of older adults. Two families described parental resistance to any suggestion about moving into supported accommodation. Sarah (6.3.2.3.1) recalled her father’s anger when she proffered a video produced by an aged care provider while, in a second case,

Harold (6.3.3.4.1) recounted the story of how his father spent a night on the kitchen floor rather than ask family members for assistance following a potentially serious fall.

*Dad has had several falls, three of which have resulted in hospital admission. After one fall, he remained on the floor all night, propped up against the wall. He and Mum were determined that they could manage the situation and didn't need to bother us.*

*Yes, we'd discussed residential care. Mum and Dad were clear that it simply would not happen - that they would live in their own home until they died. There weren't any circumstances under which they would consider a nursing home.*

Two other family carers described more convivial discussions about moving from the family home. Perhaps unsurprisingly, discussions focused on the preferred amenities of the new living environment rather than planning for the possibility of serious illness and loss of independence. Julie's story (below) highlights a series of decisions about accommodation and care that were outpaced by a decline in her mother's health status.

#### **6.3.3.1.1 Case 5 – Beryl and Julie (daughter)**

Julie explained that her mother, Beryl, had her name down for a unit at a nearby retirement village for about a year when she suffered a bout of depression. Julie's mother had struggled to accept the death of her husband (late diagnosis of melanoma) and the GP encouraged Julie to “get her mother out of that house” and to get an ACAT.

Beryl was subsequently diagnosed with cancer and as her health declined, Julie organised cleaning services while they waited for an ACAT. Julie described the amenities that they were looking for in a LLC setting.

*Mum wanted her own car. She wanted to remain in the same area where she'd always lived and where her own doctor could continue to see her ... I wanted Mum to have company and outings and to continue to play bingo.*

Within two months, fatigue, swollen legs and a heatwave resulted in cessation of driving and Julie's mother became housebound and the subsequent ACAT recommendation was for HLC. Julie's mother was admitted to hospital two weeks later.

Julie broached the idea of moving to a retirement village when both her parents were alive however the decision was made to remain in the family home. Beryl chose a retirement village following the death of her husband but her health deteriorated while waiting for a vacancy. A decision to pursue residential respite was similarly rendered obsolete and approval for HLC was followed by admission to hospital.

Beryl's trajectory is similar to that of Thomas (6.3.2.3). Both patients were diagnosed with metastatic cancer and their carers were unprepared for the rapid decline in physical function that characterised the period immediately before and during hospital admission. The lag time between social work referral and ACAT assessment (e.g., for TC) can also contribute to a misalignment of medical and social work goals of care, as described in 6.3.4.2.

### ***6.3.3.2 Drawing a line in the sand***

In three of the ten cases, family carers decided that a point had been reached beyond which they would not incur additional caregiver responsibilities. While Philip had reached this point (6.3.2.2.1), a serious health event provided an obvious transition point in two other cases. The sections below describe two cases in which the older person either declined in health or was unable to be interviewed.

#### ***6.3.3.2.1 Case 6 - Frank and Evelyn (sister)***

Frank was admitted to hospital following a fall in which he sustained a head injury. Frank has a drinking problem and this was not his first fall. He was 73 years old and had cognitive impairment secondary to alcohol abuse. Frank's wife was overseas at the time of the interviews and his sister Evelyn agreed to participate in the study.

Evelyn explains that Frank is much better having spent several weeks in hospital. She is relieved that he hasn't had any falls and explained her concern that Frank was having 'mini-strokes' and that was why he kept falling. Evelyn observed that Frank was falling even when he hadn't consumed much alcohol.

Evelyn and Frank live in the same area but Evelyn explains in a matter-of-fact way that she would rarely find Frank at home as he would either be walking to the pub or be at the pub. It was obvious that Evelyn cared deeply about Frank and accepted that he was unable to control his addiction.

Although Frank could make his way to the pub, he tired easily and Evelyn recounted a story about an afternoon they spent together. Frank wanted to sand a table but lacked the strength to do so and Evelyn had supported his arm so that he could make the strokes.

Frank sustained a major crush injury to his chest while serving in the Army. Evelyn explained that Frank was a heavy drinker as a young man then stopped drinking completely for a period of 18 years. His downfall started about 10 years ago when their mother died.

*He's always hated mornings but after Mum died he would go missing sometimes in the mornings. When I asked him he said "I get up and walk". Just recently he said to me "I've been thinking about Mum a lot". I suggested that we go and visit her grave.*

Evelyn's devotion to her brother was based on acceptance and she spoke with equal compassion about her sister-in-law who was spending time with her family in the UK. Frank had lucid moments but Evelyn knew this was not the man her sister-in-law had married.

*This time we knew there was no turning back. We didn't think he was going to live til Christmas with his head battered and bleeding and falling all the time.*



#### **6.3.3.2.2 Case 7 - John and Ruth (former partner)**

In this case, a decline in psychological wellbeing as well as repeated hospitalisations prompted a former partner (Ruth) to initiate a further conversation about RAC. Ruth's story is described below.

John was diagnosed with lung cancer four years ago. He had recurrent chest infections and when he was ill, Ruth would sleep in the spare bedroom at the back of the house. Ruth had taken on all of John's cooking and laundry in recent months and was feeling the strain. She had two friends who were also quite sick and was finding it difficult to visit them as often as she wanted.

Although Ruth and John separated 18 years ago, they continued to spend time together and enjoyed regular visits to the cinema. In recent months John had become more anxious about pollens in the air as well as the risk of infection associated with social outings and began to withdraw. John's muscle strength declined and he was no longer able to manage the stairs at the cinema. Moreover, John did not trust the seat provided for people who were unable to use the steps. Despite the shared history and obvious concern that Ruth felt for John, she had drawn a line in the sand. Ruth had a life of her own that did not include providing full-time care for John.

*I don't want to force him, but I've told his daughter that I'm not going back to the house to live with him. I've worked so hard to get back to where I lived previously and where I feel at home.*

#### **6.3.3.3 Expectations of self and others**

As described by Mary (6.3.2.1.1) and Philip (6.3.2.2.1), relationships can influence what is spoken aloud and what remains unsaid. A further case (below) highlights the nuances of family relationships that impact expectations of self and others and act as a barrier to anticipatory discussions about RAC.

#### **6.3.3.3.1 Case 8 - William and Anne (daughter)**

William was an 89 year old widower who emigrated from the UK to Australia with two young daughters. William had raised his daughters alone and the family ties were strong. Over the past 18 months or so, William had developed a fixed routine. Each day he would walk to his daughter's house and back home again. He would be out between 9.30am and 4.30pm, even on the hottest days. His daughter Anne explained that she had taken long service leave so that she could be around to help with her father.

Anne first raised the question of RAC with her sister, who expressed concern at 'taking away their father's freedom'. It was only after William became unwell and was admitted to hospital that the sustainability of the current carer arrangements was questioned.

#### **6.3.3.4 Til death us do part**

In the current study, hospital admission was preceded by a health event or change in health status that required investigation and treatment. In two cases (below), the health event was catastrophic and the care needs were the sole factor in the move to RAC.

##### **6.3.3.4.1 Case 9 - Harold and Michael (son)**

Harold had chronic obstructive lung disease, dementia and a history of falls. He required continuous oxygen therapy and had a suprapubic catheter. Harold used a rollator frame for mobility and required assistance with all personal care. Harold had an ACAT assessment during a previous hospital admission and was approved for high level respite and permanent RAC and an EACH-D package. He was discharged to home, consistent with the wishes of Harold and his wife, only to be readmitted two weeks later following another fall.

Michael explained that his parents were fiercely independent and recounted how his mother walked behind his father so that she could steady him if he began to fall. He shook his head at

the thought of what would happen if his father did fall on his mother. Michael explained that the realisation Harold wasn't coming home, had hit his mother hard.

*There was a period of about 3 weeks when Mum just wasn't coping at all - when the discussion started about Dad needing residential care. So, although used to paying the bills and managing the household, she asked me to organise a tradesman to come in, and I paid the electricity bill. She's better now.*

Harold died in hospital (pneumonia) prior to transfer to RAC.

#### **6.3.3.4.2 Case 10 - Robert, Joan (wife) and three daughters**

A second spousal carer was interviewed in the home and three daughters were present. This presented some challenges and the researcher took particular care to focus her attention on the responses of the spouse for whom English was a second language and who was struggling to accept her husband's increased care needs following a cerebral infarct.

Caroline (daughter) explained the sequence of events that led to the ACAT assessment. Her father, Robert, had suffered a stroke 11 years earlier and had residual problems with the foot on the affected side. The affected foot would drag as he walked and sometimes Robert would trip and fall. Robert would also abscond from home. He knew how to get the roller door up and would take off. Joan has a hearing problem and wouldn't hear the roller door being raised.

*That's how he ended up on Railway Terrace with a huge lump on his head. He'd tripped on the footpath and someone called an ambulance and he ended up in hospital. They did a scan but there wasn't any bleeding inside the head.*

Robert was discharged home but suffered another stroke within a few weeks of being home.

This time the deficits were more pronounced however Joan was anxious that hospital staff should have been doing more to get Robert mobile again and eating 'proper food', not the

vitamised diet that he was being given. I asked Joan if she'd planned for RAC and her response captured a simple truth, that for many couples, RAC is a last resort.

*I knew the day would come - when I couldn't manage on my own and Robert would need care. But I'd not sought out a nursing home. I wanted to keep him home as long as possible ... I knew that if it was me, I wouldn't want it [RAC].*

Joan's daughters were clear that the decision about RAC was for their mother to make. Indeed, one of Joan's daughters had spent many weeks in Adelaide caring for both parents when Joan underwent surgery earlier in the year. There wasn't a hint of self-sacrifice in relaying this information. For this family, it was simply 'what families do'.

#### **6.3.4 Professional narratives**

Analysis of interviews with social workers revealed two shared narratives which arose from responses to the question about how the process of moving from hospital to RAC could be improved for the patient and family. The narratives are described as: 'families should plan ahead' and 'hospitals are not the best environment for older persons'. A description of each of the narratives is provided in the next section.

##### **6.3.4.1 Families should plan ahead**

Narratives can reveal taken-for-granted knowledge that resides within institutions and professions. Social workers generally have a good knowledge of the aged care system and waiting periods for various services. Social workers use their professional expertise and 'insider knowledge' (Merton, 1972) to assist families to navigate their way through the system. The aged care system in Australia is complex and evolving and families rarely have the 'helicopter view' that would allow them to examine the various pathways and to position themselves to optimise access to services. Family members also have little power to negotiate priority access to services. Families don't use the same language as health professionals and may not appreciate the power of a medical diagnosis to influence resource allocation

decisions. Communications become entangled simply because family members and health professionals are operating within very different contexts with respect to the aged care system. The willingness of a carer and social worker to describe this experience helped to illuminate the dissonance between professional and lay experiences.

#### ***6.3.4.1.1 Case 8 revisited - William and Anne (daughter)***

Anne spoke candidly about miscommunications concerning the options for her father's care while waiting for a low level RAC bed. These miscommunications led to three separate ACAT assessments being undertaken in a short period of time; firstly as a pre-requisite to securing access to permanent low level RAC; then TC; and, finally, low level residential respite. ACAT assessments for 'TC only' are commonplace in the hospital setting as the purpose of TC is optimise function prior to deciding about the most appropriate setting for future accommodation and care. TC was established to deal with the challenge of older adults in hospital and unable to return home in the short term. Prior to TC, this group of older adults was often admitted to respite beds in RAC, effectively occupying places that were established to provide respite for carers of community dwelling older adults. For this reason, ACAT recommendations for residential respite are uncommon when the older person is in hospital and waiting for permanent RAC. This is an example of the rich and textured knowledge and professional norms that govern behaviour in relation to the allocation of aged care resources, but which is not transparent, or easily accessed by lay people. The professional narrative was that families should plan ahead for increasing care needs so that they are better placed to secure an outcome that is acceptable to them.

*Families shouldn't leave it until a crisis occurs. This family should have had their residential care applications in two years ago, at their four preferred facilities. The routine the family describes [extended contact on a daily basis] has been going on for 20 years.*

Although appealing, this narrative is inherently flawed. It presupposes an ability to plot the likely trajectory of a disease (vascular dementia) before it is diagnosed. It also presupposes that the family had an appreciation of waiting times for LLC versus HLC and the hospital's differential discharge policy for older adults awaiting a LLC bed.

From a professional perspective, William was approved for permanent and respite LLC.

Although William had few physical limitations, a recent diagnosis of vascular dementia indicated that his needs would increase over time. As William did not own a home and had few other assets he was eligible for government subsidised care as a 'supported resident'. Between 16 and 40 percent of RAC beds are designated as 'supported resident' beds; this varies with the socio-economic profile of the region in which the RAC facility is located. 'Extra service' places are exempt from inclusion in the denominator, leading to concerns about the emergence of a two-tiered system of aged care in Australia.

The 2014 edition of the Residential Care Manual confirms that "people do not need to have a current ACAT approval to place their name on a waiting list for an aged care service" (DSS, 2014, p. 64) however many RAC facilities request that an ACAT approval accompany a registration of interest for admission.

Later in the interview the social worker spoke of the difficulty the family experienced in advocating for their father's needs following an assessment by staff at a RAC facility. As well as highlighting gaps in medical communication about the diagnosis of vascular dementia there is also an acknowledgement that William was unlikely to be accorded priority in the allocation of scarce respite resources without professional advocacy.

*Cognitive function is easily overlooked when the patient has few physical care needs, is conversant and orientated to people, place and time. The aged care provider noted the Mini-Mental score of 24/30. However, they weren't aware that William has vascular dementia. His frontal assessment score of 11/18 indicates*

*problems with executive level functions ... But I'm not sure how aware the family are, of the diagnosis. The family came away thinking that he wouldn't be accepted for respite care. We had to convince the aged care provider of his frontal deficits.*

Closely aligned to the narrative of 'planning ahead' was the suggestion that receipt of community aged care services can facilitate timely access to additional supports as care needs increase, predominantly through case management and liaison roles. The social work outpatient clinic at the RGH was identified as a useful resource; however access is limited to veterans and their families and past inpatients of the hospital. There was a powerful counter-narrative of a family struggling to 'decode' the information they received and the hospital's expectations relating to listing multiple RAC facilities at which applications for admission would be lodged.

*I was quite naïve. We were asked to provide a list of facilities as soon as possible so I stayed up until midnight to prepare the list. I knew a couple of aged care facilities but I also listed a couple of facilities that I didn't have any knowledge of. I thought they were all okay – that is, until I went to look at them. But I understand that the application forms have only been faxed to the facilities today. In hindsight, I needn't have listed facilities in such a rush. And, of course, you have to make an appointment to view a facility. Some providers are not inclined to let you view the facility until you have lodged a formal application. Other facilities have designated days/ times to visit.*

The gap between the caregiver's experience as described above and hospital protocol (below), was considerable.

*When the family only listed four aged care facilities it was clear that there could be a significant wait for a bed to become available. Hospital protocol is that families list 8-10 facilities because of waiting lists.*

Information provided by a second family suggests that hospital expectations are not fully understood and that additional information strategies should be considered.

*Early on in the process, we were given a form to fill out and asked to list six high level care facilities. We were told that the hospital would do the rest, in terms of lodging the applications. Subsequently, we received requests in the mail for additional application details, not only from the residential care facilities we'd listed but three others that weren't on our list and were considerably outside the locality we'd requested ... I don't know why we received information from facilities we hadn't listed.*

Previous research has reported high levels of carer strain associated with a move to RAC (Davies & Nolan, 2004) which can impact negatively on the retention of new information. Communication has verbal and non-verbal components and the following excerpt describes how a daughter felt pressured to accept either a respite or TC place without fully understanding the institutional 'rules' about waiting for a low care placement, nor the system constraints which limit access to LLC beds.

*The first time I met the social worker, it was at my father's bedside. There's a real level of anxiety and you don't always take in what is being said ... We got our wires crossed this week. I was given information about the availability of respite care in two facilities. One was on my list of preferred facilities as it was close to home but they could only offer a 3 week stay. The second facility was able to provide the maximum respite entitlement – 63 days. When I phoned back the next day to say that we preferred the first facility, I found out I wasn't actually being offered the place; that from the hospital's view it had to be a minimum of 63 days; and what was I going to do when the 3 weeks was up? Doesn't the hospital have some responsibility until a permanent place becomes available?*

Despite airing concerns about differences in access to information and interpretations, carers expressed genuine appreciation for the advocacy role undertaken by social workers when their own efforts to communicate with aged care providers failed to elicit a desired response.



#### **6.3.4.2 *Hospitals are not the best environment for older persons***

A second narrative that emerged from the interviews with social workers concerned perceptions of a poor fit between the needs of older persons and the hospital environment. Specific concerns related to older persons' needs for stimulation, activity and social interaction; needs that were perceived to be met at a higher level in aged care settings.

*Having [Olga] on the ward could be detrimental to her wellbeing. There's little for her to do. The other day I found her pushing her tray table backwards and forwards.*

A common feature of rehabilitation, residential TC and other aged care settings relates to 'normalisation' and social living as expressed by an expectation that people will 'get dressed' and dine in a communal setting. While a recent study indicates many clients perceive communal dining as beneficial and to offer a more aesthetic environment, others perceive limited opportunities for valued social interaction (Baptiste, Egan, & Dubouloz-Wilner, 2014).

*The hospital environment is not a great place for older patients, physically or psychologically. I see respite as being something quite different, in terms of getting dressed, going to the dining room and increased activities.*

Social work expectations of residential TC were similarly positive, with TC providing older persons with low intensity therapy to optimise function as well as a 'second chance' to demonstrate that they could manage at home. TC was also seen to provide an opportunity for patients to reappraise their capacity for independent living and, if necessary, accept a move to RAC, without the pressure of the acute setting.

*The good thing about Transition Care is that it gives people more time to decide...to see whether, in an environment that is comparable to being at home with community services, where they are more reliant on their own resources – whether it is possible to manage at home with a similar level of care.*

In the present study, three older persons and their family carers were offered the option of TC. These included: a family waiting for a LLC place and under pressure from hospital staff to find interim care; an older person who was approved for HLC (permanent and respite) and TC following an above knee amputation; and an older person who was approved for HLC in the community and whom the social worker thought may benefit from restorative care.

*When I did the pre-morbid assessment, I found that Beryl was only receiving RDNS care for her oedema. She was independent in every other aspect of her life. I was concerned that the move from complete independence at home to high level care was perhaps too sudden. I wanted to give the patient and her family the option for rehab, in terms of room for improvement and to come to a clear picture of her level of care needs in a more permanent sense.*

For the older person who had a strong desire to return home post amputation, the move from acute care to rehabilitation and then to TC was supported by family carers. In two other cases, family carers were wary of a move to another location and care environment in the absence of any immediate benefit for the older person and with a potential for further disruption.

*It was a roller coaster. I said that it was likely that Mum wouldn't be able to stay in transition care and may need to be readmitted to hospital. It sounded too disruptive to me as the cancer was making her weaker and I didn't think it fair to set goals that she couldn't achieve.*

*And now I've been asked to consider [residential TC] ... but is that what he really needs? And it's at [name of suburb, some distance from home], which is problematic. But you feel pressured ...*

#### **6.4 Discussion**

Moving from hospital to RAC is widely recognised as a major and unwelcome transition in the lives of older persons and conversations about the move may be limited to avoid upset. Families may avoid anticipatory conversations about RAC for good reason, having being

'shut down' by a parent asserting their right to self-determination. This section discusses the implications of the present study for practice, policy and future research.

#### ***6.4.1 Involvement of the older person in the decision-making process***

Previous research suggests that the process of decision-making about the move to RAC can significantly impact on how older persons adjust to relocation. Specifically, a sense of control is argued to be critical to positive adaptation (Rutman & Freedman, 1988), whereas involuntary relocation increases mortality and poor adjustment (Bekhet, Zauszniewski, & Wykle, 2008). For persons with dementia, feelings about the way the process is arranged may persist after the move and impact on adjustment (Nwe Winn, D'Souza, & Sheehan, 2011). The present study found that anticipatory conversations about care in dependency were generally resisted by older persons and avoided by their offspring, although these conversations are thought to aid in transitions and reduce relocation trauma (Oswald & Rowles, 2006).

Older persons fear that RAC will bring a loss of privacy and the ability to 'be themselves' (Stones & Gullifer, 2014) both in terms of self-identity as well as continuity of social behaviour and circumstances (Atchley, 1989). Stones and Gullifer (2014) suggest that home connects older people to their younger selves and it follows that RAC represents the "feared-self", or "what we are afraid of becoming" (Cavanaugh & Blanchard-Fields, 2014, p. 268).

Ottenvall-Hammar et al., (2014) describe the shift from self-governance to being governed by others (or by the aging body) as a fluid process, with a constant ebb and flow depending on which activity is being performed, who is helping, and how extensive the help is. This is a useful metaphor in understanding why families struggle to openly discuss the move to RAC. While living in the community the older person is self-governing much of the time even as they struggle against their aging body and become dependent on others for assistance with

specific tasks. This is in stark contrast to a move to RAC which results in governance by others across a range of daily activities and also in the very routines that govern waking, eating, sleeping and socialisation. Similarly, within a family dynamic the older person who is developing dependence is likely to be moving between self-governance and governance by others in relation to specific activities and how much help is provided by family members. By contrast, the move to RAC may represent an act of governance by family members with long term consequences.

Consistent with other research, participants in the present study described how they were managing at home (and defended their capacity to live at home) with reference to their *abilities* rather than their *limitations* (Stones & Gullifer, 2014). For older persons, RAC is often a 'choice of last resort' (McAuley & Blieszner, 1985). For the participants in the present study, self-determination was limited by dependency on others. In some cases, dependency exceeded available community and family resources. In other cases, the rights of family carers to self-determination influenced the decision to relocate the older person to RAC.

#### **6.4.2 *Communicating with family carers***

Davies and Nolan (2004) described relatives' experiences of transition to RAC as occurring along five continua, reflecting the extent to which they felt they were operating 'under pressure', 'working alone', 'unsupported', 'working in the dark', and 'in control of events' (or not). Carers in the present study reported feeling 'under pressure' to list several RAC facilities and to accept offers of TC, or permanent or respite RAC, at short notice. Closely linked to feelings of operating under pressure were carers' concerns that they did not fully understand the implications of what was being offered and thus of 'working in the dark' and not being 'in control of events'. On several occasions, hospital staff communicated information that was incorrect, resulting in feelings of alarm and distress for aging carers. In

addition, hospital staff attempts to assist families by listing older persons at RAC facilities that were additional to the facilities nominated by families were ineffective when this information was not clearly communicated to families.

