CONSUMER DIRECTED CARE IN THE COMMUNITY AGED CARE SECTOR: A HEALTH ECONOMICS PERSPECTIVE

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ABSTRACT

Aged care policy reform in Australia in August 2013 led to the introduction of a consumer directed care (CDC) model of service delivery and heralded unprecedented changes for the community aged care sector. Consumer directed care is a model of service delivery that allows consumers to have greater control over their care by incorporating their choices about the type of care and services received, including who delivers these services and when they are delivered. From July 2015, all community aged care services in Australia are delivered under a CDC model.

This research was conducted as part of an Australian Research Council Linkage project that applied a health economic perspective to the development and evaluation of a consumer directed care model of services. The project focused on the change in policy to move towards a more flexible and consumer directed approach to the design and delivery of community aged care services. Initially, a major goal of this research was to present existing evidence of the cost effectiveness of this model of service delivery worldwide before undertaking a cost effectiveness analysis of the model with an Australian context. However, due to the rapid pace of change in policy and practice in the Australian community aged care sector (the timing of which coincided with the work conducted and reported upon in this thesis), only the former was undertaken. It was not possible to conduct a traditional economic evaluation as originally envisaged, by comparing the costs and outcomes associated with a cohort of participants in receipt of services under CDC with a matched cohort of participants receiving a traditional provider directed care model (PDC). This was because there was no longer a distinction between the CDC and PDC arms at follow-up as all study participants switched to a CDC model during the study. However, it was possible to employ a health economic approach to assess the impact of the introduction of a CDC model of service delivery in the aged care sector focusing upon the main cost drivers associated with the provision of services and factors that explain variation in the quality of life of older people receiving community aged care services (CACS) through a series of cross-sectional studies.

The overall aim of this research was to investigate the changes in quality of life associated with receipt of a CDC model of CACS and the costs associated with this model of service delivery. It was undertaken by applying a health economic perspective to the analytical framework for evaluating quality in the delivery of service innovations in health systems (comprising three main inter-linking elements namely structure, process and outcomes) first proposed by Avedis Donabedian. The structure of aged care and the process of service delivery were theoretically analysed within the context of market failure and product/service differentiation while the outcomes/impact of care were assessed within extra-welfarism theory through the measurement of changes in quality of life and capability. Two cross-sectional empirical studies were undertaken at different time points (early and late phase) reflecting the implementation of CDC in Australia to investigate the impact of CDC services on quality of life and capability using the 5-level version of the EuroQoL 5 dimensions (EQ-5D 5L) and ICEpop CAPability measure for Older people (ICECAP-O) instruments, respectively. A third empirical study was conducted to understand the costs associated with provision of a CDC model of service delivery.

Analysis of the structure and process of care delivery within the community aged care sector illustrates the presence of market failure and competition in the sector through product differentiation. The first empirical study conducted during the earliest stage of the reforms (December 2013) compared quality of life and capability between a cohort of participants receiving the newly initiated CDC services to a cohort of participants in receipt of PDC. The results revealed that overall quality of life was broadly similar for both models of service delivery. However, investigation at the quality of life dimension level revealed that, commensurate with the overarching philosophy of CDC ‘more control to clients’, the cohort of participants receiving a CDC model of service delivery reported higher levels of control/independence on the ICECAP-O relative to those receiving PDC and these differences were statistically significant (*p=0.017*). The second empirical study was undertaken between December 2015 and February 2016, following the system-wide transition of all CACS to a CDC model which took place in July 2015. This study focused on variations in quality of life and capability according to the time participants were in receipt of a CDC type of service. Higher scores were observed for both the EQ-5D-5L and ICECAP-O among older people in receipt of a CDC mode of service delivery for a shorter period (0-12 months) compared with a longer period (more than 12 months). This study demonstrated early evidence of the potential for improvements in capability outcomes for older people as service providers become more engaged with CDC and as this new model of service delivery becomes more established. The third empirical study was a costing study which found that the main cost drivers associated with the provision of a CDC model of service delivery for older people were the provision of care services, administration and care coordination/case-management. The proportion of home care package expenditures allocated to the provision of care services was approximately 50% whilst approximately 40% was allocated to administration and case-

management. The key cost drivers were the level of the home care package and the hours of formal care support received within the home care package.

Overall, it will take some time for the full impact of CDC in relation to the key cost drivers and the key outcomes of health, quality of life and capability for older people to be realised in practice. Further research, including health economic evaluation evidence reflecting longitudinal assessment to track changes in costs and quality of life and capability outcomes over time, is recommended as CDC becomes more established in the community aged care sector in Australia.

PUBLICATIONS ARISING FROM THIS RESEARCH

PUBLISHED

BULAMU, N. B., KAAMBWA, B. & RATCLIFFE, J. 2015. A systematic review of instruments for measuring outcomes in economic evaluation within aged care. Health and Quality of Life Outcomes, 13, 1-23.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4640110/

BULAMU, N., KAAMBWA, B., GILL, L., CAMERON, I., MCKECHNIE, S., FIEBIG, J., GRADY, R. & RATCLIFFE, J. 2016. Impact of consumer-directed care on quality of life in the community aged care sector. Geriatr Gerontol Int.
https://www.ncbi.nlm.nih.gov/pubmed/27530900

BULAMU, N. B., KAAMBWA, B. & RATCLIFFE, J. 2018. Economic evaluations in community aged care: a systematic review. *BMC Health Services Research,* 18**,** 967.
https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-018-3785-3

CONFERENCE PRESENTATIONS

BULAMU, N. B., KAAMBWA, B. & RATCLIFFE, J. 2015. A systematic review of instruments for measuring outcomes in economic evaluation within aged care. Australian Health Economics Society (AHES) Conference: 25th– 26th September 2014 Adelaide, South Australia

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Contributor	**Statement of contribution**
Bulamu, N.B (Candidate)	Conception and design of the sub-study (60%) Data interpretation (60%) Wrote the paper (100%)
Kaambwa, B	Conception and design of the sub-study (20%) Data interpretation (20%) Edited the paper (50%)
Ratcliffe, J	Conception and design of the sub-study (20%) Data interpretation (20%) Edited the paper (50%)

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Mckechnie, S	Edited the paper (10%)
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Grady, R	Edited the paper (10%)
Ratcliffe, J	Conception and design of the sub-study (30%) Interpretation of results (30%) Data collection (30%) Edited the paper (50%)

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.

Professor Julie Ratcliffe developed the original concept and was the principal supervisor for this research. Associate Professor Billingsley Kaambwa was the associate supervisor for the research. Both supervisors oversaw all aspects of data collection, data analysis and interpretation of the results.

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I acknowledge that an electronic copy of this thesis must be lodged with the University Library and, subject to the policy and procedures of Flinders University, the thesis be made available for research and study in accordance with the Copyright Act 1968 unless a period of embargo has been approved by the Dean of the Graduate Research.