Although family carers in the current study described inadequacies in care, it was found that carers were quick to rationalise what had happened as 'system errors' rather than to blame individual staff members or to report feeling that they were unsupported or working alone. Porock and colleagues suggest that 'putting things in perspective' enables carers to gain a sense of control and to trust the staff caring for their relative (Porock, Clissett, Harwood, & Gladman, 2013).

Another study that examined clinicians' views about strategies to improve care transitions identified a need for greater attention to verbal and written communication as well as increased vigilance around patient readiness for transfer and the ongoing care needs of the older person (Jeffs, Lyons, Merkley, & Bell, 2013). The present study also found challenges in preparing for care transitions in the absence of a complete picture of the health status of the older person. The process of admission to an acute hospital involves assessment by a number of medical staff as well as ready access to a range of investigations and diagnostic technologies. Several current participants accrued additional diagnoses while in hospital, including some that were life-limiting. These diagnoses disrupted plans to enter TC or to move to LLC. However these occurrences also affirm that hospital care is the 'right place' for older adults at particular points in the care trajectory (Howe, 2002).

#### ***6.4.3 Strengths and limitations***

Narrative analysis is concerned with the stories that people tell about themselves and others. For the researcher, a narrative approach had the best fit with the stories that participants told in response to the interview questions. Although the move to RAC was happening in the

present, its meaning was derived from the behaviours, illnesses or events of the past.

Responses to questions about how the older person was managing prior to hospitalisation and whether a move to RAC had been anticipated drew upon, consolidated and extended existing stories. Although this posed methodological and analytical challenges for the researcher, lay accounts and the privileging of subjective meaning is posited as a primary marker of rigour in qualitative research (Popay, Rogers, & Williams, 1998). Evidence of responsiveness to social context and flexibility of design was demonstrated through collaboration with the social work department, inclusion of multiple and diverse family carers and willingness to conduct telephone interviews as well as interviews in carers' homes.

#### ***6.4.3.1 Sampling***

Random purposeful sampling was employed in an effort to represent the situations in which older persons and their families were moving from hospital to RAC in the context of TC and to avoid selection bias. 'Thick description' (Geertz, 1973) was used to situate the decision to move to RAC in the context of the lives of the older person and family carers and to describe the trajectory from independent or interdependent living to dependency at the time of the interview. Use of a random purposeful sample and thick description were used to illustrate the complex life circumstances surrounding the move from hospital to RAC in a typical sample of hospitalised older persons.

The heterogeneity of the sample (aside from the requirement for the informal carer to have basic proficiency in English) was both a strength and limitation. Variability in the circumstances that led to hospital admission and the health status and dependency needs of the older adult prior to hospital admission was a strength because it challenged the popular construction of older adults in hospital as a non-descript group of 'bed blockers' who should be accommodated elsewhere (Howe, 2002). Similarly, the unpredictability of older adults' trajectories was an important 'truth' that affirmed the right of older adults to receive hospital

care, as did the frequency with which investigations undertaken during the current hospital admission resulted in new diagnoses.

The inclusion of older adults approved for LLC ( $n = 3$ ) as well as those waiting for HLC ( $n = 7$ ) added further heterogeneity to the sample. The LLC group was significant in illuminating institutional narratives about older adults in hospital. Once medically stable, there is pressure to discharge this group of patients to a rehabilitative or restorative care program, or home. While it is accepted that high occupancy in RAC facilities impacts on the flow of patients with high level needs from hospital to RAC (Lim, Chong, Caplan, & Gray, 2009; Travers et al., 2008) there is a lower threshold of tolerance of patients with low care needs.

The current study has shown that hospital staff have different expectations of family members with respect to managing the transition for patients with low care needs compared with patients with high care needs and that families are often ill-prepared and ill-equipped to meet these expectations. A lack of clarity about the respective roles and responsibilities of the institution and family can leave carers feeling intimidated by a system they don't understand. Carers of patients seeking to move from hospital to LLC may need to 'argue their case' for priority over other older persons in the community who are also waiting for a place.

The decision to exclude patients when a carer did not have basic proficiency in English was pragmatic as the study did not have funds for an interpreter. Although this decision introduced a potential for bias, each of the patients' selected (random sampling) had a family carer who was proficient in English. Study participants included older persons who had emigrated from Europe and for whom English was a second language (ESL) and as described in 6.3.3.4.2, the researcher took steps to minimise the impact of ESL on participation. Specifically, the researcher focused her attention on the spouse (Joan) while her three daughters conversed with each other and a specialist aged care nurse. Joan expressed her

frustration that health professionals frequently directed their attention to her daughters rather than speaking to, and addressing her concerns about her husband's care.

For busy clinicians, it can be easier and more efficient to communicate with individuals of a similar age, level of formal education and cultural and linguistic background. The woman's daughters spoke fluent English, were aware of their father's swallowing difficulties post stroke, understood the risk of aspiration of food and were more accepting of a vitamised diet. Joan's daughters understood their father's care in a way that aligned with the explanations provided by health professionals whilst Joan felt shut out of the conversation.

Other scholars have written about the sense of powerlessness and disconnection that people feel when health professionals and others appear not to listen or discount their experiences and beliefs (Hole et al., 2015; Simmons, Birchall, & Prout, 2011). Therefore it is essential that health professionals are mindful of the potential impact of both verbal and non-verbal communications when interacting with people from culturally and linguistically diverse backgrounds. In the present study this meant acknowledging a spouse as the authoritative source of information about her husband and how the couple were managing prior to his hospital admission.

#### ***6.4.4 Implications for practice***

The present study offers valuable insights concerning the experience of older persons who are moving from hospital to RAC and their carers. These findings can be used to improve interdisciplinary communications as well as those between clinicians, older persons and family members. Awareness of the impact of stress on the capacity of family members to deal with complex information and decisions (Davies & Nolan, 2004; LeBlanc, 2009) is critical to effective communications. Family members may not understand their responsibilities in the search for a RAC bed and clear communication about the respective roles of hospital staff



and family members is essential. Timely verbal communication about hospital policies concerning patients awaiting transfer to RAC, supported by written documentation, provides an opportunity to address misconceptions and assess the level of assistance that may be required to facilitate transfer to RAC in partnership with the patient and family.

When the next-of-kin is an older spouse, it is helpful to confirm the nominated contact person in the case of an emergency. Transfer to RAC may occur at relatively short notice and the present study has confirmed the unintended distress that can result when an older person is given information about imminent transfer that is plausible, yet incorrect.

Despite a general wariness to disclose any vulnerability or professional uncertainty, one social worker in the present study (6.3.4.2) described the challenges associated with advising older persons and families about options for care in the absence of complete information about the health status of the older person. The care plan was revised several times and the social worker reflected on how she would have approached the situation differently, had she been fully apprised of the patient's condition.

The present study was undertaken in a hospital that specialises in the care of older people and there were examples of exemplary care, as in 6.3.2.3. In this setting, the risk of missed diagnoses and inadequate treatment prior to transfer to TC or RAC may be lower in comparison with a major generalist hospital. However, critical reflection on professional practice can help to improve care, particularly where there are pressures to discharge older patients as quickly as possible (Howe, 2002).

Finally, opportunities to elicit feedback from family members about the move from hospital to RAC could be enhanced through simple strategies such as a confidential and brief survey that could be mailed to family carers a few weeks after discharge from hospital, together with a reply paid envelope.

#### **6.4.5 *Suggestions for future research***

Social work responses to questions about the factors that were important in the decision-making process did not venture far from the observations recorded in the ACCR. This wariness limited the capacity for the current study to generate new knowledge about this area of professional practice. An ethnographic study in an Australian hospital ward (if approved by relevant HREC bodies) would provide opportunities to observe staff meetings and informal conversations that may assist in further illuminating professional, institutional and family conversations (and discourses) that shape decisions about RAC. A series of interactions with consenting health professionals, patients and carers may provide further insight concerning the process of decision making and key decision points when interventions to increase patient voice may be most effective.

The present study utilised semi structured interviews and narrative analysis to examine pathways to RAC and older adults involvement in the decision making process. A mixed methods study that incorporates qualitative research within a longitudinal study design may provide additional information about the transition from home to hospital and RAC than can be achieved from interviews at a single point in time (cross sectional) and should be considered in future research. A series of interviews could also add depth and assist in interpretation of the findings of data linkage studies that have examined movements between home, hospital and RAC (AIHW, 2008, 2013, 2014).

#### **6.5 *Summary***

This chapter explored the decision to move from hospital to RAC from the perspective of the older person in hospital, family carers and social workers. The researcher aimed to capture a range of experiences and this inevitably included older adults who were unable to participate in decision-making due to advanced dementia or a serious health event. A move to RAC can be distressing and both social workers and carers vetoed the participation of some older

adults. Each of the four older adults who were interviewed expressed a desire for a greater level of participation in decisions about RAC. The present study makes a unique contribution in giving voice to the concerns and feelings of older persons in hospital and waiting for RAC. Participants included older persons with dementia who have not been well represented in studies about moving to RAC.

For some of the families in the present study the move to RAC seemed the only option. For others, physiological decline surpassed plans for future care. For a third group, a fresh approach to funding individuals rather than institutions could potentially increase the options for older persons and families. To expand this range of opinion even further, Chapter 7 examines the views of 'ordinary Australians' about the proposal for an aged care entitlement that would provide older adults with more choice about *where* they receive care in dependency.

## CHAPTER 7

### *COMMUNITY PREFERENCES FOR AGED CARE*

*My dear, here we must run as fast as we can, just to stay in place.*

*And if you wish to go anywhere you must run twice as fast as that.*

Lewis Carroll

#### **7.1 Background**

To review the state of older adults in Australia (as described in Chapter 2), life table analysis suggests that at age 65, 54% of women and 37% of men will enter permanent RAC at some time in their remaining life, the risk of admission increasing rapidly after the age of 80 years for both genders. The risk peaks in the early to mid-eighties for women, slightly later for men, and declines again for the very old (DoHA, 2011).

Increasing longevity has increased the lifetime risk of entry to permanent RAC. In the period from 1997 to 2007, lifetime risk of admission to permanent RAC increased by 3 percentage points for women and 6 percentage points for men (DoHA, 2011). The same period also saw a trend towards a delay in the age of admission to RAC. In 2011, 56.7% of residential care clients in Australia were older than 85 years and 28.6% older than 90 years (AIHW, 2012b).

Policy documents assert that older people wish to receive care at home and that admission to RAC is a last resort, when other options have been exhausted, and aged care forums support this position (Alzheimer's Australia, 2011). However, such forums do not necessarily represent all older adults. A large population-based survey of people aged 65 years and over in NSW reported that while one in five men and more than a third of women expressed a fear of loss of independence, only a small minority of men (4.9%) and women (9.5%) had specific concerns about nursing home admission (Quine & Morrell, 2007).

In describing the history of aged care provision in Australia, Chapter 2 revealed changes in community expectations of government support in dependency as well as periods of growth and contraction in government provision of housing and care for older adults. In the past decade, policy and fiscal attention has firmly focused on the provision of care in the community. Within the RAC context, government subsidies for care have been progressively separated from accommodation costs, with funding for the latter increasingly designated as the responsibility of individuals. At the same time, the Australian Government has demonstrated a willingness to fund home care to a level whereby it becomes a viable alternative to RAC. As discussed below, the choice to receive high level care (HLC) at home, however, most often requires a parallel investment of informal care.

### ***7.1.1 High level care in the home***

As described in Chapter 2, EACH packages assist older persons with HLC needs to remain living in their own homes and at 30 June 2011 there were 5.6 EACH places per 1,000 persons aged 70 years or older (AIHW, 2012a). Older adults with a co-resident carer are better placed to benefit from the provision of high level community aged care places. In 2010-11, 65% of EACH and 73% of EACH-D clients had a co-resident carer and a further 28% of EACH clients and 19% of EACH-D clients had a non-resident carer (AIHW 2012a). These figures highlight the partnership between formal and informal care that underpins a decision to receive HLC at home, rather than enter RAC. Factors that influence the provision of informal care (including cultural, familial and personal values) as well as access to formal care will thus impact on the living arrangements of dependent older persons.

### ***7.1.2 Study aims***

The objectives of this study were threefold: (1) to compare community expectations of entering RAC with estimations of lifetime risk; (2) to explore community preferences for a CDC funding model for the provision of aged care services; and (3) to identify respondents

with experience of a friend or family member entering RAC in the last 5 years. Respondents with the requisite experience of RAC were asked: (i) where the decision was made (hospital or home); (ii) the main issue that led to the decision to enter RAC; and (iii) the main concern of the older person entering RAC. A large cross-sectional survey was required to meet the study objectives and the SA Health Omnibus Survey (SA HOS) offered a rigorous and cost-effective approach to the collection of health data for clients (organisations and researchers).

## **7.2 Method**

### **7.2.1 Context**

The SA HOS is a face-to-face cross-sectional survey that has been conducted annually since 1991. The survey is administered by a private research organisation with government support and a cost recovery charge to clients who nominate questions for the survey. Questions are reviewed by a quality control committee before and after pilot testing of the survey instrument. The quality control committee includes staff from the Population Research and Outcomes Studies Unit (SA Department of Health) and representatives of survey clients. Routinely collected socio-demographic data include age, gender, marital status, education level, work and occupational status, household income, area of residence and country of birth. Questions developed by the researcher were submitted to the SA Department of Health and embedded in the HOS, following their standard review and pilot testing procedure.

### **7.2.2 Participants**

The sampling framework for the SA HOS is a multi-stage, systematic area sample. Initially, 5000 households were randomly selected within SA with 75% of the sample selected from the Adelaide metropolitan area and the remainder drawn from country centres with a population of 1000 or more. One person aged 15 years or older was randomly selected from

each household and interviewed face-to-face. A minimum of six visits were made to each household before being classified as a non-contact.

### **7.2.3 Questions**

Five questions were included in the HOS (Table 7.1). Questions included perceptions of the likelihood of entry to RAC, preferences for an aged care funding model and experience of having a friend or family member enter RAC. Prompt cards were used to assist people to choose from a set of predetermined response options. Ethical approval was granted by the SA Department of Health Human Research Ethics Committee.

### **7.2.4 Procedure**

A pilot survey of 50 interviews was conducted in January 2008 to test questions, validate the survey instrument and assess survey procedures. The word 'voucher' was removed from the second question and replaced with 'funds' in order to aid respondents' understanding. Fieldwork commenced in February and was completed on July 14 2008. Data were double punched. One in ten households were re-contacted and interviewed again on selected questions to verify accuracy of the data and confirm that the correct person was interviewed.

### **7.2.5 Analysis**

Data were weighted by the inverse of the probability of selection, as well as the response rate in metropolitan and country regions, and then re-weighted to benchmarks derived from the Australian Census. Descriptive statistics were used to summarise respondent characteristics and frequency of responses. Relationships between categorical variables were tested using the Pearson chi-squared test. Two-tailed p values are reported and statistical significance was assumed at  $p \leq 0.05$ . Standardised residuals were used to describe the difference between observed and expected values (Bewick, Cheek, & Ball, 2004). Direct logistic regression analysis (Tabachnick & Fidell, 2007) was performed to assess demographic and other

Table 7.1 Responses to survey questions

Question	N	(%)
1. How likely do you think it is that you will need long-term care in a nursing home at some point during your lifetime?		
a. Very likely	262	(8.7)
b. Likely	750	(24.7)
c. Unlikely	866	(28.6)
d. Very unlikely	635	(21.0)
e. Don't Know	520	(17.1)
2. Should you require hostel or nursing home care in the future would you prefer:		
a. The current system where the government funds the aged care provider to supply you with care	617	(20.3)
b. A system where the government provides you with funds and you purchase the care you choose	1917	(63.2)
c. Don't know/ Not stated	500	(16.5)



Table 7.1 Responses to survey questions (cont ...)

Question	N	(%)
3. In the past 5 years, has a close friend or family member moved to a hostel or nursing home? If yes: Was the decision made in hospital or at home?		
a. No	2089	(68.9)
b. Yes - Hospital	310	(10.2)
c. Yes – Home	577	(19.0)
d. Yes – Don't Know	38	(1.3)
e. Not stated	19	(0.6)

Table 7.1 Responses to survey questions (cont ...)

Question	N	(%)
4. What was the main issue that led to the decision to move into care? (n = 945)		
a. Memory loss or confusion	205	(21.7)
b. Difficulty walking	60	(6.3)
c. Amount of care required was greater than family and friends able to provide	404	(42.7)
d. Unable to access sufficient community supports and aged care services to remain at home	28	(3.0)
e. Move suggested by health professional	91	(9.6)
f. Concerns about personal safety	101	(10.7)
g. Other	36	(3.8)
h. Don't know/Not stated	22	(2.2)

Table 7.1 Responses to survey questions (cont ...)

Question	N	(%)
5. What was the main concern expressed by your friend or family member about moving into care? (n = 945)		
a. Entry cost	34	(3.6)
b. Limited choice of satisfactory facilities	33	(3.5)
c. Inability to access care close to family and friends	50	(5.3)
d. Emotional aspect	100	(10.6)
e. Loss of independence	315	(33.4)
f. The older person didn't appreciate that it was unsafe to remain living at home (impaired memory or irrational thoughts)	201	(21.3)
g. Other	69	(7.3)
h. None	84	(8.9)
i. Don't Know/Not stated	58	(6.1)

variables as predictors of perceptions of the likelihood of entering RAC and preferences for aged care funding. Odds Ratios (OR) and Confidence Intervals (CI) were calculated.

Goodness of fit of the model was assessed using the Hosmer-Lemeshow test. Measures of effect were the Cox and Snell R-squared and the Nagelkerke R-squared statistics (Bewick, Cheek, & Ball, 2005). All analyses were undertaken using SPSS Statistics 17.0.

### **7.3 Results**

Of the 5000 households selected, 3034 interviews were conducted, with a response rate of 62.8%. There were 170 vacant houses or business premises. Reasons for non-response included refusal (n = 1110), contact not established after 6 visits (n = 407), respondent unable to speak English (n = 80), illness or mental incapacity (n = 77), respondent away for duration of survey (n = 64), inability to gain access to building (n = 53) and ferocious dog (n = 5).

The mean age of respondents was 45.8 years (SD = 18.9, range = 15-94). There were 573 respondents (18.9%) aged 65 years or older and females comprised 51.3% of the sample (n = 1555). The majority of respondents (n = 2286, 75.3%) were born in Australia and 62.7% were married or in a defacto relationship (n = 1902). A modest number of respondents (n = 385, 12.7%) reported an annual household income of less than A\$20,000 and, conversely, 476 respondents (15.7%) reported an annual household income of more than A\$100,000.

#### **7.3.1 Perceptions of the risk of RAC**

A total of 262 respondents (8.7%) perceived that they were very likely to enter RAC and a further 750 (24.7%) perceived that they would likely enter RAC. Overall, 33.4% of respondents perceived that they would enter RAC; 49.5% perceived that they were unlikely to enter RAC and 17% of respondents selected the 'don't know' response. Community perceptions of the likelihood of entering RAC by age and gender are presented in Table 7.2, together with estimations of the remaining lifetime risk of receiving permanent residential

Table 7.2 Perceived likelihood of entering RAC by age and gender, compared with actual lifetime risk

Age	Valid n	Female %		Male %		Total %	
		Survey	Actual <sup>a</sup>	Survey	Actual <sup>a</sup>	Survey	Actual <sup>a</sup>
< 65	1961	43.3	46.0	39.7	28.1	41.5	37.1
65-74	292	44.4	49.9	41.8	32.4	43.1	41.2
75-84	206	37.4	54.0	38.4	37.0	37.9	45.5
85-89	39	54.2	62.5	40.0	45.6	47.1	54.1
≥ 90	13	20.0	66.0	0.0	49.6	10.0	57.7

<sup>a</sup>from Cullen (2007)

aged care at similar points in the lifecycle (Cullen, 2007). In general, women underestimated their lifetime risk while men in most age groups overestimated their lifetime risk of entering RAC. People of advanced age also tended to systematically underestimate their risk.

As shown in Table 7.3, only two of the socio-demographic variables made a unique, statistically significant contribution to the logistic regression model predicting the perceived likelihood of RAC. Respondents with experience of a friend or family member entering RAC within the previous five years were 1.6 times more likely to perceive that they might enter RAC compared with respondents without this experience. Respondents who lived in regional areas were also more likely to perceive that they might enter RAC (OR 1.3).

Table 7.3 Binomial logistic regression model for likelihood of entering RAC

Variable	Odds Ratio	95% CI
Age	0.999	0.992 - 1.007
Education	1.021	0.965 - 1.080
Household income	0.986	0.935 - 1.040
Gender	1.173	0.968 - 1.423
Country of birth	1.113	0.888 - 1.395
Marital status	0.997	0.801 - 1.241
Friend/family entered RAC	1.648	1.350 - 2.012 <sup>a</sup>
Work status	1.053	0.817 - 1.356
Area of residence	1.343	1.064 - 1.695 <sup>a</sup>
Occupational status (ASCO)	0.982	0.931 - 1.035
Constant	0.523	

<sup>a</sup>  $p \leq .05$ , CI = Confidence Interval

### ***7.3.2 Preferences for funding aged care***

When asked to express a preference between the current aged care funding model (i.e., government funds to the aged care provider) and the government providing consumers with funds to use as they choose (i.e., a 'voucher' system), more than 63% of respondents selected the voucher option. Just over 20% supported the current model and a further 15% were unsure. As shown in Table 7.4, only three of the independent variables made a unique, statistically significant contribution to the logistic regression model which also included the perceived likelihood of needing RAC. Women were 1.4 times more likely to support a voucher system than men, controlling for all other factors in the model. Respondents who perceived that they were likely to require RAC were less likely to support a voucher model (OR 0.79). For every additional year of age respondents were 0.99 times less likely to support a voucher model, controlling for other factors in the model.

### ***7.3.3 Main issue in the decision to enter RAC***

There were 925 respondents (30.5%) who indicated that they had a close friend or family member who had entered long term residential care in the past 5 years. Within this group, 310 (33.5%) reported that the decision had been made in hospital, and 577 (62.4%) said the decision had been made at home. The remainder were unsure (n = 38, 4.1%).

Respondents were asked about the main issue that led to the decision to enter RAC. The most frequent response was 'amount of care required was greater than family and friends able to provide' (404 respondents, 42.7%), followed by 'memory loss or confusion' (205 respondents, 21.7%), 'concerns about personal safety' (101 respondents, 10.7%), and 'move suggested by health professional' (91 respondents, 9.6%). 'Difficulty walking' was cited as the main issue by 60 respondents (6.3%), while 28 respondents (3.0%) reported being 'unable to access sufficient community support and aged care services to remain at home'. The

proportion of respondents who identified ‘move suggested by health professional’ as the main issue that led to the decision to enter care was higher in the hospital group compared with those where the decision had been made in the home setting (15.8% and 7.0% respectively, standardised residual 3.1,  $p \leq .001$ ). These results are shown in Table 7.5.

Table 7.4 Binomial logistic regression model for a voucher to fund aged care

Variable	Odds Ratio	95% CI
Age	0.991	0.983 - 1.000 <sup>a</sup>
Education	1.043	0.974 - 1.117
Household income	1.019	0.956 - 1.085
Occupation skill level	0.996	0.900 - 1.101
Gender	1.404	1.118 - 1.763 <sup>a</sup>
Likelihood of RAC	0.793	0.632 - 0.996 <sup>a</sup>
Country of birth	1.009	0.773 - 1.316
Marital status	0.943	0.730 - 1.220
Friend/family required RAC	0.858	0.677 - 1.088
Work status	0.937	0.694 - 1.265
Area of residence	0.893	0.679 - 1.173
Constant	4.128	

<sup>a</sup>  $p \leq .05$ , CI = Confidence Interval

### 7.3.4 Main concern of the person entering RAC

Respondents were asked to identify the main concerns expressed by the friend or family member about moving into RAC. The most frequent response was ‘loss of independence’ (315 respondents, 33.4%) followed by ‘the older person didn’t appreciate that it was unsafe to remain living at home’ (201 respondents, 21.3%); and ‘emotional aspect’ (100 respondents,



Table 7.5 Main issue in the decision to enter RAC, presented by setting

	Hospital			Home			Total <sup>a</sup>	
	N	%	Std. R	N	%	Std. R	N	%
Memory loss	52	(17.5)	-1.7	136	(24.9)	1.3	188	(22.3)
Problems with walking	26	(8.8)	1.2	32	(5.9)	-0.9	58	(6.9)
Care needs > family can provide	138	(46.5)	0.1	50	(45.8)	-0.1	388	(46.0)
Lack of services	8	(2.7)	-0.3	17	(3.1)	0.2	25	(3.0)
Health professional recommended	47	(15.8)	3.1	38	(7.0)	-2.3	85	(10.1)
Safety concerns	26	(8.8)	-1.5	73	(13.4)	1.1	99	(11.7)
Total	297			546			843	

<sup>a</sup>Respondents who were unsure about the setting were excluded from the analysis; Std. R = standardised residual; > = greater than

10.6%). Cross tabulation of responses by the setting in which the decision to enter RAC was made were not significant ( $p = .111$ ).

#### **7.4 Discussion**

Community perceptions were generally consistent with lifetime risk of entering RAC, although women tended to underestimate their risk and men to overestimate their risk. The finding that people of advanced age tended to underestimate their risk of entry to RAC is consistent with studies examining the relationship between age and self-rated health (SRH). At a given level of functional disability or measured health conditions, people of advanced age were more likely to rate their health as excellent or very good than younger people (Ferraro, 1980; Vuorisalmi, Lintonen, & Jylha, 2006). Notably, both SRH and positive self-perceptions of ageing have been found to predict health (Martinez, Kasl, Gill, & Barry, 2010; Sargent-Cox, Anstey, & Luszcz, 2012) and survival (Kaplan & Camacho, 1983; Sargent-Cox, Anstey, & Luszcz, 2014).

The decision to enter RAC was typically prompted by the amount of care required by the older person exceeding that which families and friends were able to provide. In contrast, only a small number of respondents ( $n = 28$ ) identified the deciding factor as the inability to access sufficient community aged care services. This finding emphasises how important informal care relationships are in the decision to seek RAC.

Models of CDC (as described in Chapter 3) may have unpredictable effects on informal care relationships. If family carers receive payment it is possible that this could facilitate improvements in their wellbeing. This was a key finding from the US experience of the CCDE model for older people (Foster, Brown, Phillips, & Carlson, 2005). Equally, a CDC model which discourages payment of family members may be associated with a sense of isolation of carers. This has been reported from a small pilot of disability services in Victoria

(Laragy, 2008; Ottmann, Laragy, & Haddon, 2009). Future design of CDC programs needs to account for these important carer relationships.

It is noteworthy that family and friends did not identify the impairments and disabilities that clinical staff commonly believe precipitate a move into RAC. Dementia is an important determinant for the need for care (AIHW, 2008; NDR, 2005) but only 21% of respondents identified memory loss or confusion as the main issue that led to the decision to move into care. Poor mobility associated with the need for assistance is considered a critical disability in the recommendation for HLC. However, only 6% of respondents identified difficulty walking as the main reason for deciding to enter RAC.

Not surprisingly, health professionals were perceived to be instrumental in the decision to move to RAC, particularly when the decision was made in the hospital setting (Chapter 6). Concerns that elderly people may enter residential care at the instigation of other people, who may be carers or professionals, and that older persons may have limited involvement in the decision process, are not new (Allen, Hogg, & Peace, 1992). Family members may experience feelings of guilt when 'placing' a relative in RAC and an 'expert' voice suggesting RAC is the right decision may help to shift the burden of responsibility for the decision from the caregiver.

The finding that a preference for CDC declined with age is consistent with a large community survey in the US (Mahoney, Desmond, Simon-Rusinowitz, Loughlin, & Squillace, 2002). Age was the strongest predictor of participation in the CCDE program with adults aged 18-39 years more likely to participate than those aged 65 years or more (Ottmann, Allen, & Feldman, 2009). The relationship between age over 65 years, enrolment in CCDE and participation is, however, complex. In Florida, for example, recruitment was initially undertaken by disability case managers and support coordinators (Phillips & Schneider,

2007), some of whom feared losing clients to CCDE, believed that CCDE was more suitable for younger clients, or that families could not manage the cash plan (Simon-Rusinowitz, Mahoney, Marks, Simone, & Zacharias, 2009). Age discrimination was further evidenced in the high proportion (59.2%) of participants aged 60 years or older who did not receive an allowance during the first year after their enrolment in the CCDE program (Schore, Foster, & Phillips, 2007). In California, where CDC has been the default model for people with disabilities of all ages for some time, a telephone survey of 1,095 program recipients found few differences in service outcomes by age and concluded that older adults received the care they required on terms they could manage (Benjamin & Matthias, 2001). It is likely that familiarity with the program may make it more accessible for older people.

The present study showed that an option for CDC was generally acceptable to the Australian community. The finding that acceptability decreased with age is consistent with international studies and underscores the need for organisational and staff commitment to CDC as well as efforts to ensure older people can benefit fully from CDC (Department of Health, 2008).

Given the importance of the support of families shown by this study, the role of younger family members will be central in decision making for their older relatives. Younger people viewed CDC more favourably and their involvement could be beneficial. In the Victorian experience, CDC families attended workshops, conferences and met with participants from other CDC programs (Ottmann, Laragy, et al., 2009). An awareness of similar programs helped families “think outside the square” and create new opportunities for the person they cared for and gave them hope for a better life (Laragy, 2008).

These results suggest a rise in consumer preferences for CDC over time as younger respondents enter the aged care system. This is consistent with changing consumer expectations and aspirations, growing affluence and increasing preferences for independent

living arrangements noted by the PC (2010) in a background paper to the enquiry into options for restructuring Australia's aged care system.

Despite considerable investment in CDC programs internationally, evidence for their effectiveness in delaying or avoiding transfer to RAC is inconclusive. To address the limitations of previous CDC evaluations and strengthen the evidence base for policy decisions, CDC programs need to be implemented efficiently and in a way that neither preferences nor disadvantages participants with regard to access to care and support (Carlson, Foster, Dale, & Brown, 2007; Glendinning et al., 2008).

Given delays in program implementation experienced in both the UK and US and the short time frame for policy evaluation it is essential that frontline staff are confident that older people can benefit from greater control over and flexibility in how their care needs are met and facilitate changes to care plans and service delivery arrangements in a timely fashion. The US experience has clearly shown that ageist attitudes can not only hinder recruitment to CDC programs, but also discriminate against older people in terms of program implementation at an individual level.

The findings reported here must be interpreted in light of several limitations. The second question (Table 7.1) may have been premature in eliciting community views on a topic possibly not well understood by the general population and not widely discussed in the popular media in 2008, when the survey was undertaken. Contextual information about regulatory changes to enable consumer choice was lacking. Mahoney et al. (2004) developed a vignette (scenario) to illustrate how CCDE differed from current service provision; an idea which may be usefully applied in an Australian context in future studies of this nature. A high level of support for a voucher model across population groups meant there was little variance in the data, limiting the predictive ability of the logistic regression model. The inclusion of

additional socio-demographic variables that have been found to be predictive of attitudes to consumer directed funding in previous research, for example having an informal caregiver and previous experience employing staff (Mahoney et al., 2004), may have strengthened the model.

### **7.5 Summary**

Chapter 7 has presented results from the first questionnaire administered to a representative sample of households in Australia to assess perceptions of moving into RAC and canvass community views about CDC for older dependent Australians. Considerable support for CDC was found, confirming the pivotal role of informal care arrangements in sustaining independent living arrangements for frail older adults.

Women, particularly those aged 65 years or older, tend to underestimate the lifetime risk of entering RAC while men tend to overestimate their risk. Informal care needs were identified as a critical factor in the decision to enter RAC. This preliminary study revealed broad community support for CDC, consistent with aged care reforms proposed by the NHHRC and successive reviews and trialled by the Australian Government in 2010-2011 (KPMG, 2012).

The next chapter (Chapter 8) presents the third line of enquiry, beginning with a protocol for a pragmatic RCT to assess the impact of a health literacy and coaching intervention on the quality of preparation for care transitions.

## CHAPTER 8

### *INCREASING PATIENT AND CARER INVOLVEMENT IN RESIDENTIAL TC*

#### **8.1 Introduction**

The preceding chapters have examined post hospital transitions for older adults and carers. The program of research has examined the experience of TC recipients in both community and residential settings (Chapter 5) as well as those moving from hospital to RAC (Chapter 6). Older adults' participation in decisions about their future care with respect to the themes of voice and choice has been a common thread linking the scholarly review of the literature (Chapter 2.3.4 – 2.3.6 and Chapter 3) and empirical studies (Chapters 5 and 6).

Chapters 8 and 9 comprise the third line of enquiry in the program of research (see Figure 1.1). In the current chapter (Chapter 8), the researcher describes a protocol for an intervention to support older adults and carers to have their voices heard at critical points in the post hospital trajectory and prepare them for future transitions. This protocol derives in part from the observations that have emerged from previous chapters, in part from the following review, and in part from the efforts of a broader research team of which the author was a key member.

#### **8.2 Approaches to enhance care transitions**

To review, many older people face difficult choices during or following an acute hospital episode, a period when they are particularly vulnerable. Cognitive impairments or physical disabilities may interfere with the ability to advocate for themselves and navigate within and between health and aged care systems (Coleman, 2003). Older people and their families are often unprepared for what will happen following discharge from hospital and their respective roles and responsibilities in this process (Grimmer, Moss, & Falco, 2004; Grimmer, Moss, & Gill, 2000). A sense of abandonment, disregard for individual preferences and lack of input to

care plans have been reported (Coleman et al., 2002; vom Eigen, Walker, Edgman-Levitan, Cleary, & Delbanco, 1999).

A Cochrane review has indicated that interventions to support decision-making processes for older adults facing the possibility of long-term residential care lack a rigorous evidence base. The review was unable to find any studies that compared the effects of a decision-support intervention with the routine process of entry to long-term residential care (Gravolin, Rowell, & de Groot, 2007).

To participate in their own health care consumers must understand and act on information given to them by health providers, a concept referred to as health literacy (Institute of Medicine, 2004). Health information is complex and often poorly understood (Adams, Appleton, Hill, Dodd, et al., 2009; Australian Bureau of Statistics, 2007; Oates & Paasche-Orlow, 2009) and information processing can be impaired in illness (Brown & Park, 2003). Specifically, many older people and their carers do not understand discharge medications, diagnoses or treatment plans (Makaryus & Friedman, 2005), and those with limited health literacy are less likely to ask questions of clinicians (Katz, Jacobson, Veledar, & Kripalani, 2007). Limited health literacy disproportionately affects older adults and people with a chronic disease (Oates & Silliman, 2009) and is associated with increased risk of hospital readmission (Baker, Parker, Williams, & Clark, 1998), other health care utilisation (Adams, Appleton, Hill, Dodd, et al., 2009) and even death (Adams, Appleton, Hill, Ruffin, & Wilson, 2009; Baker et al., 2007).

In the US a coaching program to prepare older adults for post hospital transfers reported reductions in readmission rates. The program focused on medication self-management, use of a patient-centred record, preparation for medical visits, understanding 'red flags' (i.e., signs of deterioration) and when to seek help (Coleman et al., 2004).



Information strategies used with older people commonly focus on the informal carer. However, this approach may contribute to the disempowerment experienced by older persons in health care settings (Edvardsson & Nordvall, 2008). Information improves knowledge, satisfaction and mood and the benefits are greatest when patients are active participants (Smith et al., 2008).

A further Cochrane review of interventions directed at patients to help them gather information in their health care consultations indicated that patient coaching and written materials prior to consultations lead to more involvement through question initiation, increased levels of satisfaction and reductions in anxiety (Kinnersley et al., 2007). Audio recordings and written summaries of consultations improve recall and are used to share information with family members and GPs (Pitkethly, Macgillivray, & Ryan, 2008). Patients with advanced cancer also have complex information needs (Fleissig, 2000; Leydon et al., 2000) and research exploring ways to improve their level of participation in treatment decisions has suggested that Question Prompt Lists (QPL) promote discussion about prognosis and end of life issues (Clayton et al., 2007; Gaston & Mitchell, 2005).

The protocol reported in this chapter aimed to determine whether a coaching intervention delivered by a geriatrician and specialist nurse in a post hospital (intermediate) care setting improved older adults' and carers' assessment of the quality of preparation for transfers. A secondary question was whether the approach improved quality of life (QOL) and reduced health care resource utilisation compared with usual care.

### **8.3 Method**

#### **8.3.1 Setting**

As noted in Chapter 2, TC was established in Australia in 2005-06 to provide time-limited (up to 12 weeks) care for older people who have completed their hospital episode and who

need more time and support to allow functional recovery and make a decision on their long-term aged care options. Entry is via an ACAT assessment with referrals accepted from both public and private hospitals. TC aims to facilitate improved capacity in activities of daily living and provides low intensity therapy, medical, nursing and social work support, personal care and case management, as required to meet the assessed needs of the individual (DoHA, 2011). TC can be provided in the community or in a residential setting (most often aged care), or as a combination of both. The study protocol nominates a residential TC setting that was established as a partnership between an aged care provider and RGH.

### **8.3.2** *Design*

A single blind RCT with masked outcome assessments at 3 and 12 months was proposed with 230 older persons (> 65 years) who entered TC following an acute hospital admission. An informal carer for each participant also took part in the trial (Figure 8.1).

A medical and nursing intervention that provided individual coaching to older adults and families on their medical conditions, medications, and future planning was compared with 'usual care' to see if the approach improved older adults' and families' assessment of the quality of preparation for discharge from TC. Recruitment closed when the target of 230 older adult and carer dyads was achieved.

### **8.3.3** *Study staff*

The researcher met with the aged care provider to discuss the research project and was responsible for recruitment, baseline measures, randomisation, delivery of the intervention in collaboration with geriatricians and scheduling outcome assessments. As the number of study participants grew, specialist aged care and research nurses were engaged to support the intervention and recruitment respectively and a research assistant was recruited to complete outcome assessments. The researcher retained responsibility for randomisation, re-consenting

patients and carers allocated to the intervention arm (Figure 8.1), disseminating the QPL, scheduling geriatrician meetings and gathering relevant clinical information as well as participation in geriatrician meetings on those days when the specialist aged care nurse was not on duty and preparing a summary of clinical information for the patient. The intervention also involved nurse-led meetings that sometimes occurred after a patient had returned home or to residential aged care and the researcher accompanied the specialist clinical nurse on these visits.

The researcher relinquished day-to-day coordination of the study in month 16, but continued to oversight the study until month 22 when recruitment was complete. The researcher was responsible for securing the release of Medicare data for the economic evaluation and for the development and maintenance of the database and study records.

#### **8.3.4 *Study participants***

Eligible participants were identified from consecutive admissions to a single residential TC facility in Adelaide, South Australia. Eligibility implied the ability to communicate in English and to nominate an informal carer who agreed to participate in the study (defined as a relative or friend with whom the participant felt comfortable discussing their medical conditions and future care needs). Those who did not have an informal carer or did not wish their carer to be approached about the study were not eligible.

#### **8.3.5 *Sample size and statistical power***

To assess the effects of the intervention, the primary outcome was the CTM-15<sup>®</sup> (Coleman et al., 2002), with mean scores compared for the intervention and usual care groups. Data from participants and informal carers were analysed separately. Based on Coleman et al. (2005), to

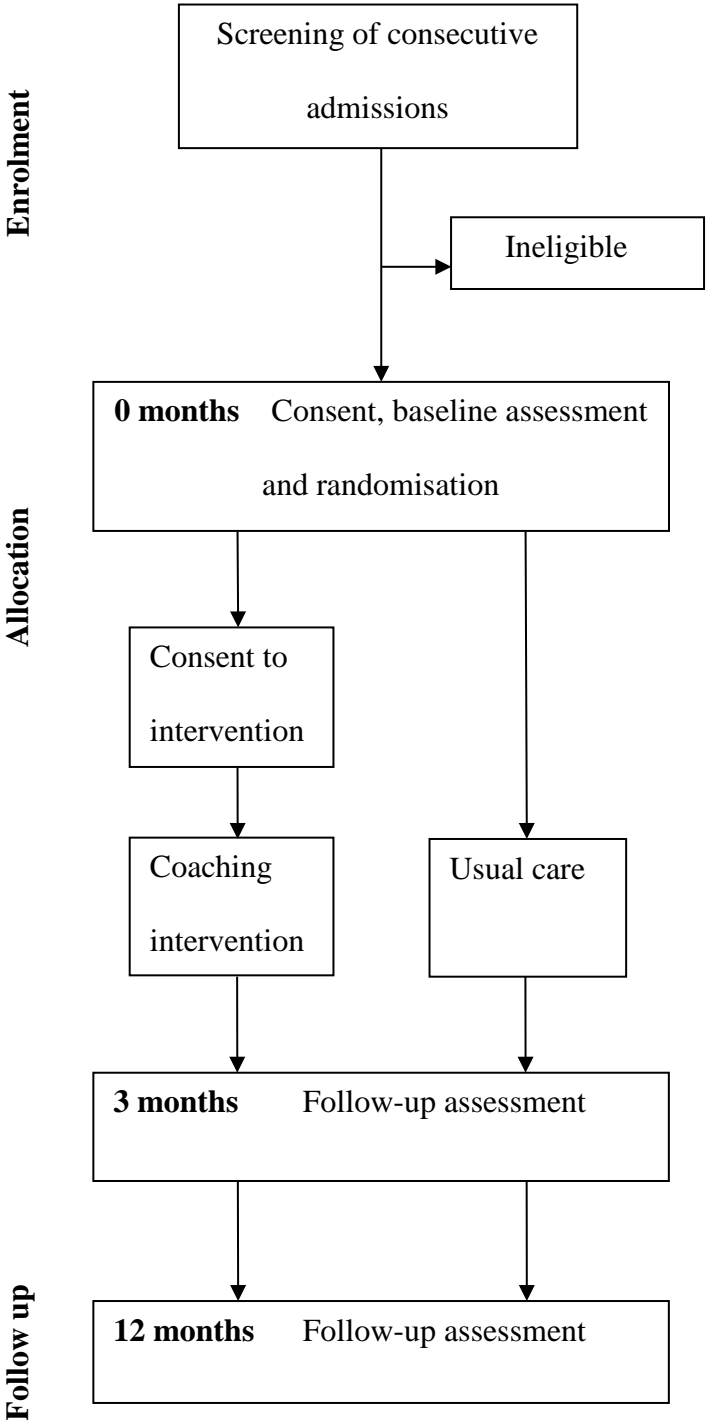


Figure 8.1 Participant flow

demonstrate a 10% improvement in the CTM-15<sup>®</sup> on an expected mean of 67.34, (SD = 13.67), assuming alpha ( $\alpha$ ) = 0.05 and power = 0.80, 132 participants were required (66 in each arm of the study). To allow for 40% attrition, 230 patient/carer dyads were recruited. The high attrition rate was based on 27% attrition in four months in a previous RCT in a similar population and setting (Crotty et al., 2005). While the study was not powered *a priori* to assess differences in quality of life, function and use of health and aged care resources, these measures were considered in the economic evaluation.

## **8.4 Procedures**

### **8.4.1 Ethics and privacy considerations**

The study was reviewed and approved by the RGH Research and Ethics Committee (90/07). Approval to access participant data relating to utilisation of pharmaceutical and medical benefits was provided by Medicare Australia, subject to provision of individually signed consent forms. The protocol was registered with ANZCTR (registration number ACTRN12607000638437).

### **8.4.2 Recruitment and screening**

Once an older adult and their informal carer agreed to participate in the study, written informed consent was sought from both parties. A modified Zelen randomised consent design (Zelen, 1979) was used. This is employed when standard consent procedures may lead to unnecessary confusion or distress (Steiner et al., 2001). The initial consent provided a full description of baseline and outcome measures and included a simple description of the intervention. Following allocation, participants assigned to the intervention group were given detailed information about each of the components of the intervention and informed consent to participate was sought. Those assigned to usual care were not re-approached. Proxy consent was sought for those with an appointed guardian or impaired cognition.

### **8.4.3 Randomisation**

Permuted block randomisation was used to achieve balanced treatment allocation (Beller, GebSKI, & Keech, 2002). A random number sequence was generated for the order of treatment allocation within the blocks using the SPSS v15 RV.UNIFORM function by a statistician external to the trial. Varying block sizes were used. The blocks were randomly arranged within larger sized blocks. Random group allocation was managed by a clinical trials pharmacist at the RGH. Sequentially numbered, opaque sealed envelopes were used to conceal treatment allocation.

### **8.4.4 Allocation concealment**

Research staff screened for inclusion criteria, sought informed consent and conducted the baseline assessment. Subsequently, the researcher telephoned the clinical trials pharmacist at RGH and the participant was assigned a unique number and allocated to the intervention or control group. While staff performing the outcome assessments were blinded to group allocation, it was not possible to blind participants and staff administering interventions.

### **8.4.5 Usual care**

All participants received usual care at the TC facility. A multidisciplinary team was responsible for comprehensive geriatric assessment, goal setting, care plans and periodic review at regular case conference meetings. Physiotherapy, occupational therapy and speech therapy were provided in individual and/or group sessions. A pharmacist reviewed patient medications, documented changes during hospital admission and the period of TC and provided education for older adults who were discharged to home. Social workers assisted older adults and their families to make decisions about living arrangements and aged care services and to access legal and social security services if required. An initial medical consultation was provided by a geriatrician but most medical care was provided by a GP and

a geriatric medicine advanced trainee who visited twice weekly, with telephone support available 24 hours a day via an on-call roster. The geriatricians only met with the patient or carer if clinically indicated after the initial review. Each patient was discussed at a multi-disciplinary case conference in the week after their admission and then again at four and eight weeks if still in the program. There was a separate weekly discharge planning meeting involving allied health and nursing staff.