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LIST OF ACRONYMS

15D: 15-Dimensions

AACC: Australian Aged Care Commission

AAT: Administrative Appeals Tribunal

ACAR: Aged Care Approvals Round

ACAT: Aged Care Assessment Team

ACFI: Aged Care Funding Instrument

ACHA: Assistance with Care and Housing for Aged

ACPC: Aged Care Pricing Commissioner

ACSAA: Aged Care Assessment and Accreditation Agency

ADL: Activities of Daily Living

AIHW: Australian Institute of Health and Welfare

AQoL: Assessment of Quality of Life instrument

ASCOT: Adult Social Care Outcomes Toolkit

CACP: Community Aged Care Package

CACS: Community Aged Care Services

CALD: Cultural and Linguistic Diversity

CASP-19: Control Autonomy Self-realization and Pleasure – 19 items

CBA: Cost Benefit Analysis

CCA: Cost Consequences Analysis

CDC: Consumer Directed Care

CEA: Cost Effectiveness Analysis

CHC: Complex Health Care

CHSP: Commonwealth Home Support Program

CIS: Complaints Investigation Scheme

CMA: Cost Minimisation Analysis

COAG: Council of Australian Governments

CSHA: Commonwealth State Housing Agreement

CUA: Cost Utility Analysis

CVS: Community Visitor Scheme

DCE: Discrete Choice Experiments

DoHA: Department of Health and Ageing

DTC: Day Therapy Centre

DVA: Department of Veteran Affairs

EACH: Extended Aged Care at Home

EACH-D: Extended Aged Care at home with Dementia

EQ-5D: EuroQol 5 Dimensions

GHQ-12: General Health Questionnaire

GP: General Practitioner

HACC: Home and Community Care

HCB: Home and Community Based

HCP: Home Care Packages

HUI: Health Utilities Index

IADL: instrumental activities of daily living

ICECAP-O: ICEpop CAPability measure for Older people

ICER: Incremental Cost Effectiveness Ratio

LTC: Long term care

MAUIs: Multi-Attribute Utility Instruments

MBS: Medical Benefits Scheme

MPS: Multi-purpose Services

MSAC: Medical Services Advisory Committee

NDIS: National Disability Insurance Scheme

NHP: Nottingham Health Profile

NHS: National Health Service

NICE: National Institute for Health and Care Excellence

NRCP: National Respite for Carers Program

OACQC: Office of Aged Care Quality and Compliance

OPQOL: Older People’s Quality of Life questionnaire

PBAC: Pharmaceutical Benefits Advisory Committee

PBS: Pharmaceutical Benefits Scheme

PCAI: Personal care assessment instrument

PCS: Personal Care Services

PDC: Provider Directed Care

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

QALY: Quality Adjusted Life Years

QWB: Quality of Wellbeing scale

RAC: Residential Aged Care

RCI: Resident Classification Instrument

RCT: Randomised Control Trial

SAAP: Supported Accommodation Assistance program

SF-12: Short Form 12 items

SF-36: Short Form 36 items

SF-6D: Short Form 6 dimensions

SG: Standard Gamble

STRC: Short Term Restorative Care Program

TTO: Time Trade-Off

UN: United Nations

VAS: Visual Analogue Scale

VHC: Veterans Home Care

WHO: World Health Organisation

WHOQoL-100: World Health Organisation Quality of life instrument

WHOQoL-Bref: World Health Organisation brief quality of life instrument

WHOQoL-Old: World Health Organisation Quality of Life Instrument-Older Adults

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CHAPTER 1

INTRODUCTION

This chapter provides a context for the thesis. It begins with an introduction to population ageing at the global level and then specifically in Australia. It conceptualises aged care as an economic good describing the nature of the aged care market, and the demand and supply of aged care services. It then outlines the trends in population ageing and the increasing demand for aged care services. It also highlights the desire by most older people to continue living in their own homes and in the community for as long as possible. This sets the scene for the rationale of this research, the analytical framework and the research objectives.

1.1 SOCIO-DEMOGRAPHIC CHANGE AND POPULATION AGEING

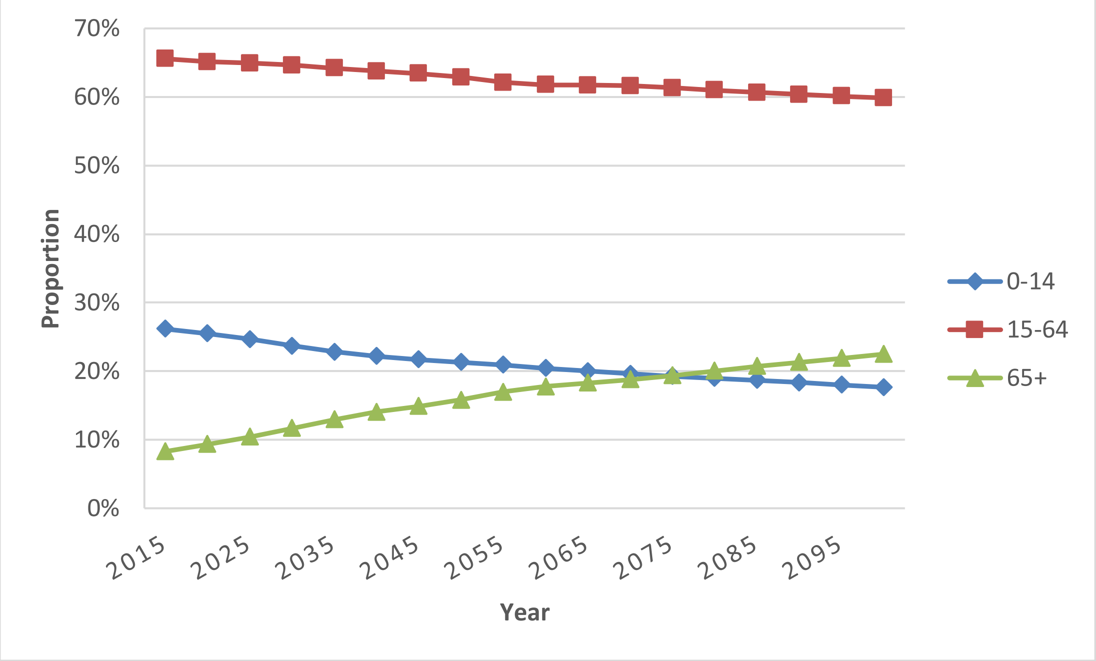
The World Health Organisation (WHO) has defined older people as persons who are 65 years or older (World Health Organisation, 2002) while the United Nations (UN) has classified persons over 60 years of age as older people (Department of Economic and Social Affairs, 2012). Age definitions vary between developed and developing countries, with old age beginning at a younger chronological age in the latter than in the former. Old age in most developed countries is defined as the retirement age or eligibility age for pension funds of 65+ years. In developing countries on the other hand with largely no formal work or retirement age and pension funds, old age has rather been defined less by chronological age and more by changes in the social role of individuals and in their physical capabilities (Gorman, 1999). The WHO has set the chronological definition of older age as 50+ years in Africa, while a more general cut-off of 60+ years is adopted for the rest of the developing world (World Health Organisation, 2002). Consistent with other developed countries, non-indigenous older people in Australia have been defined as persons who are 65 years or older. For indigenous Australians the age definition of an older person is 50 years or older (Productivity Commission, 2011a). Due to the difference in their health status, attributed to disproportionate levels of educational, economic and social disadvantage, indigenous Australians have a lower life expectancy than non-indigenous Australians (AIHW, 2011). Consequently, indigenous Australians tend to utilise aged care services at a younger age than non-indigenous people.