#### **8.4.6 Intervention**

The intervention was delivered in addition to usual care and addressed health literacy in relation to participant and carer understanding of the participant's medical conditions and medications and encouraged participation in decisions about future health care needs. Issues relating to the participant's wishes about end of life care were also canvassed. The intervention comprised four components: a QPL; medical and nursing meetings; written summary; and telephone call post discharge.

##### **8.4.6.1 Question Prompt List**

Participants and carers received the QPL a week prior to meeting with a geriatrician (see Table 8.1). A structured list of questions has been shown to enhance patient participation in oncology settings (Clayton et al., 2007) and their use aims to improve patient and carer involvement in care planning and encourage discussion about sensitive issues such as diminished capacity, long term care options and end of life care. The question prompts represent common concerns as articulated by older adults and family members and were designed to be inclusive rather than customised for individual patients and carers.

Table 8.1 Question prompts

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<ul style="list-style-type: none"> <li>• I'm not sure what the best decision is for the future, in terms of living arrangements?</li> <li>• Some days I'm okay, other times I'm unsteady on my feet. What can I do to help this problem?</li> <li>• I'm worried about Dad's memory and if it's safe for him to continue living alone?</li> <li>• I don't know if this is normal after a stroke, but I'm concerned that Mum seems to have given up on life?</li> <li>• Where do I go for advice about Power of Attorney and Guardianship?</li> </ul>
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#### **8.4.6.2 Geriatrician and nurse meetings**

A checklist was used to guide the consultation with a geriatrician and nurse and as a record of the meeting (see Table 8.2). The checklist was developed by the researcher and consultant geriatricians and included the core information components of the Care Transition Intervention. Specifically, this comprised the reason for hospital admission and comorbid diagnoses, current medications and “red flags” indicative of a worsening condition (Coleman et al., 2004). Additional topics were those generally covered as part of a comprehensive geriatric assessment (CGA) and included: depression, falls, continence, cognition, behaviour, nutrition, decision making capacity, advanced care planning and end of life care. The participants' and family members' preferences for discharge destination were elicited and, where appropriate, discussion included information about the risks associated with each of the options and strategies to mitigate those risks. Geriatricians had access to hospital and TC facility records and current medication charts immediately prior to the family meetings and brief nursing notations on the checklist were used to highlight key dates (e.g., orthopaedic review), results of cognitive testing, and clinical observations.



Participants received an audio recording of the consultation (Koh, Budge, Butow, Renison, & Woodgate, 2005; Koh et al., 2007). The nurse met with the participant and carer two weeks after the initial consultation to consolidate key educational messages concerning medications and red flags. Falls prevention, self-care, continence and behaviours associated with dementia were discussed as appropriate. Permission was sought to conduct meetings in aged care facilities for those participants who entered permanent care prior to the scheduled meetings.

Table 8.2 Checklist for geriatrician meeting

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<ul style="list-style-type: none"> <li>• Medical conditions</li> <li>• Medications – purpose, precautions</li> <li>• Red flags</li> <li>• Depression</li> <li>• Falls</li> <li>• Continence</li> <li>• Dementia</li> <li>• Behaviour</li> <li>• Nutrition</li> <li>• Discharge destination (risk)</li> <li>• Decision-making capacity</li> <li>• Good Palliative Care Plan</li> </ul>
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#### 8.4.6.3 *Written summary*

Participants and carers received a written summary of the meetings with the geriatrician and nurse. The personal summary adopted a conversational tone and utilised images and colour to improve readability. It described the medical condition that resulted in hospital admission and other medical diagnoses. The summary also included a reconciled list of medications and a

description of the medications' purposes and possible side effects. Participants were encouraged to share the summary with their GP, formal carers and family members.

#### 8.4.6.4 Telephone call post discharge

The study nurse telephoned the participant or carer two to three weeks after discharge from the TC facility to enquire about medical follow up, medication supply and community and aged care services. Participants were asked to rate the usefulness of the QPL, provider meetings, audio-recording and written summary of health conditions and medications.

Table 8.3 Components of the coaching intervention

Component	Procedure
QPL	Handed to patient and carer one week prior to meeting with geriatrician and nurse
Meetings	<p>Week 4 and Week 6 or as negotiated</p> <p><i>Information component</i></p> <ul style="list-style-type: none"> <li>Review of reason for hospital admission</li> <li>Medical conditions</li> <li>Medications and side effects</li> <li>'Red Flags' for review</li> <li>Information on health care choices</li> <li>End of life planning</li> </ul> <p><i>Doctor facilitation of patient participation</i></p> <ul style="list-style-type: none"> <li>Checks patient understanding</li> <li>Elicits participant and carer questions and values</li> <li>Offers choices, acknowledges trade offs</li> </ul>
Summary	Checked by geriatrician and delivered to patient and carer
Telephone	2-3 weeks post discharge

### **8.5 Data collection, measures and outcomes**

Baseline measures were recorded prior to randomisation. In addition to demographic details and descriptions of health conditions, the following measures were collected.

The *interRAI Post-Acute Care* (interRAI-PAC; Landi et al., 2002) is one of a suite of standardised instruments developed by an international research consortium known as interRAI (RAI = Resident Assessment Instrument). Development and validation of the RAI for nursing homes was funded by the US government in 1987 to enable comparison of resident needs across institutions, inform resource allocation, and as a foundation for care improvement (Milbank Memorial Fund, 2003). An assessment of patient performance and clinical characteristics were conducted across a three day period (and within seven days of admission) by a health professional with interRAI certification. The interRAI-PAC provides summary scores on eight scales: (i) cognitive performance; (ii) communication; (iii) Changes in Health, End-stage disease and Signs and Symptoms scale (CHESS); (iv) depression; (v) ADL – short form; (vi) ADL – long form; (vii) pain; (viii) Instrumental Activities of Daily Living (IADL); and (ix) Body Mass Index (Hirdes et al., 2008).

The *Standardised Mini Mental State Examination* (SMMSE; Molloy, Alemayehu, & Roberts, 1991) assesses verbal memory and attention and is a widely used measure in screening for dementia and delirium. Total scores range from 0 to 30 with lower scores indicating greater cognitive impairment. Values of 23 or less generally indicate significant impairment (Woodford & George, 2007).

The *Charlson Comorbidity Index* (CCI; Charlson, Pompei, Ales, & MacKenzie, 1987) is a widely used index of comorbidity and a strong indicator of mortality at 1-year follow-up. The index encompasses 19 medical conditions weighted 1 to 6 with total scores ranging from 0 to 37 (Hall, Ramachandran, Narayan, Jani, & Vijayakumar, 2004). Higher scores indicate

greater disease burden. The CCI has been adapted and validated for use with the International Classification of Disease 9<sup>th</sup> (ICD-9) and 10<sup>th</sup> (ICD-10) revisions and the Australian modification (AM) of the ICD-10. For the current study, the CCI was calculated based on the ICD-10-AM codes at hospital discharge (Sundararajan et al., 2004). Hospital admissions and Medicare information relating to pharmaceutical and medical benefits was collected for the 12 month period prior to study entry as a baseline measure for the economic evaluation.

### **8.5.1 Primary outcome**

The primary outcome for the study was the CTM-15<sup>®</sup> (Coleman et al., 2002) which was completed by participants and carers at the 3-month assessment. The CTM-15<sup>®</sup> assesses the quality of preparation for care transfers. It includes four major domains identified through qualitative research to be important to an individual's experience of a change in care setting. These are: (i) critical understanding; (ii) respect for individual preferences; (iii) preparation for self-management; and (iv) a written care plan (Coleman et al., 2005). The CTM-15<sup>®</sup> is scored between 0 and 100, with higher scores indicating a better transition. The tool has been found to discriminate between patients who do, and do not, re-present to hospital for their original condition (Coleman, Parry, Chalmers, & Min, 2006; Coleman et al., 2002).

### **8.5.2 Secondary outcomes**

Secondary outcomes were assessed at 3 and 12 months by a research assistant who was blind to group allocation. A summary of primary and secondary outcomes is provided in Table 8.4.

*Hospitalisations and admissions to aged care facilities* in the preceding period were recorded at 3 and 12 month assessments and confirmed from hospital records and/or the appropriate facility. Community service use was also recorded at each assessment, based on self or proxy reports and used in the economic analyses.

Table 8.4 Baseline and outcome measures

Measure	Completed by	Pre-morbid	0 months	3 months	12 months
CTM-15 <sup>®</sup>	Patient + carer			✓	
interRAI-PAC	Patient		✓		
SMMSE	Patient		✓		
Charlson comorbidity	Investigators		✓		
Hospitalisations	Investigators + patient	✓	✓	✓	✓
MBS/PBS	Investigators	✓	✓	✓	✓
Aged care admissions	Patient		✓	✓	✓
Community services	Patient		✓	✓	✓
Death	Patient			✓	✓
EQ-5D	Patient		✓	✓	✓
MBI	Patient		✓	✓	✓
SPPB	Patient		✓		✓
GDS-15	Patient		✓		✓
MHLC	Patient		✓		✓
CSQ-8	Patient			✓	
Patient experience	Patient			✓	
BCOS	Carer		✓		✓
NGSE	Carer		✓		✓

CTM-15= Care Transition Measure; interRAI-PAC= international Resident Assessment Instrument - Post Acute Care; SMMSE=Standardised Mini-Mental State Examination; MBS/PBS=Medicare Benefits Schedule/Pharmaceutical Benefit Schedule; EQ-5D=EuroQol 5 Dimensions; MBI=Modified Barthel Index; SPPB=Short Physical Performance Battery; GDS=Geriatric Depression Score; MHLC=Multidimensional Health Locus of Control; CSQ=Client Satisfaction Questionnaire; BCOS=Bakas Caregiving Outcomes Scale; NGSE=New General Self-Efficacy Scale

*Deaths* were recorded and verified with reference to hospital, GP or residential aged care records.

The *EQ-5D<sup>TM</sup>* (Rabin & de Charro, 2001) is a well validated and widely used generic preference based measure of health-related quality of life for application in economic evaluation. The instrument comprises two main components: a 0 to 100 visual analogue scale (VAS) representing worst imaginable to best imaginable health state and five dimensions (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) with three levels of increasing severity attached to each. Respondents were asked to rate their own health on the VAS and indicate which of the three levels for each dimension best corresponded to their health on the day of assessment. Individual responses to the five dimensions are converted to utilities (index values)<sup>1</sup> through application of a scoring algorithm based upon general population values for all possible health states defined by the instrument (Brazier, Ratcliffe, Salomon, & Tsuchiya, 2007; Viney et al., 2011).

The *Modified Barthel Index* (MBI; Shah, Vanclay, & Cooper, 1989) is a simple and rapid measure of functional independence with high reliability. It has 10 items scored from 'unable to perform task' to 'fully independent' with a total score of 100 indicating complete independence. The MBI is a mandatory assessment tool for TC in Australia (DoHA, 2011).

The *Short Physical Performance Battery* (SPPB; Guralnik et al., 1994) assesses gait, balance and lower extremity strength and endurance. It incorporates tests of standing balance (tandem, semi-tandem and side-by-side), a timed 2.4m walk at a normal pace and a timed test

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<sup>1</sup> Index values are used to calculate quality-adjusted life years (QALYs) for economic evaluations of health care interventions (van Reenen & Janssen, 2015)

of five repetitions of rising from a chair and sitting down. The SPPB is highly predictive of subsequent disability (Guralnik, Ferrucci, Simonsick, Salive, & Wallace, 1995).

The *Geriatric Depression Scale* (GDS-15; Yesavage et al., 1982) is a 15-item short-form self-report assessment designed specifically to identify depression in the elderly. Each item requires a 'yes'/'no' response and total scores range from 0-15, with higher scores indicating greater severity. The GDS-15 can reliably detect the presence of a major depressive episode among older adults as defined by accepted diagnostic criteria (Almeida & Almeida, 1999).

The *Multidimensional Health Locus of Control Scale* Form A (MHLC; Wallston, Wallston, & DeVellis, 1978) is widely used to characterise a person's beliefs about control over health status. The instrument consists of three 6-item scales: Internality (IHLC); Powerful Others externality (PHLC); and Chance externality (CHLC). The score on each subscale is the sum of the values chosen for each item where 1 = 'strongly disagree' and 6 = 'strongly agree'. Evidence for the validity of the MHLC is described as modest (Wallston, 2005; Wallston, Wallston, Smith, & Dobbins, 1987).

The 8-item version (CSQ-8; Nguyen, Attkisson, & Stegner, 1983) of the *Client Satisfaction Questionnaire* (Larsen, Attkisson, Hargreaves, & Nguyen, 1979) is a self-report measure of satisfaction with treatment, originally developed to evaluate mental health services. Each item is scored from 1-4 with higher scores indicating higher satisfaction with the treatment received. The CSQ-8 assesses global patient satisfaction and also provides a general score ranging from 8 to 32 (Marchand et al., 2011). The CSQ-8 is a widely used instrument with published data on reliability and validity (Greenfield & Attkisson, 1989) and is available in several languages.

*Patient experience* was assessed against the key requirements of the TCP using an instrument developed as part of the NETCP. Initial testing of the 9-item instrument demonstrated test-retest reliability and construct validity (Chapter 5).

The *Bakas Caregiving Outcomes Scale* (BCOS; Bakas & Champion, 1999) is a 10-item unidimensional scale of carer burden with good psychometric properties (Deeken, Taylor, Mangan, Yabroff, & Ingham, 2003). The BCOS provides an overall score of how the carer's life has changed while providing care to the participant. The BCOS uses a 7-point Likert scale that ranges in response from 'changed for the worst' to 'changed for the best' to measure change in relationships, physical health, and subjective wellbeing, respectively.

The *New General Self-Efficacy Scale* (NGSE; Chen, Gully, & Eden, 2001) is an 8-item scale that assesses perceived self-efficacy regarding coping and adaptation abilities in both daily activities and isolated stressful events. The NGSE uses a 5-point Likert scale from 'strongly disagree' to 'strongly agree'. Scores range from 8 to 40, with higher scores indicating greater self-efficacy. Tests using item response theory (IRT) confirm that the NGSE has acceptable psychometric properties (Scherbaum, Cohen-Charash, & Kern, 2006).

## **8.6 Data Analyses**

### **8.6.1 Statistical analyses**

The overall analytical strategy for the full COACH trial was as follows: intention to treat based on group allocation (Lachin, 2000), with a per protocol analysis of those who received the whole (optimal) intervention as a secondary analysis. For continuous measures, the difference in means and 95% confidence intervals were calculated. The difference between intervention and control for discrete variables were summarised using appropriate risk ratios and 95% confidence intervals. The time to first rehospitalisation (excluding elective



admissions) for each participant was analysed using a Cox proportional hazards model, with a censoring date set at 3 or 12 months follow-up for participants who were not re-admitted.

### **8.6.2 *Economic analysis***

An assessment of the incremental costs and effects of a coaching intervention relative to usual care was proposed (Masters et al., 2012). The economic analyses were conducted alongside the RCT and comprised a cost effectiveness study of the intervention versus usual care. The proposed primary measure of outcome for the economic analysis was the incremental cost per quality adjusted life year (QALY) as measured by the EQ-5D. Resource use collected within the evaluation included that associated with the provision of the intervention plus the frequency and duration of in-patient admissions, Pharmaceutical Benefits Scheme (PBS) and Medicare Benefits Schedule (MBS) utilisation for all trial participants. Resource use associated with the proposed intervention included staff time spent preparing and administering the intervention according to the frequency, type and level of health care professional. Data on the frequency and duration of hospital in-patient admissions was obtained from medical records, and PBS and MBS utilisation data from Medicare. Unit costs were derived from published data sets including PBS, MBS and Australian Refined Diagnosis Related Groups (AR-DRG) cost weights (AIHW, 2012).

It was proposed that confidence intervals be presented around the incremental cost effectiveness ratios, and cost effectiveness acceptability curves for varying threshold values of cost effectiveness also be presented (Glick, Briggs, & Polsky, 2001). An assessment of the sensitivity of the results to variation in measured resource use, effectiveness and/or unit costs was proposed using appropriate one-way and multi-way sensitivity analyses (Briggs, O'Brien, & Blackhouse, 2002).

## ***8.7 Discussion***

This protocol was designed to test the impact of a health literacy and coaching intervention on patient and carer assessment of the quality of preparation for discharge from TC. It derived in part from observations that emerged from the studies reported in Chapters 4 and 5, in part from a review of the literature and in part from the efforts of a broader research team of which the author was a key member (Masters et al., 2012).

An assessment of the impact of the intervention on carer burden and self-efficacy was proposed, as well as the risk of hospital readmissions and adverse drug events (ADE) that frequently accompany transfers between different care settings. In addition, the study assessed the impact of investing specialist geriatric resources into consultations with families in a residential TC setting where decisions about returning to community living or moving to RAC are being made.

Reducing the risks associated with transfers for older people is increasingly a key aim for many health systems around the world. Up to one in five people aged 65 years or older discharged from hospital to home health services have been reported to experience an ADE in the first month following discharge (Gray, Mahoney, & Blough, 1999). Prospective reviews of medical records and patient interviews suggest that 53% of ADE-related admissions are preventable (Chan, Nicklason, & Vial, 2001). Deficits in self-care knowledge (Dedhia et al., 2009) and absence of timely medical review following hospital discharge increase the risk of re-hospitalisation related to the original admission and costs of care. Medicare claims data in the US have revealed that half of all patients readmitted to hospital within 30 days have not been billed for a doctor's visit between the date of discharge and readmission (Jencks, Williams, & Coleman, 2009). The intervention described in this protocol addressed both medications and signals for medical review, with a focus on empowering older people and

preparing families for their role as health advocates. Appointment of a health advocate is recommended as an effective 'work around' strategy to address the impact of health literacy limitations that disproportionately affect older adults on health outcomes and health care utilisation (Berkman et al., 2011).

For older people approaching the end of life, an acute hospital admission is associated with a high risk of entry to RAC and several countries have introduced intermediate care units where older people can transfer for several weeks to recover function and confidence. Staff in this setting often focus on improving function but the time spent in these units also provides an opportunity to deliver interventions which empower families and older people (Andrews, Manthorpe, & Watson, 2004) and prepare them for future care transitions. One of the core underpinnings of TC in Australia is that frail older adults and their families need time to decide on the most appropriate future care options and that this decision should be made once the older person's independence has been optimised. This principle recognises that, for older adults and their families, decision-making is a process rather than a discrete action (Popejoy, 2005). Health literacy is a key component of patient centred care and a critical requirement for effective participation of patients and carers in health decisions (Australian Commission on Safety and Quality in Health Care [ACSQHC], 2010). Having specialist medical and nursing professionals deliver the intervention provided scope and flexibility in responding to the complex and diverse medical, legal and psychosocial needs of older adults in an intermediate care setting.

As reported in Chapter 6, decisions about whether to move into residential care or to stay at home are complex and little is known about the best ways to provide older people and their families in this situation with support (Van Spall, Toren, Kiss, & Fowler, 2007). Older adults with cognitive impairment are frequently excluded from research projects yet this is the

group most likely to be confronted with this dilemma. In the protocol reported here, cognitive impairment and end stage disease were removed as exclusion criteria, meaning that study results will be generalisable to the population of older adults who have experienced an acute hospital admission and have not fully recovered, and are at risk of movement into RAC.

Informal carers often have limited experience of aged care, are unprepared for their role as health care advocates and guardians, and face a myriad of demands within the context of a limited choice of aged care places and pressure to make rapid decisions. The current study recognises the crucial role of the informal carer by recruiting the carer as a research participant in his or her own right.

### **8.8 Summary**

This intervention is expensive because of the involvement of specialist medical and nursing staff. Therefore a careful assessment of the costs and benefits of the intervention is required in this group of TC recipients (residential TC) who are known to have high mortality and readmission rates (Giles et al., 2008). A pragmatic clinical trial design, policy relevant endpoints and economic evaluation allowed greater insight into the potential usefulness of this approach with older adults in a residential TC setting. However, as will be explained in Chapter 9, not all of the data are available to the researcher to be included in this program of research.

If the study findings are positive and indicate favourable cost effectiveness, this approach to supporting health literacy, participation and decision making among those about to enter (or at risk of entry to) RAC could be more widely adopted by other post-acute services. Chapter 9 reports on the analyses of the CTM-15<sup>®</sup> (i.e., primary outcome) and examines quality of life in the sample recruited to the RCT.

## CHAPTER 9

### *THE COACH TRIAL: SELECTED RESULTS*

#### **9.1 Introduction**

Chapter 8 described a study protocol termed Coaching Older Adults and their Carers to have their Preferences Heard (COACH) trial. This study aimed to determine whether a coaching intervention delivered by a geriatrician and specialist nurse in an intermediate care setting improved older adults' and carers' assessment of the quality of preparation for care transitions, as measured by the CTM-15<sup>®</sup>. This chapter reports on analyses of the primary outcome for the COACH study, implemented on the basis of this protocol (Chapter 8).

##### **9.1.1 A note on data ownership**

As noted above, only limited analyses are to be described in Chapter 9. This restriction has arisen due to the level of contribution of the researcher in various aspects of the COACH study. Results to be presented are those allocated to the researcher for her own program of research. Further analyses of COACH data are available for review (Kaambwa et al., 2015; Milte, Luszcz, Ratcliffe, Masters, & Crotty, 2015; Milte, Ratcliffe, et al., 2015).

#### **9.2 Method**

The analyses to be reported in the following section form a subcomponent of the study described in Chapter 8. Therefore the Method to be described in section 9.2 focuses on the primary outcome.

Perceived quality of care transitions was assessed by the self-rated CTM-15<sup>®</sup> (Coleman et al., 2002) at 3 months. The CTM-15<sup>®</sup> uses a 4-point Likert scale that ranges in response from 'strongly disagree' to 'strongly agree'. Mean scores are computed for each respondent and converted to a score from 0-100 using linear transformation. Higher scores indicate a better transition (Coleman et al., 2002; Parry, Kramer, & Coleman, 2006).

Respondents were asked to record their level of agreement with statements that assessed understanding of the care plan, preparation for self-management, receipt of a written care plan and the extent to which individual preferences were taken into account in planning future care. The CTM-15<sup>®</sup> was developed to assess the quality of transitions from hospital to home but is applicable to a variety of settings, including rehabilitation. For the present study, the word ‘hospital’ was replaced with the name of the TC facility. The CTM-15<sup>®</sup> is available from the Care Transitions Program<sup>®</sup> at [www.caretransitions.org](http://www.caretransitions.org).

### **9.3 Data Analyses**

To assess the effects of the intervention, mean scores on the CTM-15<sup>®</sup> (Coleman et al., 2002) were compared for intervention and usual care groups using the Student’s independent samples t-test. Data from older persons and informal carers were analysed separately. The analysis was by intention to treat based on group allocation (Lachin, 2000). All analyses were undertaken using IBM SPSS Statistics version 22.

Secondary analyses were undertaken to determine if group differences in health-related quality of life at baseline, as measured using EQ-5D, were sustained at the 3 month follow-up. A decision to record EQ-5D at 3 months was taken mid-way through the study and resulted in a significant number of missing values ( $n = 92$ ). Analysis of covariance (ANCOVA) was used to assess the impact of the intervention on quality of life at 3 months, adjusting for baseline scores.

## **9.4 Results**

### **9.4.1 Demographics and baseline measures**

Participants in the present study similarly reveal characteristics that are associated with frailty and decline, including advanced age, cognitive decline and increased health service utilisation. In total, there were 48 participants (20.9%) aged 90 years or older and 43.7% of

all participants had a MMSE below 24 and were classified as cognitively impaired. The mean length of stay in hospital before transfer to TC was 25 days and most participants were admitted to hospital for a musculoskeletal injury, such as a fall or fracture. On average, participants had experienced two admissions in the 12 months prior to admission to TC (Table 9.1).

The majority of participants ( $n = 143$ , 62.2%) were living alone in the community prior to admission to TC. Overall, 52 participants (22.6%) were living with a spouse/partner and a further 25 participants (10.9%) were living with relatives. Nine participants (3.9%) were living in RAC. Most participants reported having an informal carer ( $n = 179$ , 77.8 %).

Despite randomisation, group differences were found between intervention and usual care groups in baseline quality of life measures and health locus of control. Older persons in the intervention group recorded lower scores on the internal component of the MHLC measure as well as EQ-5D VAS and utility scores (see 9.5.2). No differences were found in physical or cognitive function as assessed by the MBI, SPPB and MMSE.

#### **9.4.2 Measures of carer strain and self-efficacy**

Carers of older persons in the intervention and usual care groups reported similar levels of caregiver strain at baseline, as assessed by the BCOS, but differed in self-efficacy. Carers in the intervention group recorded lower scores on the NGSE compared with the usual care group, with differences significant at  $p < 0.05$  (Table 9.1).

#### **9.4.3 Comparison of group means for the CTM-15<sup>®</sup>**

Older persons and carers in the intervention group recorded higher scores on the CTM-15<sup>®</sup> compared to the usual care group, indicating better preparation for care transitions, and the differences were significant at the  $p < 0.05$  and  $p < 0.001$  levels, respectively (Table 9.2). The effect size ( $d = 0.30$ ) suggests small differences in CTM-15<sup>®</sup> scores between the patient

Table 9.1 Characteristics of participants included in analysis

Variable	Usual care ( <i>n</i> = 114)		Intervention ( <i>n</i> = 116)	
Age (years)	84.22	(6.53)	84.18	(7.51)
Male, <i>n</i> (%)	44	(38.60)	46	(39.70)
Admissions in 12 months prior <sup>†</sup>	2.04	(1.17)	2.26	(1.55)
Acute admission length of stay (days) <sup>‡</sup>	26.72	(19.25)	24.65	(14.88)
Reason for acute admission, <i>n</i> (%)				
Musculoskeletal	52	(45.60)	62	(53.40)
Neurological	16	(14.00)	11	(9.50)
Infection	11	(9.60)	11	(9.50)
Other	35	(30.70)	30	(25.90)
Mini-Mental State Examination	22.79	(5.28)	23.52	(5.11)
Modified Barthel Index	60.78	(20.10)	59.01	(21.71)
Short Physical Performance Battery	3.76	(2.67)	3.57	(2.67)
Geriatric Depression Scale	4.43	(2.95)	5.18	(3.10)
EuroQol Visual Analogue Scale	63.85	(16.80)	57.63	(20.07) <sup>a</sup>
EQ-5D utility score	0.51	(0.29)	0.42	(0.30) <sup>a</sup>
Multidimensional Health Locus of Control				
Internal	24.65	(4.98)	23.14	(5.62) <sup>a</sup>
Chance	21.14	(5.22)	21.08	(6.33)
Powerful Others	25.04	(5.52)	23.67	(5.80)
Bakas Caregiving Outcomes Scale	36.97	(9.50)	36.10	(7.87)
New General Self-Efficacy Scale	31.28	(5.11)	29.71	(5.24) <sup>a</sup>

Data are presented as mean (standard deviation) unless otherwise stated. <sup>†</sup>Number of hospital admissions in the 12 months prior to transition care. <sup>‡</sup>Length of stay (days) of the hospital admission directly prior to admission to transition care. EQ-5D, EuroQol five-dimension three-level; <sup>a</sup>*p* ≤ 0.05



groups. By contrast, the effect size ( $d = 0.64$ ) suggests moderate-to-high differences in CTM-15<sup>®</sup> scores between the carer groups (Sullivan & Feinn, 2012).

Table 9.2 Comparison of group means for CTM-15<sup>®</sup>

Variable	Allocation	N	Mean (SD)	p	d
CTM-15 <sup>®</sup> (Patient)	Usual care	89	59.58 (15.78)	0.031	0.30
	Intervention	87	64.27 (12.64)		
CTM-15 <sup>®</sup> (Carer)	Usual care	90	55.36 (23.07)	< 0.001	0.64
	Intervention	90	68.45 (17.70)		

#### 9.4.4 Secondary analyses (EQ-5D)

Mean scores on the EQ-5D by allocation (usual care or intervention) were examined in the sub-samples of patients who completed the EQ-5D at baseline and 3 months and no significant difference was found (Table 9.3). Further assessment using ANCOVA to adjust for baseline scores confirmed the absence of a statistically significant difference in EQ-5D scores by group allocation (Table 9.4).

Table 9.3 Comparison of group means for EQ-5D at 3 months

Variable	Usual care (n = 52)	Intervention (n = 48)
EuroQol Visual Analogue Scale	71.00 (22.63)	70.23 (18.21)
EQ-5D utility score	0.59 (0.34)	0.57 (0.31)

## 9.5 Discussion

These analyses examined the impact of a multi-component health literacy and coaching intervention on the quality of preparation for care transitions. The intervention was delivered

Table 9.4 Difference in the EQ-5D as assessed by Analysis of Covariance

	<b>Usual care (<i>n</i> = 52)</b>		<b>Intervention (<i>n</i> = 48)</b>		<b>Estimated between group difference</b>	<b>p</b>
	<b>mean (se)</b>	<b>change</b>	<b>mean (se)</b>	<b>change</b>	<b>estimate (95% CI)</b>	
<b>Baseline</b>	0.49 (0.04)	0.19	0.41 (0.04)	0.19	-0.07 (-0.18 to 0.03)	0.18
<b>3 months</b>	0.68 (0.04)		0.60 (0.04)			

CI, confidence interval

to older persons and a nominated carer and both parties were asked to complete the primary outcome measure three months after randomisation. Patients and carers allocated to the intervention group were found to report a higher quality of preparation for care transitions compared with those assigned to 'usual care'.

These findings are perhaps unsurprising as the intervention was designed to provide older persons with a voice in decisions about their future care arrangements as well as equip family carers with information that would enable them to advocate for the older person, where appropriate. As described in Chapter 8, a range of information and communication tools and technologies were utilised to increase participation, enable participants to revisit the information in written and audio format as well as share information with family members who were unable to be present at the family meetings. These simple interventions address several of the communication challenges described by older persons and carers in Chapter 6 and which contribute to dissatisfaction and poor quality care transitions.

### ***9.5.1 Strengths and limitations***

One of the strengths of the protocol, and hence the results described, is the representation of very old persons (90 years or more) as well as those with cognitive impairment, functional dependence and reduced health-related quality of life. Previous studies have reported that older persons who transition from hospital to a residential transition care facility have higher levels of functional dependence (AIHW, 2011) and are more likely to transfer to RAC at the end of a period of TC (Giles et al., 2008) compared with those who receive TC in the community.

The results of the present study should be considered in light of some limitations, however. The CTM-15<sup>®</sup> is based on self-report and some of the items are complex with respect to the number of words, use of abstract concepts such as health goals and preferences and subtle

differences in the wording of consecutive items. This presented challenges for older persons with limited formal education as well as those with cognitive impairment or English as a second language and contributed to incomplete responses. Other self-report measures, including the MHLC, were similarly affected.

Problems with comprehension may have contributed to the smaller effect size for differences in CTM-15<sup>®</sup> between older persons in the intervention and control groups in comparison with carer groups. The difference in group means between the intervention and control groups were larger and of greater practical significance for carers compared with older persons.

Family carers are often instrumental in enacting the care plan following hospital admission of an older person (including discharge from TC) and the greater practical significance of differences in CTM-15<sup>®</sup> scores recorded by carer groups supports interventions to involve family members in care planning discussions in a considered way. Other possible explanations for the larger effect size recorded by carer groups is that the intervention was more effective in preparing carers for the move from TC to home or RAC or more closely aligned with carers' interests than those of older persons. Further testing of the CTM measure in adults of various age groups or with the experience of recent hospital admission would assist in interpreting the results of the present study and provide direction for future research in this area.

A further limitation arose from randomisation of individuals within a single TC facility and concerns that potential 'leakage' of the intervention from the treatment to the usual care arm of the trial may have occurred. The intervention was an adjunct to usual care and the geriatricians had both clinical and research responsibilities. Similarly, the advanced practice nurse who conducted most of the interRAI assessments for the trial was a senior member of the clinical team at the TC site. The geriatricians drew upon clinical assessments conducted

by TC staff (nursing and allied health) and, as part of the study intervention, reviewed and initiated changes to medications, counselled patients and families about advance care plans, and occasionally ordered tests or referrals that had to be communicated to TC staff. In this clinical environment it was not possible to isolate the intervention and there was a perception that the quality of usual care improved over the duration of the trial.

Group differences in the EQ-5D and internal locus of control measures at baseline warranted further examination due to the in-trial observation of a greater number of deaths in the intervention group compared with the usual care group<sup>1</sup>. Of the affected measures, only the EQ-5D was available at 3 months and, even then, fewer than half of the sample completed the measure. The number of cases available for secondary analysis was therefore small and attention was directed to the change in the EQ-5D from baseline to 3 months in intervention and usual care groups, adjusting for baseline EQ-5D.

### ***9.5.2 Recommendations for future research***

Group differences in baseline EQ-5D and observed differences in the number of deaths at 12 month follow-up raise questions about the predictive value of the EQ-5D measure particularly given evidence that a global measure of SRH is a predictor of older persons' health trajectories, including major health outcomes such as stroke, disability, health care use and mortality (Sargent-Cox, Anstey, & Luszcz, 2010).

To review, the EQ-5D measures health using three levels of severity in five dimensions (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression). Responses are

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<sup>1</sup> The number of persons deceased at 12 month follow-up was 35 (30.2%) in the intervention group compared with 19 (16.7%) in the usual care group ( $p = 0.019$ ).

converted to utilities, where a score of '0' indicates a health state equivalent to being dead and a score of '1' indicates an ideal state of health (Brazier, Ratcliffe, Salomon, & Tsuchiya, 2007; Viney et al., 2011). The EQ-5D is a generic measure, thus allowing for comparisons between people of various ages and with different disease pathologies (Ankri et al., 2003). It is brief, uses simple language and has been validated in people with Alzheimer's disease and other dementias (Ankri et al., 2003; Karlawish et al., 2008). *Preferences* for different health states has been assessed in the general public (Sackett & Torrance, 1978), hospitalised patients aged 80 years or older (Tsevat et al., 1998), older women at risk of falls and hip fracture (Salkeld et al., 2000), and in specific disease states such as metastatic breast cancer (Lloyd, Nafees, Narewska, Dewilde, & Watkins, 2006). Clarke et al. (2002) have used data from the UK *Prospective Diabetes Study* to examine health utility values associated with type 2 diabetes and to estimate the impact of diabetes-related complications on utility values determined from the EQ-5D. This group of researchers has also examined the usefulness of the EQ-5D utility values in assessing risk of vascular events and other complications as well as all-cause mortality (Clarke et al., 2009).

Two studies have provided comparative health utility values determined from the EQ-5D specific to older patients in hospital or post-acute settings. The first examined health utilities in older adults within 72 hours of admission to hospital and again at discharge. A mean EQ-5D utility score of 0.37 (mean EQ VAS 63.2) on admission and 0.66 (mean EQ VAS 72.5) following a period of inpatient rehabilitation was reported (McPhail & Haines, 2010). The sample had a mean age of 73.3 years and a median length of stay of 38 days. Patients with moderate to severe cognitive deficits were excluded from the study (McPhail & Haines, 2010).

The second study examined baseline utility values and gains over time in 351 participants of TC in six community sites in SA and Queensland (Comans, Peel, Gray, & Scuffham, 2013). In this population, the mean EQ-5D utility score on admission to TC was 0.55 and 0.60 at both 3 and 6 month follow-up. The mean age of study participants was 79 years and the median length of stay in hospital prior to TC was 27 days.

Future data analyses might usefully examine the association between baseline EQ-5D and discharge destination on completion of an episode of TC, as well as living arrangements at 12 month follow-up and mortality. The relationship between characteristics of the older person, and carer strain and self-efficacy would also benefit from further examination.

## **9.6 Summary**

Only the primary outcome was able to be reported in Chapter 9 due to the level of contribution of the researcher in various aspects of the COACH study. However, patients and carers allocated to the intervention group were found to report a higher quality of preparation for care transitions, as assessed by the CTM-15<sup>®</sup>, compared with those assigned to usual care. The practical significance of these findings was confirmed through calculation of effect size values. These positive results affirm that a specialist intervention can enhance participation of older persons with functional dependency and cognitive impairment in decisions about their future care needs and assist in preparing carers for a role as advocate in future health care encounters.

Baseline differences in EQ-5D led to a preliminary examination of the clinical significance and predictive value of health utility scores for older persons transitioning from hospital to residential TC. The utility values derived from the present study will provide useful information for other researchers on the utility of older people who are unable to return home following a prolonged hospital stay and add to the body of knowledge about utility gains in

this population at 3-month follow-up. Chapter 10 provides a general discussion of the overall program of research including implications for policy and future research.



## CHAPTER 10

### *GENERAL DISCUSSION*

#### ***10.1 Introduction***

This chapter presents the opportunity to review the research program documented in this thesis and underline key findings from the three lines of enquiry: perceptions of TC, decision-making about entry to RAC and the efficacy of a coaching intervention in TC. The benefits and challenges of the research undertaken are discussed and consideration given to the implications of the findings for policy and practice. The chapter concludes with recommendations for future research to develop the knowledge base around older persons' experiences of post-hospital transition.

#### ***10.2 An overview of the research program***

The overarching research question for the body of work as introduced in Chapter 1 is reproduced below as a focus for the present chapter.

*What is the experience of older Australians as they transition from hospital to home or RAC via an intermediate care program?*

Chapter 1 provided an overview of the full program of research which began with an historical review and contemporary commentary on the state of aged care in Australia. An initial question was posed that would establish the context for the empirical studies, as follows:

1. What is the historical and policy context for the program of research described in this thesis? (Chapter 2)

A description of key policy decisions relating to housing and care for older Australians reveals both intended and unintended consequences. Expectations of government assistance in the provision of housing for older Australians were established in the 1950s (Cullen, 2003) and successive governments have sought to slowly shift the responsibility for the cost of accommodation back to individuals, including those with complex and high level needs. A policy of ageing in place and removal of the distinction between low and high care (DoH, 2014) were prerequisites for implementation of refundable accommodation deposits (or daily accommodation payments) for all RAC beds from 1 July 2014. The median age at which older Australians enter RAC has been steadily increasing (DoHA, 2011a), care needs have intensified and length of stay in RAC has also increased (AIHW, 2011d). However, competing interests of governments and aged care providers have meant that in general, the proportion of skilled nursing staff and quality of care in RAC has not improved (PC, 2011).

Reforms in the provision of community care have been numerous, with increasing efforts to ensure that older Australians are afforded access to home care packages on the basis of need to achieve more equitable access across aged care regions (DoH, 2016b). Income testing and greater user contributions have been applied to contain costs and enhance sustainability of aged care provision (PC, 2011) as the number of Australians aged 65 years or older increase, along with those aged 85 years or older who are most likely to use aged care services (PC, 2008).

One of the most significant, and increasingly controversial, changes in home care provision is the introduction of CDC. Initial discussions about the application of CDC in Australia emerged in 2001 (Howe, 2003; Rees, 2011) and were followed by a series of consultations in 2007 (Bruen & Rees, 2007). On the basis of these early discussions, a second contextual question was posed:

2. What is the international experience of CDC in home care for older adults and what are the lessons for Australia? (Chapter 3)

At its core, CDC in Australia is concerned with consumer empowerment through the ability to exercise choice of service provider and to be involved in decisions about the type of services that will be provided. In addition to trying to influence care provision through communication (voice), Australian consumers will (from February 2017) be able to transfer their package to another service provider and retain any unspent funds (DoH, 2016c). However, older Australians may be dissuaded from changing providers due to exit fees (Belardi, 2016; DoH, 2016c).

Chapter 3 advances a conceptual framework that views CDC in Australia as the product of a philosophy of consumer empowerment, personalisation through the provision of individual budgets (aged care subsidies) and the implementation of a quasi-market in aged care (i.e., marketization). While consumer empowerment and individual budgets have garnered most of the attention in Australia to date, family members and other consumer advocates are beginning to express concern about the raft of fees and charges that are being applied to home care packages (Belardi, 2016).

Chapter 3 also describes health services research as an appropriate methodological framework for the thesis and identifies the key benefits and limitations of the research methods applied to the empirical studies.

Specific research questions were introduced in Chapter 1 and are discussed in relation to the three lines of enquiry (10.3.1 – 10.3.3). The first line of enquiry concerned TC, a new program at the interface between the hospital and aged care systems. The current program was able to assess the perceptions of service providers regarding the extent to which TC is goal oriented, patient-centred and restorative, providing a seamless transition from hospital to

home or RAC. More specifically, the researcher examined the level of congruence between the 'key requirements' of the TC program, as set out in the TCP guidelines (DoHA, 2005) and actual performance as self-reported by TC services (Chapter 4). A measure of older adults' experience of TC was also developed to align with TC services' self-reports and initial testing was undertaken as part of a national telephone survey of TC recipients three months after discharge from TC (Chapter 5). Two research questions were addressed:

1. To what extent are TC services compliant with program requirements relating to care plans, general practitioner (GP) and family involvement, medication management and other aspects of care? (Chapter 4)
2. How feasible is it to ask TC recipients about their experience of setting goals for TC and the extent to which they experience care as restorative and patient-centred? (Chapter 5)

The second line of enquiry concerned decision making about entry to RAC. Chapter 6 examined decision making in the hospital setting and from the perspectives of older patients, family carers and social workers. In addition the views of 'ordinary Australians' about the proposal for an aged care entitlement that would enable more older Australians to be cared for at home were examined. These views were elicited through a representative Health Omnibus Survey (HOS; Chapter 7). Research questions for the second line of enquiry were:

3. How is the decision made to enter RAC from a hospital bed? (Chapter 6)
4. What does a community survey contribute to our understanding of: (i) the reasons older persons enter RAC, and (ii) preferences for an aged care subsidy (voucher) at the point of entry to RAC? (Chapter 7)

The third line of enquiry nominated a protocol to assess the efficacy of a health literacy and coaching intervention in a residential TC setting (Chapter 8). This opportunity was provided through the researcher's contribution to design, implementation and coordination of all aspects of the RCT for which selected results were presented (Chapter 9). The research question addressed by the third line of enquiry was:

5. Do patients and carers allocated to the intervention group report higher scores on the CTM-15® compared with those who receive usual care? (Chapter 9)

### ***10.3 Key study findings***

Sections 10.3.1 – 10.3.3 present key findings from the three lines of enquiry of the research program, benefits and challenges of this work, as well as discuss how the results might inform future policy and practice. The specific research questions within each line of enquiry are addressed individually.

#### ***10.3.1 Perceptions of TC***

Two closely related studies examined perceptions of quality in TC from the perspectives of i) service providers, and (ii) TC recipients.

##### ***10.3.1.1 RQ 1***

The first research question examined the extent to which service providers reported compliance with key requirements of the TCP in their first year of operation:

- To what extent are TC services compliant with program requirements relating to care plans, general practitioner (GP) and family involvement, medication management and other aspects of care? (Chapter 4)

TC providers reported delays in transfer of client information from hospital to TC and difficulties in achieving optimal discharge arrangements for recipients at the end of the period

of TC. There was generally a waiting list for home care packages and some providers reported that they were unable to secure the type and frequency of services to best meet the continuing care needs of the recipient. GP and pharmacist involvement in care planning and medication reconciliation for TC recipients were also not well evidenced.

Examination of the first quality reports submitted by TC providers was one of six studies conducted as part of the NETCP<sup>1</sup>. A comprehensive report of each study was submitted to DoHA and a summary of studies is included in the final evaluation report (Giles et al., 2008). Content analysis of the quality reports provided early indication of challenges encountered by providers in achieving seamless care for patients and GP engagement.

A key recommendation arising from the study was that additional mechanisms for review (such as site visits and discussions with stakeholders) be considered to expand on the evidence cited in the quality reports, particularly in those areas where compliance with program requirements was questionable. The recommendation for site visits is enacted through external health or aged care accreditation standards and review processes (DoH, 2015b; DoHA, 2011b) in deference to the accountability load of TC providers (DoHA, 2005).

#### ***10.3.1.2 RQ 1 Strengths and limitations***

The self-report data presented practical challenges, including the need for transcription of responses prior to analysis, and the methodology approved by DoHA did not include triangulation of the findings. This would have been beneficial in providing another perspective on provider performance against TCP requirements.

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<sup>1</sup> Other studies included: Regional Characterisation Study; Models of TC; Recipient Snapshot Study; Controlled Comparison Study; and a Costs and Effects Study.

### ***10.3.1.3 RQ 1 Implications for policy and practice***

The study was undertaken as part of the NETCP (2006-07) and the findings reflect early experiences of implementing a new program of care. A longitudinal perspective on TC in Australia, encompassing the period 2005-06 to 2012-13 (AIHW, 2014c), documents relative stability in rates of discharge from TC to hospital and entry to RAC both within jurisdictions and at a national level. Differences between states and territories in the proportion of TC recipients discharged to RAC are consistent with differences in the mix of residential and community TC places (AIHW, 2014c) and provision of sub-acute services (Giles et al., 2008). Stable rates of discharge from TC to hospital suggest consistency in the risk profile of older adults entering TC and provide an indirect measure of both the quality of hospital care (Sacks et al., 2016) and post-acute services that may substitute for hospital care (Mor, Rahman, & McHugh, 2016).