Some researchers have chronologically classified older people in developed countries further based on their age as the young-old (above 65 years), the old-old (above 75 years (McCrae et al., 2008) or 71-80 years (Kvavilashvili et al., 2008) or even 85+ years (Yates et al., 2007, Cohen-Mansfield et al., 2013)) and the oldest-old (over 80 years (Chou and Chi, 2005) or above 85 years (Stek et al., 2004) or over 95 years (Cohen-Mansfield et al., 2013)) with blurs between the age cut-offs. Older people have also been categorised as being in the ‘third age group’ (65-84 years) and the ‘fourth age group’ (beyond 85 years), the transition happening at 80-85 years of age.

Older people are also defined by their health care needs which are often complicated by chronic co-morbidities and social and psychological limitations that may affect their quality of life (Cohen-Mansfield et al., 2013). For instance, older people aged beyond 85 years have traditionally been characterised by increasing prevalence of pathology, physical and psychological dysfunction (Neugarten, 1974 , Baltes and Smith, 2003). Increasing age and deterioration of bodily systems and functions ushers in physical and cognitive changes that generally have negative impacts upon health. Older peoples’ health is often complicated by different levels of frailty such as reduced mobility, increasing their risks of falls and physical harm; reduced sensory activity such as vision, hearing, smell and touch; reduced immunity and increased predisposition to diseases, reduced cognitive function and reductions in the capability to undertake activities of daily living (Baltes and Smith, 2003, Berrut et al., 2013, Cohen-Mansfield et al., 2013).
For this thesis the Australian definition of older people as persons aged above 65 years was applied.

In 2000, 11% (600 million) of the world’s population was aged above 60 years, this figure is predicted to double to 22% (2.1 billion persons) by 2050 and triple (3.2 billion) by 2100 (Department of Economic and Social Affairs, 2012 , United Nations Department of Economic and Social Affairs, 2015). In line with these estimates, 600 million people were aged over 60 years in 2000 compared with 810 million in 2012 (an increase of approximately 30% in 10 years) and 906 million (12%) in 2015, a growth rate of 3.26% per year (United Nations Department of Economic and Social Affairs Population Division, 2017). The oldest old (over 80 years of age) cohort is estimated to grow fastest, with a marked global increase from 125 million (1.7%) in 2015 to 434 million in 2050 and 944 million in 2100 (United Nations Department of Economic and Social Affairs, 2015).

Figure 1.1: Estimate of the world population by age groups 2015-2100



Adapted from Probabilistic Population Projections based on the World Population Prospects: The 2017 Revision (United Nations Department of Economic and Social Affairs Population Division, 2017)

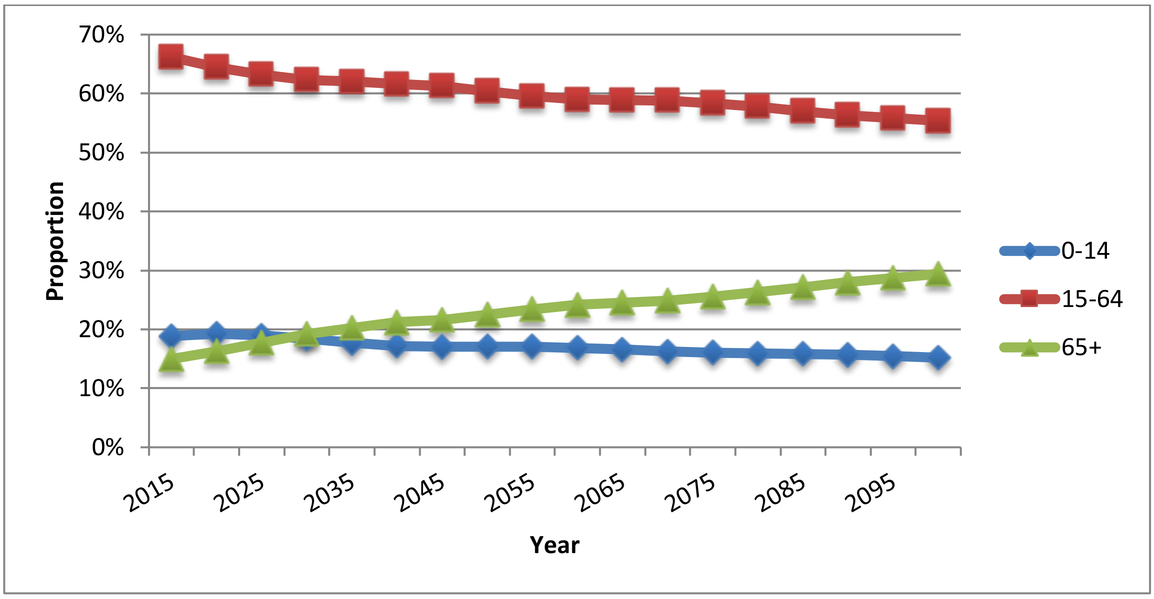
These changes in world demographics have been largely attributed to reduced fertility, reduced mortality and increased longevity (Department of Economic and Social Affairs, 2012 , Shetty, 2012). With urbanisation and advances in health, people are living longer than ever before; with a current global average life expectancy at birth of 70 years, up to 84 years in developed countries and 62 years in developing countries (United Nations Department of Economic and Social Affairs, 2015). Longevity is attributed to medical advances such as vaccination, public health advances such as improved sanitation and housing, and increased emphasis on preventative health care and wellbeing such as not smoking, increasing physical activity and diet to improve cardiovascular health and reduce obesity (Kontis et al., 2017, Shetty, 2012). In addition, advances in health and technology targeted at older people including anti-aging medicines, hearing aids, pacemakers and hip replacements, have not only contributed to longevity but also improved the quality of life of older persons (Susan et al., 2004, Lichtenberg, 2015, McKee et al., 2012).

1.1.1 Population ageing in Australia

Older people (aged 65+ years) constituted 14% (3.2 million, of which 0.4 million were over the age of 85 years) of Australia's population in 2012. This was predicted to rise to 22% (7.5 million, 1.8

million of whom will be over the age of 85) by 2050 and 27% by 2100 (Australian Bureau of Statistics, 2013, DoHA, 2012).

Figure 1.2: Australia population by age groups 2015-2100



Adapted from Probabilistic Population Projections based on the World Population Prospects: The 2017 Revision (United Nations Department of Economic and Social Affairs Population Division, 2017)

The trend of population growth for older people in Australia is like that in the rest of the world. As in the rest of the world, changing demographics in Australia skewing the population towards older people are largely attributable to sustained reduced fertility, advances in health and a greater focus on preventative health leading to improved longevity (Attorney-General's Department, 2010).

It is Australian government policy and the wish of the vast majority of older people to remain, and be cared for, in their own homes for as long as possible (DoHA, 2012). This is beneficial to older people and their families, as it enables older people to remain in the community with less disruption and the ability to be cared for and supported to undertake activities of daily living in a familiar environment (Oswald et al., 2010, Wiles et al., 2012, Boldy et al., 2009, Kendig et al., 2017). Consistent with this philosophy and the key socio-demographic changes highlighted above, current trends show increasing demand for the provision of community aged care services with rising proportions of older people accessing community aged care services 27% in 2015 compared with 19.8% in 2007 and more people (who may previously have been admitted into residential care) actively choosing and therefore being supported to remain living in their own homes for longer time periods (AIHW, 2016).

Section 1.2 that follows describes the market for aged care services in Australia. The application of the Donabedian analytical framework for quality of care on which this thesis is based is described in Sections 1.3 followed by section 1.4 which describes the rationale and objectives of this research.

1.2 THE MARKET FOR AGED CARE

The aged care sector in Australia makes significant direct and indirect contributions to the Australian economy accounting for 1.1% of the Australian GDP in 2014/15 (Deloitte Access Economics, 2016). Direct contributions are made through employment and investment in facilities necessary for the provision and operation of community and residential aged care services. Indirect contributions are made via other services which provide support to the sector including the food industry, the real estate industry and the health care industry.

1.2.1 The Supply of Aged Care Services

The federal government, as the principal funder of the aged care sector, regulates the supply of aged care services through the allocation of aged care places (also referred to as the aged care provision target ratio) and the approval and assessment of aged care service providers. The provision target ratio is the number of subsidised operational aged care places funded for every 1000 persons aged over 70 years of age every year (Aged Care Financing Authority, 2016). (This age is above the retirement age of 65 because most older people remain active and living independently in the community and do not actually seek care until age 70 or above). The allocation of aged care places for both community and residential care is determined based on the nationwide population of older people in need of aged care services. Consistent with socio-demographic changes and the increased demand, the provision ratio has steadily increased from 108 in 2004 to 113 in 2014 and is set to rise to 125 in 2022 while the operational ratio which reflects actual utilisation of services grew from 105 in 2006 to 111.5 in 2015 (Aged Care Financing Authority, 2016). The balance of services between community and residential care is also shifting in line with the central objective of the federal government to reduce the growing pressure of aged care on public expenditures but also based on consumer preferences to ‘age in place’. The set target ratio for community/home care services will progressively increase from 27 to 45 or from 90,000 to 140,000 community/home care places, and the residential target ratio will reduce from 88 to 78 by 2022 (Aged Care Financing Authority, 2016). In the recent (2018) federal budget, additional funds were allocated for 14,000 high level home care packages (level 3 and 4) in lieu of 26,700 residential aged care places over the next four years (Centre for the Health Economy, 2018). This is in addition to the 6,000 high level HCPs announced in the 2016/17 budget and totalling up to an additional 5,000 packages annually until 2022.

About 1.2 million older people in Australia received aged care services in 2014/2015, increasing to 1.3 million in 2015/2016 and estimates indicate that over 3.5 million older people will utilise aged care services annually by 2050 (Australian Bureau of Statistics, 2013, Department of Health, 2016). Such strong predicted increases in demand present major challenges for the supply of aged care services in terms of the physical availability of resources as well as the efficient use of these resources through cost effective models of care (type and mode of delivery).

Aged care services are provided by for profit, not-for-profit and government organisations that have been approved by the government. As would be expected, most service providers are in the metropolitan areas, although a good proportion of these also operate in regional areas. Services are provided as community aged care services under the home and community care (HACC) and the home care services or home care packages program and as institutionalised care in residential aged care facilities. In 2014/15 the majority of services were provided by not-for-profit organisations, with the remaining proportion of community services shared almost equally between for profit and government organisations (Deloitte Access Economics, 2016). Almost 70% of providers offer community aged care services (52% for HACC and 16% offered home care services) and 31% offer residential aged care services (Aged Care Financing Authority, 2016).

Prior to February 2017, the government allocated aged care places as home care packages (HCP) to service providers through an annual competitive assessment process referred to as the aged care approvals round (ACAR) (Australian Government Department of Health, 2017). Following assessment by the aged care assessment team (ACAT), older people in need of care applied for admission to service providers with the appropriate packages. After policy reforms in February 2017, there is no longer an ACAR for community-aged care; HCPs are allocated to individuals according to their level of need as determined by an ACAT assessment. Older people can then choose to purchase services from their HCP funding from a single provider or a mix of providers.

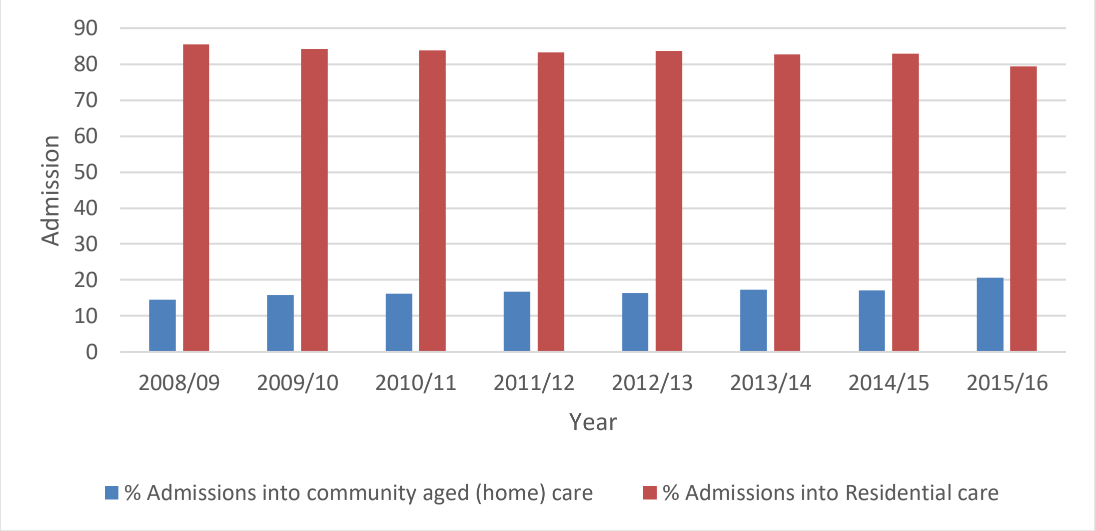
1.2.2 The Demand for Aged Care Services

As previously highlighted, it is Australian government policy to support older people to continue living in their own home in the community for as long as possible. This not only satisfies their desire to age in place but also is less costly compared with admission into residential aged care facilities (Graybill et al., 2014, Jutkowitz et al., 2012).