TC was developed to address the risk of older persons entering RAC prematurely after an episode of acute hospital care. However, TC increases the overall number of handovers as clients frequently transfer to another aged care provider on conclusion of the period of TC which is generally of seven weeks' duration (Giles et al., 2008). About one in five recipients of TC are readmitted to hospital (AIHW, 2011a) and thus a picture of multiple transfers emerges, each accompanied by the risk of disruption to care, miscommunication or adverse events. This frequency of transitions highlights the importance of working with older adults and family members as the one 'constant' across multiple care levels and settings (Jeffs, Lyons, Merkley, & Bell, 2013).

Concerns about gaps in care at the conclusion of TC were also reported by Walker et al. (2015). In their study, TC recipients and family carers described a lack of information about the availability of TC and a perception that they may have 'missed out' on the opportunity to return home with TC support, had they not heard about the program through informal

channels (Walker et al., 2015). This raises questions about access to TC and the extent to which patients who may benefit from the program have an opportunity to do so.

Another study (Comans, Peel, Cameron, Gray, & Scuffham, 2015) points to the role of hospital staff in referral of patients for TC as well as integration of TC within rehabilitation services as part of a continuum of care. Comans et al. (2015) followed 351 recipients of community TC across six sites in two states of Australia and reported an overall rate of readmission to hospital of 40.5% in the six months after admission to TC. Most day admissions were for dialysis, cancer treatment and participation in day rehabilitation, with overnight admissions for rehabilitation also common. These findings suggest that TC is helping to fill gaps between an acute care episode and an older person's readiness for more intensive rehabilitation as well as providing extra assistance for patients who are receiving outpatient treatment for cancer or kidney failure. Utilisation of TC by these patient groups is consistent with the policy intent of TC to free up hospital beds, provide restorative care and prevent premature admission to RAC but may preference substitution for a hospital bed over restorative care.

TC reduces the delays typically associated with access to community aged care services following hospital admission. Additionally, TC may provide 'slow stream' rehabilitation, including physiotherapy, occupational therapy and other therapies as well as nursing, personal care, home help and case management services. Most TC services are managed by state government health authorities and this may influence the type of services that are provided (Comans et al., 2015). For example, TC places may be utilised to manage transitions between acute and subacute care and to support treatment regimens that require repeated day hospital admissions, as reported by the aforementioned study. This emphasis on older people with one or more planned readmissions may impact on access to TC for other groups of patients.



By June 2011, the requirement for pharmacist review of the discharge medication list was removed from TCP quality standards (DoHA, 2011b) and has not been reintroduced (DoH, 2015b). This change may have been triggered by the researcher's analysis of quality reports submitted by TC services, a summary of which was published in 2008 (Masters, Halbert, Crotty, & Cheney, 2008) and reviewed by DoHA as part of NETCP contractual arrangements.

#### **10.3.1.4 RQ 2**

The second research question examined the feasibility of including TC recipients in the assessment of the quality of TC using a standardised questionnaire with the intent to assess recipients' experience of TC in relation to program requirements and thus complement the quality reports submitted by providers. The question posed was as follows:

How feasible is it to ask TC recipients about their experience of setting goals for TC and the extent to which they experience care as restorative and patient-centred?

(Chapter 5)

Factor analysis of participants' responses to the measure of patient experience of TC identified three factors: restoration of health, independence and physical function (restoration), continuity of care upon discharge from TC (continuity) and involvement in decisions about future care arrangements (involvement). These factors are congruent with the objectives of the TC program and the latter theme 'involvement in decisions about future care arrangements' informed the major empirical study in Chapter 8.

#### **10.3.1.5 RQ 2 Strengths and limitations**

There were challenges in the development and testing of a questionnaire for TC recipients (or their proxies) and family carers, with the measure developed as part of a suite of assessment measures for the *Recipient Snapshot Study* undertaken as part of the NETCP (Giles et al.,

2008). Only a small number of additional items could be incorporated in the telephone survey and there was no opportunity to pilot test the items.

Nevertheless, the telephone survey yielded rich information about the experience of TC and highlighted differences in the complexity of health care needs of those receiving TC in a residential (usually aged care) setting, compared with the community. The researcher was involved in the conduct of more than 140 of these interviews and regular team meetings provided an opportunity to share what was learned through the stories that participants provided in response to the survey questions.

#### ***10.3.1.6 RQ 2 Implications for policy and practice***

Overall, TC recipients, proxies and carers were willing to discuss their experiences of TC with patient reported outcome measures likely to provide a useful adjunct to the quality reports submitted by providers. At the end of the quality report form there is a list of simple quantitative measures that TC services can use to assess the quality of service provision (Appendix A). These measures include information that could be collected through an audit of care plans or client records as well as feedback from clients and other stakeholders about their level of satisfaction with the process or outcomes of their TC. Nevertheless, in 2007 when the study was undertaken and in 2015 when the TCP guidelines were last updated, there was no formal requirement to assess satisfaction with TC, or the degree to which patient experience is consistent with program requirements. The 2015 guidelines draw attention to consumer satisfaction surveys and other feedback mechanisms to inform a review of the effectiveness of service provision however, these are not mandatory (DoH, 2015b).

The NETCP found that overall, 93% of TC recipients or their proxies were satisfied or very satisfied with the care they received (Giles et al., 2008). However, satisfaction surveys typically generate high levels of approval (Collins & O'Cathain, 2003) and other

methodologies are required to elicit more sensitive information about older adults' experiences of care (Russell & Kendig, 1999). Inclusion of a small number of open ended questions may have provided greater insight into those aspects of TC associated with the highest levels of satisfaction as well as areas for further improvement. Consent to record qualitative responses would have enabled the retention of data that was otherwise lost to the evaluation and its readership.

Care for older adults has become increasingly fragmented as they move from acute hospital beds to home or RAC via several pathways that may include rehabilitation and TC. A patient reported measure may provide insight into the extent to which care for older adults is experienced as restorative, is inclusive of individual preferences, and achieves continuity of care. Routine assessment of older Australians' experience of care transitions would seem to be an important step towards a genuinely patient-centred system of care.

### ***10.3.2 Perspectives on moving to RAC***

The second line of enquiry examined decision making about entry to RAC from the perspectives of (i) older patients in hospital awaiting placement and their carers, and (ii) a community sample. Community preferences concerning a personal aged care subsidy (or voucher) that could provide consumers with more choice about who would provide their care and in what setting were also examined.

#### ***10.3.2.1 RQ 3***

Despite a substantial literature about the risks that accompany care transitions, much less is known about the experience of older persons and family carers as they move between systems of care. The specific research question addressed through this study was:

How is the decision made to enter RAC from a hospital bed? (Chapter 6)

The study presented in Chapter 6 found that older persons generally perceive limited involvement in decisions about RAC and little power to influence their future care arrangements. This lack of power was a result of dependency on others for assistance with ADL or, in some cases, to meet psychological, social or health care needs.

This does not negate hospitals as institutions in which older people may be disempowered and at risk of admission of RAC (Faulkner, 2001; Hicks, Sims-Gould, Byrne, Khan, & Stolee, 2012), or policies that determine the options that are available to support older people at home (e.g., capped supply of aged care packages). It does however underline the pivotal role of family and other informal carers in determining if an older person can continue to live in the community.

Four key narratives were elicited from the interviews with carers. First, ‘early conversations about future care’ described anticipatory conversations about a move from home to a retirement village or other accommodation designed to provide for increasing support needs of older adults. These conversations were either met with resistance on the part of the older person, or the plans were outpaced by rapidly increasing health care needs. Second, an alternative narrative was provided by spousal carers ‘drawing a line in the sand’ at a specific point in the care trajectory and indicating that they were not willing to take on responsibility for the increased care needs of their spouse/former partner. An appreciation of the history of the caring relationship was key to understanding the relative ease with which these decisions were made.

Third, other carers ‘struggled with expectations of self’ as they considered the available options to meet the care needs of the older person. The nuances of these relationships made it difficult for sons and daughters to put their own needs before those of their parent. The narratives included an example of a daughter who was able to advocate for the needs of her

disempowered mother while also demonstrating empathy and being present as her father worked through his grief at the loss of an imagined future. Fourth, a final narrative was ‘til death us do part’, describing spousal carers who had a deep and abiding commitment to their less able partner, were determined to maintain the caring role as long as possible and accepted a degree of risk in return for quality of life.

Interviews with social workers revealed two dominant narratives; firstly that families should plan ahead and secondly, that hospitals are not the best environment for older persons. For older persons and their families, planning ahead was posited as a way to maximise choice about the location and amenity of RAC accommodation. This model presupposes a decision to enter RAC that is unrelated to hospital admission despite evidence that many older persons only accept RAC when something has happened that threatens their ability to live independently or in a dependent relationship with a carer. To put this another way, older persons appear to preference living in the community ahead of choice of RAC facility. Some older adults and family carers will also be aware that selection of a preferred RAC facility provides little control over the timing of admission, with availability of a government subsidised bed and priority of need being the key determinants in 2016.

#### ***10.3.2.2 RQ 3 Strengths and limitations***

This study found that older persons have limited voice in decisions about RAC. Concerns such as these have been raised previously but seldom have the accounts of older persons been reproduced from a narrative position that “takes seriously that people not only live their lives, but also imagine the lives they are living, and stories express those imaginations” (Frank, 2014, p. S16).

The studies comprising the present research program were based on the assumption that people with dementia are able to talk about their lives, experiences and needs in a meaningful

way (Hellstrom, Nolan, Nordenfelt, & Lundh, 2007). While interviewing people with dementia is often perceived as posing the challenges of credibility and reliability, Dewing (2002) argues that the real issue is accessing the meaning of what is communicated. The present thesis uses narrative to access and communicate meaning, drawing on Frank's (2010) argument that narrative provides insights into the lives of others that other methodologies generally cannot.

### ***10.3.2.3 RQ 3 Implications for policy and practice***

As discussed in Chapter 2, aged care in Australia is heavily regulated; eligibility and the level of care subsidy are based on assessed need and the number of places are capped. Income tests and co-payments are extending across all home care services and in RAC, accommodation and care are billed separately. All Australians have access to RAC regardless of capacity to pay, although waiting lists mean that hospital patients, those with urgent needs, and those who can contribute to the cost of their accommodation may receive priority. This regulatory context provides few incentives to plan ahead and may contribute to a general unwillingness on the part of Australians to imagine a future that includes dementia or maximum dependence on others for ADLs (Browne, 2013).

The normative expectation that older adults and family members should plan ahead for dependency (Chapter 6) fails to fully appreciate the expressed desire of many older adults to remain living at home (PC, 2015) as well as the policy and funding context that limits choice and the degree of personal control over admission to RAC. Moreover, the present funding model creates a relationship whereby government attempts to slow the growth in aged care expenditure (e.g., through adjustments to the ACFI) produce responses from aged care providers to reduce staffing and other costs in an effort to maintain profit margins, with results that generally do not contribute to better quality of care for older Australians (PC, 2011). Individual budgets (aged care subsidies) place the consumer between the government

and service providers. The consumer has a voucher, is contributing his/her own funds and is responsible for choice of provider. Some consumers will pursue value for money while others may prefer a broader selection of services or specialist staff.

It is anticipated that deregulation of aged care places and the introduction of a personal subsidy for RAC will increase the availability and choice of facility (PC, 2011) as well as increasing choice of services within RAC. As discussed in Chapter 3, development of a quasi-market for aged care services requires a change in the behaviour of older adults (and family carers) from passive recipient to informed consumer. If older Australians become more confident about the ability to secure higher levels of care when they need it (i.e., reduced waiting times) and in the location of their choice (home or RAC), planning ahead may become more palatable (PC, 2011).

The relationship between ACAT recommendations and service use is complex (AIHW, 2011b, 2014b), with the case studies in Chapter 6 portraying individuals who are unable to remain at home with the supports available to them (formal and informal). The simplicity of this statement is underpinned by a set of beliefs about individual autonomy and expectations of government subsidised care in dependency that are consistent with social democratic and neo-liberal influences in social policy in Australia (Deeming, 2014). Governments continue to subsidise the care needs of older Australians (while increasing the onus on individuals to fund the cost of accommodation) and support carers through payments and access to respite services. However eligibility for RAC is on the basis of assessed need of the 'patient' and carers are not expected to forgo their own right to autonomy.

Historically, the assessment of care needs has differentiated between functions required for independent living (e.g., managing finances, ability to use transport, shop for food and prepare meals) and ADLs (e.g., the ability to bathe, dress and feed oneself, transfer between a

chair and bed, and continence). Deterioration in the ability to undertake ADLs requires more intensive support from others, both formally and informally. As dependency increases, the older person requires care more often and for a greater number of hours, beyond that provided by government subsidised services. At this point in the trajectory, high level care from both formal and informal carers is necessary but often unsustainable, with the older person requiring admission to RAC. Alternatively, the need for specialised services (e.g., to manage behavioural and psychological symptoms of dementia, or for palliative care) may hasten entry to RAC.

Qualitative methods can identify factors that are important in decision-making which can then form the basis of a discrete choice experiment (DCE) to assess preferences for different models of care (Ryan, Bate, Eastmond, & Ludbrook, 2001). A DCE study of preferences for intermediate care (IC) in the UK found that location of care was the most important service characteristic, with respondents expressing a strong preference for care in the home (compared with outpatient, hospital or nursing home care) and a dislike for very frequent care contacts. Sick patients showed a preference for nurse-led care (Dixon, Nancarrow, Enderby, Moran, & Parker, 2015). Participants in the study presented in Chapter 6 also expressed a strong preference for care in the home. Burdened by pain and fatigue, one patient wanted to move into supported accommodation. Another patient expressed a desire to 'cash out' his entitlement to RAC to enable him to purchase the level of assistance he required to remain living at home. These preferences are important but represent only one person within the patient-carer dyad and miss the nuances of decision-making within dependent relationships. Qualitative methods allow more sensitive information to be collected while case studies can present the perspectives of each of the key constituents in the decision to enter RAC. A narrative approach provided the researcher with a way to encapsulate and convey the meaning that the decision to enter RAC held for older persons. Talking to older adults about



entry to RAC did not appear to cause distress, with most expressing a desire for more discussion with family members. This finding is consistent with Franks' (2004) assertion that a narrative approach can provide older persons with "an opportunity to hear themselves tell their own stories, and probably to tell stories repeatedly, until they find a version they can live with, at best a version worth living with" (Frank, 2014, p. S17).

The stress experienced by family carers in searching for a RAC place is well documented (Cheek & Ballantyne, 2001; Liken, 2001; Sandberg, Lundh, & Nolan, 2002) however the timing of the interviews in the present study (prior to relocation) generated new insights concerning impact of the illness trajectory on carer experience. Some carers found that their plans for future care and accommodation were surpassed by new diagnoses or further decline in the health status of the older person. Frequent and uncertain changes to care plans increased the risk of communication errors, which in turn contributed to carer stress.

The present study suggests that moving to RAC may be best understood as a longitudinal process requiring multiple adjustments given that the need for RAC did not necessarily arise at a single point in time or in response to a catastrophic health event. Case studies also included older adults with plans to relocate to accommodation for seniors. However, older adults were generally reluctant to discuss the possibility of RAC even with family and friends. Despite the time that has elapsed since the empirical studies were undertaken, this reluctance of older Australians to plan for dependency continues to be of concern (Aged Care Sector Committee, 2016; PC, 2015).

Pathways through health and aged care services are of interest to policy makers (AIHW, 2011c), as well as clinicians. However, research in this area remains underdeveloped.

Specifically, an examination of care pathways may illuminate missed opportunities to support informal carers to maintain older persons in the community, provide specialist services in the

home that would otherwise be provided in a hospital, and to provide restorative care for older persons. The program of research presented in this thesis affirms the role of geriatric medicine in ‘making sense of’ symptoms experienced by older persons and diagnosing conditions that may substantially impact on future care plans. The case studies in Chapter 6 drew attention to the fragility and generally poor prognosis of older persons who enter RAC from a hospital bed. Recent reports from the PC have also noted the intensification of health care needs among those entering RAC with references to RAC as an ‘end of life care service’ (PC, 2015).

For some of the families in Chapter 6 the process of moving to RAC involved the option of residential TC. In one case, residential TC was sought as interim accommodation while a family waited for a LLC place and in another case to provide time to (re)assess long term care needs. Family members were generally wary of residential TC and cited additional travelling time as a barrier as well as concerns that the older person’s medical needs were not yet fully resolved. As with the move to permanent RAC, social workers have a key role in introducing older persons and carers to the concept of TC and thus in managing expectations of TC.

When IC was introduced in the UK, academics and clinicians expressed concerns that it represented a poor substitute for hospital care (Grimley Evans & Tallis, 2001), generally lacking an evidence base (Ebrahim, 2001) and marginalising older people (Connelly, 2001). In Australia, TC was introduced with less overt criticism although concerns were raised about where the program fits in the current distribution of health services (Giles, Halbert, Gray, Cameron, & Crotty, 2009) and the program’s cost-effectiveness in achieving functional gains for older people (Gray et al., 2012; Hall, Peel, Comans, Gray, & Scuffham, 2012). However, patient and family perceptions of TC have received little attention in Australia.

A qualitative study in a UK nurse-led inpatient unit (NLIU) reported considerable variation in patients' perceptions of the unit's purpose, and marked differences in the experience of care (Wiles, Postle, Steiner, Walsh, & Southampton, 2003). Some patients perceived the unit as a 'dumping ground' whereas others described convalescent and rehabilitation functions as key features. As the unit accepted referrals of people who were waiting for RAC as well as those returning home, the authors hypothesised that nurses' preferences for patients undergoing rehabilitation (the primary role of the NLIU) or differential care provision, or both, impacted patients' experiences of care (Wiles et al., 2003). These findings are consistent with broader concerns about the care of older adults that were explored in Chapter 2, revisited in Chapter 6 and informed the intervention in Chapter 8.

More recently, a Swedish study examined differences in the 'positioning' of older persons with and without dementia in interactions with aged care providers to negotiate service provision (Österholm & Samuelsson, 2013). The study found that persons with dementia are positioned as less competent by professionals and their next of kin and that this affects the ability of the person with dementia to have their preferences heard. Interactional analysis further revealed how persons with dementia may reposition themselves as competent and self-governing through finding their 'voice' and actively contributing to the discussion (Österholm & Samuelsson, 2013).

The position of older persons with dementia with respect to family members and service providers is one of disempowerment, with the perceptions and observations of carers often considered more valid than those of the person with dementia (Nygård, 2009). As reported in Chapter 6, persons with dementia want to be engaged in decision making about their ongoing care but may lack the confidence to initiate this conversation. Gill et al. (2011) proposed several strategies to assist persons with dementia to contribute their views about aged care services, including (i) taking the time to get to know the person and build rapport; (ii)

observing non-verbal cues, (iii) asking simple questions and allowing adequate time for an answer; (iv) listening attentively; and (v) understanding that references to past experiences may provide insights into the person's values and preferences.

Hospitalisation for older adults is frequently accompanied by a loss of physical function and one of the aims of TC is to restore function through the application of physical and occupational therapies. Older adults who are admitted to hospital often have complex medical conditions that can be overshadowed by their need for personal care and accommodation. As a frequent site of referral for RAC it is important that hospitals adequately assess and document medical conditions that can alter the way that patient symptoms or behaviour are understood and responded to by RAC staff.

Interviews were undertaken in a hospital that provided specialist rehabilitation care (inpatient and outpatient) and in 2003, had partnered with an aged care provider to establish a residential TC service (Crotty et al., 2005). In this context, patients identified as likely to benefit from rehabilitation or TC were routinely offered these services subject to availability. Older adults who were approved for permanent RAC would ordinarily have been assessed as being on a trajectory that was less amenable to restorative care (e.g., advanced dementia or end of life care) (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003). However, as noted in Chapter 6, there is an overlap between transitional and end of life care that is not always apparent to hospital staff or families.

#### ***10.3.2.4 RQ 4***

Chapter 7 presented the findings from a large representative survey of SA households that provided an opportunity to examine community perceptions of the likelihood of entry to RAC as well as experience of a family member or friend entering RAC and the reasons for the move. The research question addressed through this study was:

What does a community survey contribute to our understanding of: (i) the reasons older persons enter RAC, and (ii) preferences for an aged care subsidy (voucher) at the point of entry to RAC? (Chapter 7)

The main issue which was identified to precipitate a decision to enter RAC was the amount of care required by the older person exceeding that which families and friends were able to provide. This finding emphasises the importance of informal care in the decision to seek RAC (Heppenstall, Keeling, Hanger, & Wilkinson, 2014) and suggests that improved access to home care and more flexible delivery could alleviate carer burden. However, only a small number of respondents identified being unable to access sufficient home care services as the deciding factor.

In addition, the HOS investigated the preference for an aged care subsidy that would enable greater flexibility to purchase care in the home or RAC. This survey was unique in that it involved people *not* currently affected by the issue. The HOS found a high level of support for an aged care entitlement that people could use to purchase the services they required. As introduced in Chapter 3, the CDC initiative represents an important step towards enabling a greater number of older Australians with high care needs to make choices about the type of services they receive (within a pre-determined budget) and to choose their provider. An increased number of high level home care packages means that, to a greater extent than previously, older Australians can choose to receive services at home that would otherwise be provided in RAC. However, some older persons were negatively impacted by the introduction of CDC, specifically those who were receiving more hours of care than generally allocated to a CACP or home care package (DoH, 2016a). For these individuals, CDC has reduced the hours of care that can be purchased from their individual budget. Policy makers may have underestimated the level of cross subsidisation that was occurring within the former model of block funding.

#### ***10.3.2.5 RQ 4 Strengths and limitations***

The limitations of survey methodology in examining complex issues such as decision making to enter RAC must be acknowledged. Specifically, the researcher's budget and the survey methodology enabled only a small number of closed questions to be included in the HOS. Moreover, the questions developed by the researcher didn't intersect in a way that may have yielded explanatory power. For example, a question about utilisation of home care services may have helped to identify pathways to RAC that are amenable to improved access to home care as well as those that are less likely to change.

SA households were asked to consider the notion of a personal aged care subsidy shortly after the idea was first promulgated in Australia as part of a series of consultations with aged care providers, academics, consumers and government officials led by Alzheimer's Australia (Bruen & Rees, 2007; Tilly & Rees, 2007). Unlike the consultations that were conducted in several states in Australia, survey respondents did not have the benefit of information about the policy changes that would enable consumers with high care needs to choose between home and RAC.