The demand for aged care places since the transition to CDC in community aged care in July 2015 has been relatively stable compared with the pre-reform period, 83.2% in 2015/16 compared with 85.8% in 2014/15, but is expected to rise over time with the increasing supply of aged care places predicted as a consequence of more providers entering into the aged care market coupled with the ageing of the population (Aged Care Financing Authority, 2017a).

Figure 1.3 below presents data obtained from the Australian Institute of Health and Welfare. It shows the trend of admissions into both residential and CACS before and after introduction of CDC. Consistent with the increased provision ratio for community aged care services highlighted in section 1.2.1 above, a notable change is observed in 2015/16 with a 4% increase in community (home) aged care admissions and subsequent decrease in residential care admissions. This suggests an increased demand for CACS following policy changes in July 2015. More recent data has reported a more marked (10.2%) increase in the number of consumers taking up home care packages between 30 June 2016 and 31 March 2017 (Department of Health, 2017a).

Figure 1.3: Trend of Admission into home care and residential care between 2008/09 and 2015/16



With an increasing desire for older people to retain their independence by staying at home or in the community for as long as possible and to exercise choice and control over their care, existing aged care services are being challenged by the increasing scope and intensity of community care requirements coupled with older people's growing expectations and preferences (Tanner, 2001, Kelly, 2002, Leeson et al., 2003, Quine and Carter, 2006, Boldy et al., 2009). The emerging older population primarily consists of the baby boomer generation (Pruchno, 2012, Wilson, 2012). The baby boomer generation comprises the cohort of older people born after the second world war; 1946-1964 (Productivity Commission, 2011a, Australian Government, 2013). For the past half century this generation has greatly contributed to the productive workforce and economies of their respective countries (Ford, 2006, Robinson, 2007, Quinn, 2010, Malcolm Anderson, 2008). However, the baby boomer generation has now come to retirement age, is rapidly exiting the workforce into the pensionable age group and gradually transitioning into the population in need of support from health and aged care services. Unlike previous generations who have tended to be characterised as quite accepting of the aged care services provided to them, the current generation of older people typically have higher levels of education, higher levels of income and higher expectations of the quality of care received (Frey, 2010, Richman, 2012, Roth et al., 2012). This generation is generally more physically active and more technologically exposed requiring more services than has traditionally been provided such as Internet access, cable television, hotel style accommodation and ultimately greater access and involvement with their communities (Richman, 2012, Crisp et al., 2013, Robison et al., 2013). Coupled with an increased capacity to pay and ability to make greater co-contributions for their care, many baby boomers expect to continue living independently in their homes for as long as possible. When accessing a residential care facility, high quality accommodation and 'hotel type services' are increasingly in demand, which necessitates capital investment in the infrastructure of the system and may influence aged care policy and reform in relation to future models of care (Richman, 2012, Crisp et al., 2013, Robison et al., 2013).

There is also increasing cultural diversity in Australia's older population comprising diverse racial, ethnic and socio-cultural backgrounds which have to be considered in the type and model of service delivery (Davidson et al., 2004). In general, people pay more attention to their culture and traditions as they age and tend to place a greater reliance on family and informal support networks like church and community networks. Older people with dementia often revert back to their mother tongue with reduced use of learned languages such as English (AIHW, 2012c). These culture and language intricacies affect access to and the delivery of health and aged care services (Davidson et al., 2007). For example, Aboriginal Australians and non-English speaking communities create the need for and increased use of interpretation services in the aged care system. Some cultures also require that care is provided by workers with similar gender and cultural backgrounds (Davidson et al., 2004, Davidson et al., 2007). Incorporating these needs requires restructuring of the current aged care service models and investment into the system to ensure that a range of culturally appropriate and linguistically diverse models of care are available to meet the needs of all older Australians. In addition, there are an increasing number of gay and lesbian couples enrolling in the aged care system who require special consideration of their social and cultural identity through the provision of appropriate services that deter discrimination, homophobia and elder abuse (Barker et al., 2006, Callan, 2006).

The aged care system in Australia is also faced with an increasing number of older Australians living outside of metropolitan areas in regional and remote areas (Australian Bureau of Statistics (ABS), 2015). This cohort of older people has limited access to health and aged care infrastructure and services, lower economic resources and tightly knit communities built on trust that are averse to new entrants (Davis and Bartlett, 2008, AIHW, 2017). Improving access to and distribution of services for rural and remote areas require greater emphasis on community services and an increasing role for the older person and their families in directing their own care.

1.2.3 Consumer directed care

Meeting the varied and intricate needs/preferences of consumers (older people, their carers and families) in the aged care market is at the core of the new government policy to introduce consumer directed care (CDC) where community aged care services are provided based on consumers' needs. In 2010, the Australian government instituted a major review of the aged care sector conducted by the Productivity Commission. The Productivity Commission is an independent body of the Australian government charged with conducting research, reviewing government policies and regulations and providing advice on economic, social and environmental issues that are relevant to the Australian community (Australian Government). This review proposed a number of substantial changes to the sector, at the heart of which was the introduction of CDC to address concerns of limited consumer choice over services and service providers (Productivity Commission, 2011a). This is an approach to service delivery 'that allows consumers to have greater control over their own lives by allowing them to make choices about the types of care and services they access and the delivery of those services, including who will deliver the services and when' (DoHA, 2013a).

Although widely applied since the mid-1990s among older people receiving social care services in other developed countries, CDC has only recently been implemented in Australia, having been initially introduced into the disability sector in 2013 (NDIS, 2015). The influential aged care policy review produced by the Productivity Commission in 2010 recommended extension of the CDC philosophy beyond the disability sector into the community aged care sector and at a later phase into the residential aged care sector (Productivity Commission, 2011a). A pilot program was introduced in 2010/11 as the 'CDC initiative' for older people (over 70 years of age) still living in their own homes or in the community and their family carers (KPMG, 2012). It commenced with 500 community aged care places allocated as a CDC model of service delivery in the first phase and a second phase of another 500 CDC places in 2011/12.

CDC is a demand driven model of service delivery aimed at promoting consumer choice and control, consumer participation and rights, respectful and balanced partnerships, and transparency. In principle, the provision of community aged care services through a CDC model, will facilitate the transition of the aged care sector to better meet the intricate and diverse needs of older people highlighted above. Under the CDC approach, the consumer is allocated an individualised budget based on their level of assessed care needs and they are provided with regular account statements which indicate what funds are available and how funds are being expended. Consumers identify care goals they would like to achieve for example to maximise their independence, develop their social relationships and enhance their wellbeing/quality of life. A care-plan is then designed together with their chosen provider/s to facilitate the achievement of these goals. The consumer may choose to be involved in managing their care through coordination of services, decision-making and choosing care-workers. The care-plan is reviewed routinely to ensure appropriateness, whether set goals are being achieved and to identify any changing needs or goals (Productivity Commission, 2011a, DoHA, 2013a).

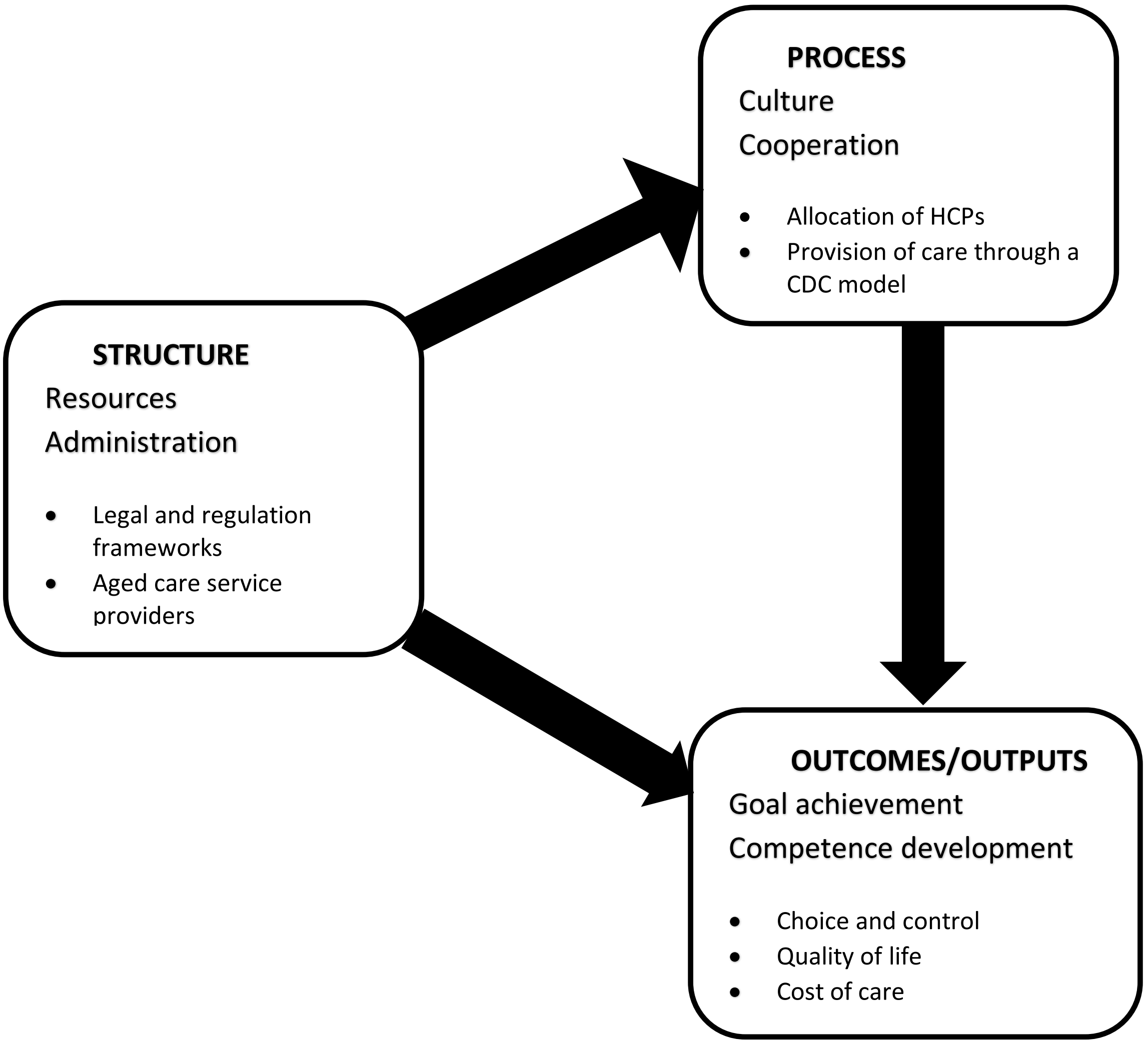
The initial stages of implementing CDC in community aged care were primarily driven by changes in government policy supported by innovative service providers who initially piloted the introduction of CDC as an alternative model of service delivery to older people (existing and new clients) who expressed interest or who were deemed capable of directing their own care. Following the success of the pilot phase and commencing July 2015, all community aged care places in Australia are now provided under a CDC model of services.

1.3 THE DONABEDIAN FRAMEWORK FOR QUALITY OF CARE

The Donabedian quality assessment framework provides a conceptual and analytical model for assessing the quality of service innovations (Ayanian and Markel, 2016, Crawford et al., 2009, Gardner et al., 2014, Liu et al., 2011, Moore et al., 2015). Although originally developed in relation to the health care sector, the framework has relevance and applicability to the aged care sector. Donabedian emphasises the causal relationship and interdependency of the structure, the processes and outcomes in determining the quality of care services (Donabedian, 1988, Donabedian, 1978). Quality of care is defined in terms of 'outcomes measured as the expected improvements in health status or quality of life attributable to care' (Donabedian et al., 1982). Structure refers to the stable elements or organisational factors that determine the setting in which care is provided; this comprises physical characteristics (material resources such as the facility and equipment) and staff characteristics (human resources and administrative structures, policy and legal frameworks) that support the provision of care (Donabedian, 2005, Campbell et al., 2000). Process refers to the activities involved in seeking and receiving care, both the technical interventions and the interaction between providers and recipients of care (Donabedian, 2005, Campbell et al., 2000). Donabedian defines outcomes as the consequences of care or effects of care such as change in health status and/or quality of life of the recipients, changes in knowledge and behaviour, satisfaction with care received as well as the cost to achieve those outcomes (Donabedian, 2005, Donabedian et al., 1982). Outcomes are directly or indirectly dependent on both the structure and the processes of care, however, the relative importance of each of these components varies in different circumstances and the relationship between all three is not always linear (Donabedian, 1978, Campbell et al., 2000).