#### ***10.3.2.6 RQ 4 Implications***

The main issue which was reported to precipitate a decision to enter RAC was the amount of care required by the older person exceeding that which families and friends were able to provide. In contrast, only a small number of respondents ( $n = 28$ ) identified being unable to access sufficient community aged care services as the deciding factor. This finding emphasises how important informal care relationships are in the decision to seek RAC, and aligns with the carer narrative of 'drawing a line in the sand' as presented in Chapter 6. Home care services can assist older adults to remain living in the community however, some older persons (or family members) may prefer informal care. As care needs increase, family carers

may 'draw a line in the sand', or indeed may be unable to provide the level of care that the older person requires due to their own health needs or physical limitations.

Chapter 7 presented results from the first questionnaire administered to a representative sample of households in Australia to assess perceptions of moving into RAC and canvass community views about CDC for older dependent Australians. Considerable support for CDC was found, confirming the pivotal role of informal care arrangements in sustaining independent living arrangements for frail older adults.

Women, particularly those aged 65 years or older, tend to underestimate the lifetime risk of entering RAC while men tend to overestimate their risk. Informal care needs were identified as a critical factor in the decision to enter RAC. This preliminary study revealed broad community support for CDC, consistent with aged care reforms proposed by the NHHRC and successive reviews and first trialled by the Australian Government in 2010-2011 (KPMG, 2012).

### ***10.3.3 Improving care transitions for older persons***

In Chapter 8, a protocol was nominated (COACH protocol) to improve care transitions for older persons. The intervention included a QPL, geriatrician-led family meeting, audio-recording, care plan and specialist aged care nurse follow-up in a residential TC setting. This protocol established the first RCT in residential TC in Australia.

#### ***10.3.3.1 RQ 5***

The final research question examined group differences in the quality of preparation for care transitions following delivery of a multi-component health literacy and coaching intervention in residential TC. The residential TC setting is significant because almost one in two (46%) older persons will transfer to permanent RAC on conclusion of their episode of care (AIHW, 2014c). This setting thus provided an opportunity to examine the effectiveness of an

intervention in preparing older persons and their carers for transition to permanent RAC as well as those transitioning home. In order to investigate the effectiveness of the intervention, a comparative group was used.

The key question addressed by the researcher was:

Do patients and carers allocated to the intervention group report higher scores on the CTM-15<sup>®</sup> compared with those who receive usual care? (Chapter 9)

Older persons and carers in the intervention group reported higher scores on the CTM-15<sup>®</sup> compared with a usual care group (Chapter 9), indicating better preparation for the transition to home or RAC.

#### ***10.3.3.2 RQ 5 Strengths and limitations***

Strengths of the protocol included the use of a comparative group and random allocation, hallmarks of an RCT design. Use of a multi-component intervention that included face-to-face interaction, a printed summary of meetings (care plan) and audio-recording was a further strength as it catered for people with different learning styles or sensory deficits.

A further strength was the inclusion of older persons with cognitive impairment, made possible through recruitment of a family carer to the study and active engagement of the older person and carer in all aspects of the intervention, including the QPL, geriatrician-led and nurse-led consultations, audio-recording of the geriatrician meeting and follow-up telephone call following discharge from TC.

Integration of the intervention within existing case conference and discharge planning processes in the TC unit helped to avoid duplication and confusion. This was achieved through research team member attendance at multidisciplinary team meetings, liaison with



individual nursing and allied health staff as well as ensuring that intervention staff had access to both hospital and TC records prior to meeting with older persons and family carers.

The intervention was an adjunct to usual care and the research was undertaken in a single TC facility. This posed challenges for the research team, some of whom had clinical as well as research responsibilities. Potential 'leakage' from the specialised intervention to usual care was noted in Chapter 9 and represents a limitation of the study. In primary care research, cluster randomisation is commonly used to avoid contamination of the control group (e.g., Coventry et al., 2015) however, this was not feasible due to the lack of comparable residential TC facilities in SA.

Recent evidence suggest that patients who participate in stroke research receive better quality care and have reduced mortality compared with non-research participants (Purvis, Hill, Kilkenny, Andrew, & Cadilhac, 2016). This finding is consistent with the researcher's experience of research in residential TC. In a setting with minimal staffing and basic skill levels the research team were advocates for older persons allocated to both intervention and control groups. Consent processes required engagement with family members who frequently had concerns about the older person, sometimes related to specific symptoms or behaviours or investigations that were planned but had not occurred prior to discharge from hospital. Advocacy of the part of the researchers led to geriatrician review, further investigation and diagnoses of neurological conditions and cancers in usual care patients as well as those allocated to the intervention group. Although these diagnoses did not prolong life, families were relieved to have their concerns validated and for the older person to be transferred to hospital and provided with a level of care that was consistent with their increasing needs. Knowledge informs practice and the challenge in a residential TC setting is that there may be an insufficient number of staff with the requisite knowledge to know when something is amiss with the older person, or to filter information provided by family members.

The level of unmet care needs that research staff were confronted with when interacting with research participants was a continuing challenge. In a hospital ward, the researcher can walk away with a reasonable degree of confidence that staff will attend to the patient's needs. An aged care setting is different. There were several sentinel cases that highlighted failures in communication and care and remain etched in the researcher's memory. One case is described to illustrate the potential to impact on the stated preference of an older patient to return home following TC.

The older person had difficulty managing their ileostomy and leakage of fluid occurred on several occasions. After initial instruction in self-management failed, staff decided the person needed RAC. The older person's desire to return home was considered unrealistic by staff despite family members expressing a willingness to support discharge to home. On the first occasion that the researcher approached the older person about the study the person asked the researcher if she could provide advice about hastening death. Several weeks later and in an attempt to ameliorate the problems with leakage from the ileostomy bag the older person began refusing medications. The geriatrician who met with the family as part of the research study suggested a weekend trial at home that was accepted by all parties. On Friday afternoon the researcher spoke to the older person and a family member and when it became clear that the family member had no experience of ileostomy care or familiarity with the equipment, a demonstration was provided. Despite leakage occurring on the first evening of the weekend trial the family managed the situation and the older person was able to live out his final months at home.

A residential TC facility is a complex and demanding research environment with the facility a 15 minute drive from the academic unit and senior clinicians. The Zelen consent process and multi-component intervention (i.e., QPL, two family meetings, audio-recording and written record of meetings) required several purposeful interactions with the older person while the

ward environment provided a high level of visual contact between the researchers and participants, as well as interactions with allied health and facility staff.

### ***10.3.3.3 RQ 5 Implications for policy and practice***

The analyses presented in Chapter 9 demonstrated that frail older persons can benefit from an intervention that aims to involve them in decisions about future care and that these benefits extend to older persons with cognitive impairment. Associated analyses found that shared decision making (SDM) increased with the length of the consultation (not reported in the thesis; Milte et al., 2015). Taken together, these findings suggest that geriatrician-led meetings with older persons and their carers can achieve multiple functions including information transfer, initiation of discussion about end-of-life care, responding to questions, and also achieve SDM, at the cost of a longer consultation. The mean duration of geriatrician-led family meetings was 38 minutes (Milde et al., 2015), not including review of patient records and clinical documentation. The intervention is resource intensive and this may limit feasibility of the intervention as part of usual care in residential TC.

The impact of a health literacy and coaching intervention on preparation for care transitions has the potential to be sustained beyond the immediate transition to home or RAC. Having relevant information about medications, for example, may enhance medication adherence in the older person and carer confidence to enquire about medication changes. Encouraging older persons and carers to ask questions of health care providers can create an expectation of involvement in decisions that, in turn, may have a positive influence on the SDM behaviours of clinicians.

Preparation for care transitions is likely to yield benefits for older persons who enter RAC as well as those who transition home following a period of residential TC. A systematic review found that the incidence of transfer from RAC to ED is 30 transfers per 100 RAC beds per

year (Arendts & Howard, 2010) with data from public hospitals in New South Wales indicating that approximately 75% of patients transferred from RAC to ED are admitted to hospital (Arendts, Dickson, Howard, & Quine, 2012).

As discussed in Chapter 2, contemporary health care for older adults is generally characterised by low priority treatment in ED, short stay in acute care followed by discharge home or transfer to sub-acute (rehabilitation, geriatric evaluation and management, or palliative care), post-acute (TC or other post discharge care) or RAC. Within this complex system of care, clinical handover and continuity of care may be less than optimal and the benefits of an informed significant other who can advocate on behalf of the older person should not be underestimated. If the intervention was shown to have benefits that were sustained over time, the value would increase and cost may become more acceptable.

#### ***10.4 Relevance for other jurisdictions***

The studies reported in this thesis were undertaken in a specific policy context and at a particular time (2007-2011) that limits generalisability to other jurisdictions. However, the conceptual framework may have broader application in highlighting both philosophical and economic objectives that determine the degree of choice that CDC affords older adults. There are a variety of different models of CDC internationally which, in part, reflect variation in commitment to consumer empowerment and marketisation as well as sociopolitical contexts and economic conditions.

In Australia, the pace of reform in aged care, and human services more generally, continues unabated. In 2016 the number of home care packages remain capped and older Australians with high care needs are approved for Level 3 and 4 packages that they are unable to access. In this context, older adults are encouraged to accept a Level 2 package as an interim measure, which may be ‘topped up’ with services funded under the CHSP program or

purchased privately. For these consumers and families, choice is an illusion and there may be pressure to accept a home package that fails to meet the needs or preferences of the older person (Gill et al., 2011; KPMG, 2015).

The UK experience provided valuable lessons about the potential of DPs to improve the experience of care through enabling adults with disabilities to employ their own care workers and negotiate activities that improved quality of life and sensitivity to personal needs as well as continuity of the care relationship (O'Rourke, 2015). Researchers in the UK also questioned the capacity for choice and social engagement for older adults whose payments were substantially lower than those for people with disabilities with similar ADL restrictions (Kane, Priester, & Neumann, 2007; Moran et al., 2013). These experiences and policy expositions shaped the researcher's understanding of the model of CDC model that has been implemented in Australia. In turn, the conceptual framework advanced by the researcher encourages reflection on the elements that combine to shape consumer experience of CDC.

### ***10.5 Future directions for research***

There are three key directions for future research that arise from the program of research presented. The first proposal concerns research to elucidate effective interventions to reduce risks associated with post hospital transitions in older adults with cognitive impairment. A second proposal is to consider the experience of TC of culturally diverse and Indigenous populations. A third proposal is to examine the utility of the EQ-5D, a simple measure of health-related quality of life, as a routine outcome measure for TC.

#### ***10.5.1 Reducing post hospital risks in older adults with cognitive impairment***

The COACH protocol incorporated core elements of the Care Transition Intervention (CTI) that has been shown to be effective in reducing rates of rehospitalisation at 30, 90 and 180 days in both public (Coleman, Parry, Chalmers, & Min, 2006) and fee-for-service settings

(Parry, Min, Chugh, Chalmers, & Coleman, 2009). CTI recipients report high levels of confidence in communicating with members of the healthcare team and self-managing their medical conditions and medications (Coleman et al., 2004). Qualitative research suggests that perceptions of a caring relationship lead to greater patient investment in the program and, in turn, better self-management (Parry, Kramer, & Coleman, 2006). This finding is consistent with previous research which found patients define good quality care as individualised, patient-focused, related to need and provides them with a sense of being cared about (Attree, 2001).

Despite this wealth of data, the efficacy of the CTI for frail older persons with cognitive impairment has not previously been demonstrated (Gilmore-Bykovskyi, Jensen, & Kind, 2014). Given rapid ageing of the population and the resulting increase in the proportion of the population with cognitive impairment, research is urgently required to elucidate effective interventions to reduce the hazards of post hospital transitions in this subgroup of older persons. Future cohorts of older adults, including those with cognitive impairment, are likely to demand full participation in decisions about their accommodation and care. It is also timely to foster research studies that are concerned with the health care needs of those aged 80 years or older who are most likely to use aged care services, rather than continuing to translate findings from studies in which participants are generally aged from 65 to 75 years (Zulman et al., 2011) and in an active stage of retirement (PC, 2015).

### ***10.5.2 A focus on cultural diversity in TC***

In 2012-13, 0.7% of TC recipients identified as ATSI and 19.6% reported that they were born in a non-English speaking country, including 11% from Southern or Eastern Europe. Of those born in a non-English speaking country, about half reported that they preferred to speak a language other than English at home including 44% of those born in Southern Europe (AIHW, 2014c). This has obvious implications for older TC recipients both in terms of

communication of their care needs and preferences and in being understood by TC staff and others.

Many older Australians experience difficulty in navigating the health and aged care systems and as described in Chapter 6, the implementation of residential TC as a potential pathway to RAC may be perceived as inconvenient (due to location) or inappropriate due to uncertain health care needs. A lack of basic proficiency in English and difficulty in comprehending the purpose of TC are likely to present barriers to access and uptake of TC while cultural and familial roles may influence preferences for SDM and engagement in care planning.

In 2012-13, 3.8% of all overnight acute separations were for Indigenous people (AIHW, 2014a) and it is reasonable to suggest that ATSI are underrepresented in TC. Preferences to receive care on their land and from Indigenous staff (Alzheimer's Australia, 2011) as well as concerns about the cultural appropriateness of services are likely to impact uptake of TC. Indigenous care recipients are also more likely to return to hospital (20.2%) compared with non-Indigenous recipients (16.5%) (AIHW, 2014b). These data reveal tensions between the preferences of Indigenous people and their experience of structural disadvantage and complex chronic disease (AIHW, 2015).

Further research should examine the experience of TC by recipients born in Australia and other English speaking countries compared with the experience of those born in non-English speaking countries and Indigenous recipients, notwithstanding the additional resources required for translation and interpreter services. Cultural diversity within the nursing and personal care workforce is likely to present additional challenges.

The formative evaluation of the Home Care Packages Programme (HCPP; KPMG, 2015) describes the experience of special needs groups, including: (i) people from ATSI or culturally and linguistically diverse backgrounds; (ii) people who live in rural or remote areas

or are financially or socially disadvantaged; (iii) veterans; (iv) people who are homeless or at risk of becoming homeless; (v) care leavers (Stolen Generations of Indigenous people forcibly separated from their parents, the Forgotten Australians of people raised in institutional care settings during the 20th century, former child migrants); and (vi) lesbian, gay, bisexual, transgender and intersex people. The issues raised by special needs groups and service providers highlight a general wariness of both the aged care assessment process as well as inviting aged care workers into their lives (living arrangements, specific health needs, relationship status or personal history). These findings are of relevance to TC generally, and residential TC specifically with regard to communal dining and social areas and limited privacy.

Service providers interviewed for the evaluation of the HCPP expressed uncertainty about working with special needs groups, underlining the importance of further education and training in the sector. Of concern to people with CALD backgrounds and those living in rural and remote areas is that the cost of translation and interpreting services (if required for delivery of personal care or services not directly related to the operation of the HCPP) and travel are deducted from individual budgets (DoH, 2015a). Additional costs associated with supporting people with special needs also need to be accommodated within the available budget (National Aged Care Alliance, 2013) although supplementary payments are available for people with dementia or cognitive impairment, veterans, people with oxygen or enteral feeding requirements and those experiencing hardship (DoH, 2015a).

### ***10.5.3 Measuring health-related quality of life***

Further research to assess the acceptability of the EQ-5D to older Australians and TC providers should also be considered. The EQ-5D has been used to assess provider performance in the NHS and its applicability to a range of Australian settings in which older persons receive health and restorative care, warrants further examination. The EQ-5D could



be a useful adjunct to provider assessment of dependency as rated using the MBI. Further knowledge exchange between researchers and policy and program staff may facilitate use of simple patient reported outcomes in older populations for whom language and cognition may act as barriers to participation. Of course there may be other brief, generic measures of patient experience, outcomes, and quality of life that have been validated in patients with dementia (e.g., DemQol; Smith et al., 2007) that may also warrant examination.

Analyses of COACH data reported similar health-related quality of life gains in intervention and usual care groups, evidenced by a positive mean improvement in the EQ-5D scores from admission to 3 month follow-up. Older adults who receive TC in a residential setting are more dependent, more likely to have cognitive impairment, and are more likely to transition to permanent RAC compared with those receiving TC in the community (Giles et al., 2008). The characteristics and outcomes of this comparatively small group are understated in recent reports on the outcomes of the TCP (e.g., AIHW, 2011a) and the introduction of a measure such as the EQ-5D could shift the measurement focus from functional gains to incorporate a subjective measure of health-related quality of life.

### ***10.6 Summary of the research program***

Hospital admissions and re-admissions of older people impose major health care costs, and recent years have seen an increasing emphasis on transitioning older patients to less expensive sites of care once they are medically stable. The TCP was implemented in Australia in 2005 to provide timely access to nursing and allied health as well as personal and home care services. Post hospital transitions are associated with a risk of medication-related errors as well as discontinuity of care and gaps in knowledge and understanding of the care plan (Boling, 2014). There is a developing evidence base for interventions that focus on

improving health literacy and self-management among older adults. However, these interventions need to be tailored for those with cognitive impairment and family carers.

The last decade has also witnessed changes in community expectations of ageing and aged care. Most people want and expect care in the community and are delaying entry to RAC, perceiving it to be a 'last resort'. Admission to hospital following an injury or acute medical event can precipitate entry to RAC, although interventions to support older adults' participation in discussions about RAC remain under-developed.

HSR is concerned with the way people access health care and what happens to them as a result of their interaction with the health system. RCTs provide the strongest evidence concerning the effectiveness of a particular intervention and in combination with an economic evaluation provide policy relevant endpoints, including health service utilisation and cost effectiveness. However, patient experience may not feature in this study design.

HSR provides evidence to inform policy and health service researchers are frequently commissioned to undertake evaluation of policy implementation. Formative evaluation is commonplace as governments seek to implement and evaluate programs contemporaneously and within an election cycle. One of the limitations of formative evaluation is that the experience of clients and other stakeholders are sought in the early months of implementation and before a program is bedded down. The formative evaluation of CDC in home care in Australia (KPMG, 2015) provided valuable insights into the views of aged care providers, peak bodies and consumer advocacy groups however, the voices of the 57 consumers and carers who were interviewed remain largely unheard. Consumer experience of choice under CDC was not addressed in the report, nor was there any discussion of consumer and carer experience of monthly financial statements. This would seem to be an important omission.

### ***10.7 Contribution of the present program***

The overarching question for the program of research, as introduced in Chapter 1, was:

*What is the experience of older Australians as they transition from hospital to home or RAC via an intermediate care program?*

The various research methods used to examine the experience of post-hospital transitions of older Australians provided rich data and a variety of perspectives on this important topic. In combination, the studies provide a more comprehensive insight into the experience of post hospital transitions of older adults than could be achieved using a single method.

The program of research identified challenges in engaging GPs and Geriatricians in TC, meeting the requirement for a pharmacist-led review of medications and securing appropriate levels of ongoing care on completion of the TC episode. In 2007, these findings provided a timely insight into a new program of care. Development of a standardised measure of patient experience of TC using data from the NETCP offered a practical tool to elicit the consumer's perspective of the quality of care in TC.

The nuances of decision making within dependent relationships were explored in a third study that examined the process of entry to RAC from a hospital bed. Narrative analysis was used to interpret and communicate the thoughts and experiences of older persons who were waiting for a RAC bed, including those with dementia. Narratives provide glimpses into past lives and illuminate the role of identity in ageing and may assist emerging researchers in ageing to more fully appreciate the person in the hospital bed.

In 2008, a representative sample of households was asked to respond to a question about an aged care entitlement at the point of entry to RAC that would provide choice about receiving care at home or RAC. While the line of questioning would have benefited from further

development, most respondents supported the idea of an entitlement. Further research to compare the views of home care package recipients in Australia with a comparison group matched by age may offer useful information in the contemporary context.

In the final study, a pragmatic RCT reported that a health literacy and coaching intervention improved the quality of preparation for future care transitions as measured by the CTM-15<sup>®</sup>. The intervention was expensive and future research to examine the effectiveness of a single family meeting should be considered. Modification of the study design to incorporate an additional intervention arm would provide a further opportunity to compare the effectiveness of Geriatrician and nursing-led interventions on the quality of preparation for care transition.

In addition to suggestions for specific follow-up studies, a broader research agenda is described in 10.5 which encourages greater attention to transitions in adults aged 80 years or older who are at increased risk of developing dementia and delirium as well as those from CALD backgrounds. The role of carers as advocates for vulnerable older adults is critical for communication across care settings, yet interventions to prepare carers for this role remain underdeveloped. The potential for greater utilisation of simple patient reported outcome measures such as the EQ-5D, both in TC and aged care more generally, was also described.

In 2016 TC is well established and attention is focussed on reform of home-based care. Initial trials and subsequent implementation of CDC have been evaluated (KPMG, 2012, 2015) however evidence of consumer empowerment through voice and choice is yet to be established (Gill et al., 2016). The five novel empirical studies presented in this thesis provide valuable information for clinicians developing targeted intervention programs designed to enhance patient and carer participation in planning for future care. Such interventions have the potential to improve the transition experience and reduce adverse outcomes commonly associated with care transitions.

## **Appendix A**

### *TRANSITION CARE QUALITY REPORT FORM*

# APPENDIX A: TRANSITION CARE QUALITY REPORT FORM

Notes for electronic data entry:

- Click on the check boxes to select and to unselect
- Click on the left hand corner to enter text into a text field

This is:  a self assessment report OR  a team review report, which covers:

1. Name of **Approved Provider** (State/ Territory):

.....

2. Name of Transition Care Provider **Organisation/Agency**:

.....

3. Name of Transition Care **Service**:

.....

4. **Address** of Transition Care Service:

.....

5. **Size and funding** of this Transition Care Service:

residential places       community places      \$      estimated total funding 2005-06

6. Please provide a **brief description** of the Transition Care service at this location. Please include an outline of the service model and a staff profile, including the number and professions of allied health and other clinical and care staff dedicated to transition care.

[guide 200 words]

7. Please indicate what **quality accreditation** the organisation/ agency has that is relevant to the services provided under Transition Care and the **period** of this accreditation. If providing **residential** transition care, please also indicate which building requirements are met. If you have more than one service with different accreditation, list one per row.