In relation to the community aged care sector, the existing legal and regulation frameworks that guide policy, organisation and funding of aged care services form the basis of the structure of aged care service delivery. The process of care involves the allocation of aged care places through the ACAT and the aged care funding instrument (ACFI) and activities involved in the provision of care from community aged care service providers through a consumer directed model. The desired outcomes of community aged care services provided on a CDC basis are increased choice and control for older people, improvements in quality of life and reduction in cost to care recipients. Figure 1.4 below illustrates the application of the Donabedian framework to evaluate the delivery of community aged care services under CDC.

Figure 1.4: Analytical framework for CDC in the community aged care sector



1.3.2 Structure and process of care delivery

From a theoretical perspective, the structure and process of the CDC model of community aged care service delivery in Australia may be analysed within the context of market failure and product differentiation.

Market failure

Market failure has been observed and analysed in health care markets worldwide, however, there is a dearth of research evaluating aged care services within this context (Arnould and DeBrock, 1986, Morris et al., 2007a, Watts and Segal, 2009, Mwachofi and Al-Assaf, 2011, Morris et al., 2007c). Market failure refers to a situation in which there is an inefficient allocation and pricing of goods and/or services often resulting in a net welfare loss to society (Morris et al., 2007c, Pearce,

1992). In common with health care, the market for aged care does not meet the conditions of a perfectly competitive market where the ‘invisible hand’ allocates resources optimally through demand and supply forces leading to economic efficiency (Morris et al., 2007c). Economic efficiency requires that all goods and services are marketable, there is demand and supply certainty, information symmetry, no price discrimination, risks to the consumer are avoidable and all suppliers seek to make profits. Such a market is typically characterised by many buyers and sellers who individually cannot influence the price of a product, products sold are homogenous, sellers freely enter and exit the market, buyers have perfect knowledge of the goods and their prices, and there are no externalities to production or consumption of the goods or services. However, in the aged care sector there are barriers to entry e.g. through high capital and investments costs associated with the provision of buildings and the initiation of care services and most service providers are not-for-profit. There is also a degree of information asymmetry as, whilst CDC is improving transparency in this regard, older people do not typically possess consistently perfect knowledge of the funds allocated to their care or the suite of available services. Price discrimination exists because of means testing; and some providers can operate as monopolies, particularly in rural and remote areas. Consequently market failure may manifest in the form of supplier induced demand, adverse selection and moral hazard, which prevent production and consumption of services at the optimal level (Morris et al., 2007c). Adverse selection within the market for aged care may occur where only the frailest older people who are in most need of care apply for and are enrolled into aged care (Shi et al., 2017, Buchmueller and Dinardo, 2002) leading to higher than expected demand for higher level services, while moral hazard is the excessive utilisation of aged care services by older people without necessarily being in need of such services. The risk of moral hazard is increased when services are free at the point of service or incur a low/fixed cost regardless of the quantity consumed (Van den Berg, 2005).
To ensure optimal supply and demand of aged care services, a third party, the government, steps in to regulate the provision of such goods and services mainly through price-setting and quantity-setting. Government intervention usually targets two broad categories of causes of market failure namely demand and supply issues (mainly moral hazard) and information asymmetry issues (adverse selection and supplier induced demand). Moral hazard may be addressed through a number of measures such as the introduction of user fees, gap fees and waiting lists to create a cost to the consumer in an effort to deter unnecessary consumption (Morris et al., 2007c). To mitigate the potential for supplier induced demand, the federal government may act in the role of market regulator, providing information about the available services to equip consumers with the

necessary knowledge to choose what is appropriate for them as opposed to providers/suppliers imposing services which may not necessarily reflect the needs of the consumer. In addition, regulatory bodies e.g. the Australian Aged Care Quality Agency act to monitor prices and the quality of goods and services provided while adverse selection can be prevented through needs screening by the ACAT. Capitation payment mechanisms for service providers are also implemented to prevent supplier induced demand (Kantarevic and Kralj, 2016, Debpuur et al., 2015). Another mechanism employed by health insurance companies in the health care sector to prevent adverse selection is experience rating of consumers by service providers where the former's consumption history is used to inform how much they would be charged for future services or premiums (Morris et al., 2007c). However, there is currently no evidence to suggest the application of capitation and experience rating in community aged care.

Product/service differentiation

A 'product is differentiated if any significant basis exists for distinguishing the goods (services) of one seller from those of another' (Chamberlin, 1962). Such distinguishing features may include both tangible and intangible attributes that appeal to consumers' preferences and make the product or service more desirable such that buyers are paired to sellers based on preferences and not by chance or at random as is the case in a perfectly competitive market (Chamberlin, 1962). Although the products or services offered by different providers fulfil the same need, they are not perfect substitutes, their features are not identical as they seek to adapt to consumer preferences and their changing environments.

Two types of differentiation are highlighted in the literature, vertical and horizontal product or service differentiation. Vertical differentiation is said to exist if there are similar goods in a market 'but they can be ordered according to their objective quality from the highest to the lowest' (Piana, 2003). Vertical differentiation is also referred to as differences based on product or service quality (Gaynor, 2006). Horizontal differentiation on the other hand exists if the features by which the goods or services differ cannot be ranked objectively (Piana, 2003). Horizontal differentiation generates a variety of the same product or service with differences that address consumer preferences (Gaynor, 2006).

Similar to market failure, differentiation has been explored quite extensively in health care but remains relatively unexplored in aged care (Hilsenrath, 1991). In health care for example, hospitals may differentiate themselves from others by a number of defining characteristics including offering specialist services, more amenities for patients and their families, more high technology services (vertical differentiation) by virtue of location (horizontal differentiation) (Zwanziger et al., 1996, Gaynor and Town, 2011); branded versus generic pharmaceutical products (horizontal differentiation) (King, 2002); differentiation of individual practitioners based on personality and customer interactions (horizontal differentiation); different levels of access and benefit offered by health insurance plans (Teisberg et al., 1994, Rivers and Glover, 2008).

1.3.3 Outcomes of care delivery

Considering that aged care is a public good with significant investment from government, there is an opportunity cost to the public expenditures allocated to aged care services as these could fund other public goods with associated potential benefits to overall social welfare. According to welfare economics, social welfare is ‘a product of the utilities of individual members of society’ (Morris et al., 2007g). The desirability of a good or service is based on the utility individuals obtain from consuming this good or service and its relative desirability over other goods or services. However, like health care, the provision of aged care services does not perfectly fit into the theory of welfare economics because utility obtained from aged care services is not individualistic. Aged care services are typically characterised by caring externalities i.e. utility from one’s own consumption and the consumption of others one cares about, in this case informal carers (Brouwer et al., 2005). Also, analogous to the demand for health care, the demand for aged care services is a derived demand as older people do not primarily seek services for the utility obtained from the services themselves, rather utility is obtained from the extent to which the services improve their quality of life and wellbeing.