Name of service	Service type(s) provided	Quality Accreditation of broker / sub-contractor or other external regulation								If providing residential transition care, please indicate:		
		Residential aged care accreditation	ACHS EQuIP	QIC	ISO 9001	Community Care	HACC	Other – please name	Period of accreditation mm/yy to mm/yy	building requirements met:		Period covered: mm/yy
										Residential aged care certification	Other – please name:	
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		to			to
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		to			to
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		to			to
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		to			to
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		to			to
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		to			to
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		to			to

8. Does the service **broker or sub-contract** the delivery of services to other agencies or individuals?

No

Yes- If yes, please list all other agencies or individuals in the following table:

Name of broker / sub-contractor	Type of service provided by broker / sub-contractor	Quality Accreditation of broker / sub-contractor or other external regulation							If providing residential transition care, please indicate:			
		Residential aged care accreditation	ACHS EQulP	QIC	ISO 9001	Community Care	HACC	Other – please name	Period of accreditation mm/yy to mm/yy	building requirements met:		Period covered mm/yy to mm/yy:
										Residential aged care certification	Other – please name:	
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		to	<input type="checkbox"/>		to
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		to	<input type="checkbox"/>		to
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		to	<input type="checkbox"/>		to
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		to	<input type="checkbox"/>		to
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		to	<input type="checkbox"/>		to
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		to	<input type="checkbox"/>		to



## Overview of service

9. Are there any **particular aspects** of the Transition Care Service which the provider(s) would like to highlight? For example, this may include new or innovative arrangements for Transition Care such as shared care arrangements or protocols established within the provider organisation or with other services.

[guide 150 words]

10. Have any **formal complaints** been received about the Transition Care Service?

No

Yes- If yes:

- were the complaints resolved to the satisfaction of all parties?  No  Yes
- please state under which complaints process these were handled:
  - Internal service specific complaints mechanism;
  - State / Territory Health Complaints process;
  - Australian Government Aged Complaints process;
  - Other – please describe:
- please describe any changes to the way you provide services made as a result of the complaint(s):

11. Please describe any particular **challenges** faced by the service and how these have affected the service model and/or clients:

[guide 150 words]

12. **Contextual information:**

Prior to visiting the transition care service, the Approved Provider, the Transition Care service provider and the assessors of the visiting team will receive a service report based on data collated via the Australian Government payments system. This information is intended to provide a broad quantitative overview of service outputs of the Transition Care service.

Table A attached to this report lists a range of information which may be useful in thinking about the results of Transition Care service delivery. All of these items may not be available but as the Transition Care Program rolls out, additional information is likely to become available. You may collect some information through sampling, say 10%, of care plans or client files.

### 13. KEY TRANSITION CARE REQUIREMENTS & EVIDENCE

13.1 *Transition Care objective: Clients' social, physical, emotional, cultural and community independence is optimised.*

Transition Care Criteria	Service's evidence of meeting Transition Care Requirement <sup>1</sup>	Comments / suggestions	If requirement not met, please describe any <b>action</b> required /recommended so that requirement is met in the future:
Transition care is linked to the agreed goals of clients, carers, families and other key stakeholders involved in the client's longer term care, and to the promotion of self-sufficiency and self-management.			
The selection and use of therapies are informed by evidence based research and leading practice information.			
Transition care is delivered in a manner designed to optimise independent functioning following discharge. (SCS 3.2 refers)			
Clients receive timely and appropriate access to care and equipment, throughout the health, aged and community care sectors.			
Any <b>additional comments</b> ?			
Any <b>other improvement ideas or suggestions</b> ?			
Any examples of <b>interesting practice</b> which the service is prepared to share with other transition care providers:			

<sup>1</sup> Sources of evidence may include client files, policy and procedural documentation, service and brokerage agreements, stakeholder feedback and results of interviews and observations. Evidence may be quantitative or qualitative. Examples of possible quantitative background material are provided in Table A attached to this report.

13.2 Transition Care Delivery Strategies:

- Goal oriented, individualised, time limited specified care and services are provided to clients while in Transition Care.
- Low intensity therapies and services, likely to meet objectives efficiently and effectively, are provided in an appropriate setting.

Transition Care Criteria	Evidence of meeting TC Requirement <sup>2</sup>	Comments / suggestions	If requirement not met, please describe any action required /recommended:
Each transition care client has a current care plan, which is informed by hospital and discharge assessment and planning. (SCS 3.2 refers)			
<p>Each transition care plan / client file incorporates:</p> <ul style="list-style-type: none"> <li>• the client's functional capacity with activities of daily living on admission to transition care, any changes while in care, and on discharge, assessed using a recognised, standardised and validated instrument,;</li> <li>• the client's desired destination on discharge as well as an alternative discharge destination if the desired destination cannot be achieved;</li> <li>• the client's Quality of Life expectations and goals considering lifestyle, community participation, relationships, emotional well-being and activities;</li> <li>• consideration of the views and wishes of carers, families and others likely to be involved in the client's longer term care;</li> <li>• low intensity therapy and other clinical goals, strategies and delivery plans consistent with optimising achievement of client goals, and where possible those of carers and other key stakeholders;</li> <li>• an assessment of the likelihood of achieving desired client goals and actions required if goals remain unmet;</li> <li>• support, activities and counselling appropriate to each client's reactions to anticipated changes in his/her life as a result of the effects of his/her acute/sub-acute care episode and likely transition care outcomes;</li> <li>• the expected transition care timeframe;</li> <li>• a discharge process and plan; and</li> <li>• results against goals while in transition care, and on exit.</li> </ul>			
Transition care delivery reflects current care plans, with plans and delivery monitored, reviewed and refined to reflect changing client goals, function and preferences. (SCS 3.2 refers)			
With consent, copies of each client's care plan and discharge summary are given to his/her GP and all involved services.			

<sup>2</sup> Sources of evidence may include client files, policy and procedural documentation, service and brokerage agreements, stakeholder feedback and results of interviews and observations. Evidence may be quantitative or qualitative. Examples of possible quantitative background material are provided in Table A attached to this report.

Transition Care Criteria	Evidence of meeting TC Requirement <sup>3</sup>	Comments / suggestions	If requirement not met, please describe any action required /recommended:
<p><i>13.2 Transition Care Delivery Strategies continued.....</i></p> <p>Residential transition care services are provided in a more home-like setting within a non-hospital environment , with the setting including:</p> <ul style="list-style-type: none"> <li>• communal living space / living room environment completely separate from sleeping areas and location of acute/subacute care provision, ie a space that encourages family/carers and visitors to spend time with clients;</li> <li>• a dining area and clients encouraged not to eat in bed;</li> <li>• clients being encouraged and supported to dress everyday;</li> <li>• facilities to prepare snacks etc for self and visitors;</li> <li>• privacy particularly for personal care and bathing arrangements;</li> <li>• space for clients to mobilise especially outdoors; and</li> <li>• physical arrangements which support the involvement of carers in the therapeutic activities.</li> </ul>			
<p>Each client leaves transition care with a refined care plan and discharge summary which has been negotiated and agreed with the client, carer/guardian/ advocate and all involved services and which records:</p> <ul style="list-style-type: none"> <li>• all services to be received following discharge, with key contact details;</li> <li>• a list of pharmacist-checked discharge medications; and</li> <li>• other follow-ups / referrals which are the responsibility of the client / carer / guardian or advocate.</li> </ul>			
<p>Discharge notes for each client record:</p> <ul style="list-style-type: none"> <li>• their length of stay in transition care;</li> <li>• their destination post transition care;</li> <li>• the goals which the client agreed had been achieved and not achieved;</li> </ul>			

<sup>3</sup> Sources of evidence may include client files, policy and procedural documentation, service and brokerage agreements, stakeholder feedback and results of interviews and observations. Evidence may be quantitative or qualitative. Examples of possible quantitative background material are provided in Table A attached to this report.

<ul style="list-style-type: none"> <li>the reasons for non-achievement of goals; and</li> <li>client functional levels on discharge from transition care, assessed using the same recognised and standardised instrument used on admission.</li> </ul>			
Where required, transport is provided or arranged to ensure safe passage of the client home or to his/her residential aged care home.			

Any <b>additional comments</b> ?	
Any <b>other improvement ideas or suggestions</b> ?	
Any examples of <b>interesting practice</b> which the service is prepared to share with other transition care providers:	

### 13.3 Transition Care Characteristics:

- **Multidisciplinary, skilled team applies aged friendly principles and practices.**
- **A collaborative service delivery and learning model is used which extends the skills of staff involved with transition care clients and impacts positively on the wider aged and health care sectors.**

Transition Care Criteria	Evidence of meeting Transition Care Requirement <sup>4</sup>	Comments / suggestions	If requirement not met, please describe any action required /recommended:
Each transition care client has received in hospital a multi-disciplinary assessment, preferably involving a geriatrician or another geriatric specialist.			
In the Transition Care service, multidisciplinary, qualified, experienced and skilled staff, proficient in aged care practices in a non-hospital setting, assess each client and support care planning and review. (SCS 3.4 refers)			
Care is informed by discussions with and between the relevant Geriatrician and the client's GP, where possible, and/or other appropriate medical input.			
Allied health, medical and nursing staff involved in Transition Care assessment, care planning and therapy oversight, have the relevant professional standing.			
Transition care staff work collaboratively with involved acute/sub-acute, residential and community care staff to ensure effective service delivery as well as information and skills transfer.			
Each year, staff have attended in service training on, or met with peers from other providers to review, leading practice in transition care.			
Staff utilise other opportunities to be informed of leading practice directions in relation to the provision of transition care (including literature and interaction and sharing practice strategies with other transition care providers).			
Joint or cross sector training occurs across all staff working with transition care clients.			
Any <b>additional comments</b> ?			
Any <b>other improvement ideas or suggestions</b> ?			
Any examples of <b>interesting practice</b> which the service is prepared to share with other TC providers:			

<sup>4</sup> Sources of evidence may include client files, policy and procedural documentation, service and brokerage agreements, stakeholder feedback and results of interviews and observations. Evidence may be quantitative or qualitative. Examples of possible quantitative background material are provided in Table A attached to this report.

13.4 *Transition Care Characteristic: Care is timely, seamless and offers flexible and reliable support linked to other services.*

Transition Care Criteria	Evidence of meeting Transition Care Requirement <sup>5</sup>	Comments / suggestions	If requirement not met, please describe any action required /recommended so that requirement is met in the future:
Transfer and admission to transition care is at the very latest within 4 weeks of ACAT approval for transition care, but preferably much less.			
With consent and privacy considerations, key hospital assessment results, plans, health and other information are transferred with the client to avoid duplication in information collection.			
The service maintains effective linkages with all related services (including hospitals, and health, residential aged and community care services) and all relevant workers to optimise achievement of clients' transition care goals. (SCS 3.2 refers)			
Equipment, support services and modifications necessary for effective discharge from transition care are arranged as required. (SCS 2.10 for community settings refers)			
Collaboration between acute/sub-acute care, aged, community and primary care is reflected in protocols and agreements, such as those areas covered by Appendix 1 of the Age-Friendly Principles and Practices.			

Any <b>additional comments</b> ?	
Any <b>other improvement ideas or suggestions</b> ?	
Any examples of <b>interesting practice</b> which the service is prepared to share with other transition care providers:	

<sup>5</sup> Sources of evidence may include client files, policy and procedural documentation, service and brokerage agreements, stakeholder feedback and results of interviews and observations. Evidence may be quantitative or qualitative. Examples of possible quantitative background material are provided in Table A attached to this report.



**ONLY COMPLETE THIS SECTION IF** the Transition Care Service does not have some form of external accreditation.

**13.5 Transition Care Characteristic: Care is safe for clients, staff and other stakeholders.**

Transition Care Criteria	Evidence of meeting Transition Care Requirement <sup>6</sup>	Comments / suggestions	If requirement not met, please describe any action required /recommended so that requirement is met in the future:
Occupational health and safety and incident records show that: <ul style="list-style-type: none"> <li>• appropriate occupational health and safety checks and training occur;</li> <li>• care delivery and safety meets or exceeds industry safety and performance standards; and</li> <li>• that where safety or other adverse incidents have occurred, practices and policies have been reviewed and refined to avoid recurrences.</li> </ul>			
All transition care buildings comply with the relevant residential aged care, Australian Building standards, State legislation and/or local regulations.			

Any <b>additional comments</b> ?	
Any <b>other improvement ideas or suggestions</b> ?	
Any examples of <b>interesting practice</b> which the service is prepared to share with other transition care providers:	

<sup>6</sup> Sources of evidence may include client files, policy and procedural documentation, service and brokerage agreements, stakeholder feedback and results of interviews and observations. Evidence may be quantitative or qualitative. Examples of possible quantitative background material are provided in Table A attached to this report.

14. Have any concerns been identified about areas of **immediate health, safety or well-being risks** to consumers, staff or other stakeholders?

No       Yes – if yes, please **describe the concern(s) and actions** to be taken:

15. What **improvements** are proposed to the Transition Care service?

	Priority 1	Priority 2	Priority 3
<b>Area:</b>			
<b>What we want to achieve:</b>			
<b>What we intend to do:</b>			
<b>Who is responsible?</b>			
<b>Planned completion date:</b>			

This report was completed on ... / / by the following members of **staff / Transition Care Review Team:**

Name: .....  
 Organisation: .....  
 Position: .....

Name: .....  
 Organisation: .....  
 Position: .....

Name: .....  
 Organisation: .....  
 Position: .....

**Table A:** Possible quantitative items which may be useful contextual information.

**Please note:** Transition Care Services are not required to complete this table.

	Number	% of Sample	Sample size
Clients whose functional skills (measured by standardised and validated measures) have been maintained or improved while in Transition Care.			
Clients and other stakeholders who have indicated via feedback that they are satisfied with the outcomes of their transition care.			
Care plans/case notes which display continuation of community and other key contacts and activities while in transition care.			
Clients who have achieved their personal transition care goals.			
Clients who have achieved their clinical transition care goals.			
Clients who have been discharged to their desired destination (recorded at admission).			
Clients who have returned to the community or to their former residential setting.			
Clients and other stakeholders who have indicated via feedback that they were satisfied with the timeliness and duration of their transition care.			
Care plans which have been reviewed and refined during transition care.			
Client's case notes which show evidence of planning for their post discharge setting from early in their transition care episode.			
Sample of care plans which show that therapy services are delivered as predicted in care plans.			
Clients and other stakeholders who have indicated via feedback that they are satisfied with the quality and responsiveness of the transition care and support received.			
Care plans and care delivery notes which demonstrate multidisciplinary input and collaboration of medical, therapy and care staff from all involved services.			
Staff who have attended in-service training on, or met with peers from other providers to review, leading practice in transition care over past year.			
Client documentation which shows that the duration between ACAT approval and admission to transition care is less than 4 weeks.			
Clients and other family stakeholders who have indicated via feedback that they are satisfied with the types and amount of support proposed to be received on discharge.			
Transition care and other staff who have reported, via feedback: - satisfaction with the collaboration and/or joint training between transition care and other services; and - enhanced skills and understanding arising from this collaboration and/or joint training.			
Transition care and other staff and service representatives who have indicated, via feedback, that inappropriate blockages and delays have reduced or been eliminated.			
Care plans which show that any barriers to accessing needed support have been identified and that attempts have been made to remove or reduce these barriers.			
Clients and other stakeholders who have indicated via feedback that discharge from transition care and organisation of subsequent support was timely.			
	<b>This service</b>	<b>Average for State/Territory</b>	
The average length of stay of transition care clients at this service compared with the average for this State/Territory.	weeks	weeks	
The average duration between ACAT approval and admission to transition care for this service compared with other services in this State/Territory.	weeks	weeks	
Comparisons with other Transition Care services*:			

\* Other comparative data may be available from services taking up benchmarking opportunities with other Transition Care Services.

## **APPENDIX B**

### *SUMMARY OF ETHICS APPLICATIONS*

## APPENDIX B: Summary of Ethics Applications for NETCP

<b>National Applications</b>	<b>Due date</b>	<b>Date submitted</b>	<b>Date of meeting</b>	<b>Final approval</b>
Department of Health and Ageing Departmental Ethics Committee	18 Oct 2006	18 Oct 2006	06 Nov 2006	13 Dec 2006
Flinders Clinical Research Ethics Committee	27 Nov 2006	30 Oct 2006	11 Dec 2006	18 Dec 2006
<b>ACT Government</b>				
ACT Health and Community Care Human Research Ethics Committee	28 Nov 2006	23 Nov 2006	11 Dec 2006	26 Feb 2007
<b>Victorian Government</b>				
Austin Health Human Research Ethics Committee	28 Nov 2006	23 Nov 2006	12 Dec 2006	28 Feb 2007
Barwon Health Research and Ethics Advisory Committee	21 Nov 2006	21 Nov 2006	28 Nov 2006	12 Dec 2006
Bundoora Extended Care Centre Human Research Ethics Committee		Have asked for project to be overseen by the Northern HREC (in same health region)		30 Nov 2006
Eastern Health Research and Ethics Committee	QA Process	21 Nov 2006	14 Dec 2006	Not Required
Human Research Ethics Committee - A St Vincent's Health Melbourne	QA Process	21 Nov 2006	13 Dec 2006	Not Required
Melbourne Health Human Research Ethics Committee	QA Process	04 Dec 2006	06 Dec 2006	18 Jul 2007
Peninsula Health Research & Ethics Committee	17 Nov 2006	16 Nov 2006	06 Dec 2006	06 Dec 2006
Southern Health Human Research Ethics Committee B	QA Process	21 Nov 2006	14 Dec 2006	Not required
The Alfred Research & Ethics Unit (Bayside)	20 Nov 2006	21 Nov 2006	21 Dec 2006	02 Jan 2007
The Northern Hospital Human Research & Ethics Committee	17 Nov 2006	16 Nov 2006	28 Nov 2006	30 Nov 2006
Victorian Department of Human Services Human Research Ethics Committee	22 Nov 2006	20 Nov 2006	06 Dec 2006	19 Dec 2006
<b>Queensland Government</b>				
Bayside Health Service District Human Research Ethics Committee	06 Dec 2006	29 Nov 2006	14 Dec 2006	14 Dec 2006
Cairns Base Hospital Ethics Committee	16 Jan 2007	19 Dec 2006	01 Mar 2007	09 Mar 2007
Gold Coast Health Service District Human Research Ethics Committee	17 Jan 2007	15 Dec 2006	31 Jan 2007	23 Apr 2007
Mackay Health Service District Human Research Ethics Committee		19 Dec 2006	17 Jan 2007	approved
Princess Alexandra Hospital Human Research Ethics Committee	17 Nov 2006	16 Nov 2006	05 Dec 2006	16 Apr 2007
Queensland Health Research Ethics Committee	06 Dec 2006	28 Nov 2006	18 Dec 2006	28 Feb 2007
Redcliffe-Caboolture Health Service District Ethics Committee	17 Jan 2007	15 Dec 2006	07 Feb 2007	04 Apr 2007



## APPENDIX B: Summary of Ethics Applications for NETCP (cont ...)

National Applications	Due date	Date submitted	Date of meeting	Final approval
Rockhampton Health Service District HREC	07 Feb 2007	15 Dec 2006	22 Feb 2007	01 Mar 2007
Royal Brisbane and Women's Hospital Human Research Ethics Committee	11 Jan 2007	15 Dec 2006	19 Feb 2007	06 Jun 2007
The Prince Charles Hospital Health Service District HREC	29 Nov 2006	28 Nov 2006	13 Dec 2006	13 Dec 2006
The Townsville Health Service District Institutional Ethics Committee	23 Nov 2006	21 Nov 2006	07 Dec 2006	05 Feb 2007
Toowoomba Health Service District Human Research Ethics Committee	29 Nov 2006	27 Nov 2006	14 Dec 2006	06 Dec 2006
West Moreton Health Service District Human Research Ethics Committee	20 Nov 2006	17 Nov 2006	04 Dec 2006	26 Feb 2007
<b>NSW Government</b>				
NSW Department of Health Human Research Ethics Committee	23 Nov 2006	20 Nov 2006	14 Dec 2006	01 Feb 2007
<b>SA Government</b>				
SA Department of Health Human Research Ethics Committee	26 Oct 2006	26 Oct 2006	08 Nov 2006	09 Feb 2007
<b>Tasmanian Government</b>				
Southern Tasmania Health & Medical Human Research Ethics Committee	09 Nov 2006	09 Nov 2006	11 Dec 2006	04 Dec 2006
<b>WA Government</b>				
Confidentiality of Health Information Committee		29 Jan 2007	06 Feb 2007	19 Feb 2007
<b>NT Government</b>				
Central Australia Human Research Ethics Committee	26 Oct 2006	21 Nov 2006	23 Nov 2006	24 Nov 2006
Human Research Ethics Committee of Northern Territory Department of Health & Community Services and Menzies School of Health Research	15 Nov 2006	14 Nov 2006	07 Dec 2006	13 April 2007



## APPENDIX C

### *THE RESEARCHER'S CONTRIBUTION TO STUDIES IN THE PRESENT THESIS*

#### **Chapter 4: Assessing quality in the TCP**

The researcher was not involved in the design of the study; one of six studies undertaken as part of the NETCP, or data collection. The researcher led the analysis and interpretation of data and drafted the following manuscript.

**Masters, S.,** Halbert, J., Crotty, M., & Cheney, F. (2008). What are the first quality reports from the Transition Care Program in Australia telling us? *Australasian Journal on Ageing*, 27(2), 97-102.

#### **Chapter 5: Assessing patient experience of the TCP**

The researcher designed the measure of *patient experience* and was involved in data collection, interviewing more than 140 recipients of transition care, or a proxy, via telephone as well as interviewing a nominated carer for each recipient. The researcher analysed the survey patient experience data from the telephone survey and drafted the following manuscript.

**Masters, S.,** Giles, L., Halbert, J., & Crotty, M. (2010). Development and testing of a questionnaire to measure older people's experience of the Transition Care Program in Australia. *Australasian Journal on Ageing*, 29(4), 172-178.

**Chapter 6: Decision making about entry to RAC from a hospital bed**

The researcher was a Chief Investigator on this study and was involved in the study design, submission of the ethics and grant applications and consultation with social workers. The researcher formulated the research questions, conducted the interviews and analysed the data.

**Chapter 7: Community preferences for aged care**

The researcher designed the research questions and submitted the ethics application but was not involved in data collection. The researcher analysed and interpreted the data and prepared the following poster presentation.

**Masters, S.,** Whitehead, C., Ratcliffe, J., & Crotty, M. (2010). What does the community think of consumer directed care for dependent older people? – a population interview survey of 3034 households in Australia. Poster presented at the Australian Hospitals and Healthcare Association and Australian Institute of Health Policy Studies (AHHA-AIHPS) Congress: HealthCon 2010, Sept 23-24, Hilton Adelaide.

**Chapter 8: Increasing patient and carer involvement in residential TC**

The researcher was a Chief Investigator on this project and was involved in the study design, design of the study instruments, submission of the ethics application and liaison with pharmacy, aged care and hospital staff. The researcher was responsible for all aspects of study implementation and day to day coordination of recruitment, data collection, delivery of the intervention and outcomes assessment from 2008-2010, including staff training and supervision. The researcher was also a member of the team that delivered the intervention. The researcher is lead author on the protocol paper and a poster presented at the 2010 Annual Scientific Meeting of the Australian and New Zealand Society for Geriatric Medicine.



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