Extra-welfarism theory is as ‘an approach to social choice that admits arguments other than individual utilities into the social welfare function’ (Morris et al., 2007g) and as such it offers a more appropriate theoretical framework in the context of health and aged care. This theory broadens the definition of social welfare or the benefits or outcomes of consuming a good/service beyond individual utility to include other sources of welfare such as ‘non-good characteristics of individuals (like whether they are happy, out of pain, free to choose, physically mobile, honest)’ (Culyer, 1989) that are relevant to wellbeing. Extra-welfarism complements utility information with other non-utility information, by offering a broader perspective that considers the quality of the utility and the ability to function as a result of consuming the good or service (Brouwer et al., 2008, Coast et al., 2008c). Brouwer et al. (2008) have likened the extra-welfarism approach to Sen's capabilities approach that 'is concerned primarily with the identification of value-objects and characterises the evaluative space in terms of functionings and capabilities to function' (Sen, 1993, p. 32)' (Brouwer et al., 2008). In contrast to welfarism that defines the benefit of health as the utility obtained from consuming health care, extra-welfarism argues that the selection of outcomes under extra-welfarism is context dependant: in the health care sector for example, relevant outcomes under extra-welfarism include health or health gain and other measures that are directly influenced by health status such as patients' ability to function, choice and control and caregiver burden (Brouwer et al., 2008, Coast et al., 2008c). In the case of aged care, a CDC model of service delivery may be assessed by outcomes beyond individual utility such as quality of life and capabilities i.e. what older people are able to do and be because of directing their care. This research therefore assessed the outcomes of a CDC model of service delivery within the theory of extra-welfarism as older people's quality of life and capabilities.

1.4 RATIONALE OF THE RESEARCH

There is a paucity of research that has considered the costs associated with, and quality of life outcomes for older people receiving community aged care services according to a CDC model. Glendenning and colleagues evaluated the pilot of a similar model of service delivery, the individualised budgets program, in England, taking into account the quality of life outcomes and aggregate costs associated with the provision of care (Glendinning et al., 2008). In this form of CDC, some older people received direct cash payments while some received funding through a third party but they were involved in designing the care plan and managing care. This study applied the General Health Questionnaire (GHQ-12) to measure psychological wellbeing and self-perceived health and the Adult and Social Care Outcomes Toolkit (ASCOT) measure for social care related outcomes to assess quality of life. Costs and outcomes associated with individualised budgets were compared with traditional provider directed care services. Older people receiving individualised budgets were found to exhibit lower psychological wellbeing overall which was mainly attributed to increased anxiety over the planning and management of their own care (Glendinning et al., 2008). However, they also noted that some older people, who had support in managing budgets either through previous work experience or an informal carer, embraced the choice and control accorded by the individualised budget model. The findings of the economic evaluation indicated that there was limited evidence for the cost effectiveness of individualised budgets for older people in England where outcomes were assessed using the ASCOT (a preference-based measure of social care outcomes). An important limitation of their study was that complete implementation had not been achieved for all enrolled participants by the time of the review. A significant proportion of participants receiving individualised budgets had not yet initiated a service-plan by the 6-month follow-up due to system delays in the implementation process.

Other researchers have considered cost savings and the quality of life and wellbeing outcomes associated with the ‘cash and counselling’ program, a form of CDC operating in the United States (Brown et al., 2007, Carlson et al., 2007, Dale and Brown, 2007). Older people in need of personal care and home or community-based assistance received services through government certified agencies under the Medicaid State Plan optional personal care benefit. To allow for greater consumer choice and control over care, Cash and Counselling was introduced where consumers received monthly allowances for the purchase of care-related goods and services and hiring of care workers. The program also offered counselling and fiscal management services for the consumers. A pilot of this program in three states (Arkansas, Florida, and New Jersey) was evaluated compared with traditional agency-supplied services. Outcomes were assessed based on a survey questionnaire administered over the phone nine months after enrolment into the program while costs were assessed two years after enrolment. Consumers of the Cash and Counselling program utilised fewer hours of care, had their needs met and were more satisfied with care but no discernible differences in health were observed compared with recipients of agency-supplied services. The cost of personal care was higher than agency services; this finding was attributed to the fact that cash and counselling enabled consumers to obtain all the care authorised in their care-plans unlike agency-supplied services that were inadequate in fulfilling consumers’ care-plans. The results of this evaluation demonstrated an increase in the cost of care under Cash and Counselling in the first year but variations were observed in the second year; no differences were observed in Arkansas while increased costs were still observed in Florida and New Jersey. Like the study in the UK, one of the main limitations of this evaluation was the practical challenges experienced in the start-up phase with providers taking up to one year after enrolment to develop a care-plan with consumers and initiate services; hence a proportion of study participants had not received services at the time of their outcome interviews.

Although the previous studies focused on CDC type models implemented among recipients of social care services in the community and included older people, none of them has investigated the costs and outcomes associated with the introduction of the CDC model in the Australian context. The CDC model being implemented in Australia is different from the ones evaluated above. Older people are involved in the process of developing their care-plan and in managing their care in terms of what services are purchased. However, the aged care service provider retains the responsibility for fiscal management as well as the hiring and supervision of care-workers.

1.4.1 Research objectives

The novel research presented in this thesis aims to provide a health economics perspective to the assessment of the costs and quality of life outcomes associated with the transition to a CDC model of service delivery in the aged care sector.

The primary research objectives were to:

1. identify instruments that are suitable for measuring and valuing quality of life outcomes among older people receiving aged community aged care services;
2. investigate the impact on quality of life and capability of a consumer directed model of community aged care services when compared to a provider directed model and the time consumers are in receipt of a CDC model of service delivery
3. identify the costs associated with and the main cost drivers in the delivery of a consumer directed model of community aged care services and assess whether these costs vary according to the time consumers are in receipt of CDC services

The secondary research aims were to:

- present an overview of consumer directed model of community aged care services in Australia and in countries with comparable aged care services;
- provide an economic theoretical framework for evaluating the performance of consumer directed model of community aged care services; and
- present existing evidence on the value for money of consumer directed models of aged care services globally.

1.4.2 Thesis Outline

Following on from the introduction and conceptual framework described here in chapter 1, the following chapters demonstrate how this framework can be implemented in analysing the structure, process and outcomes of a consumer directed model of service delivery in the community aged care sector and answering the objectives set above.

Chapter 2 provides a background to the Australian aged care sector both before and after the major reforms introduced in August 2013. It describes the structure of community aged care services, particularly the home care package program in the post reform period and provides analysis of the sector within the context of market failure and product differentiation.

Chapter 3 describes the structure of the different forms of consumer directed care that have been implemented globally. These systems are analysed within the context of market failure and product differentiation and evidence is provided for the impact of CDC on quality of life and consumer choice and control.

Two systematic reviews (chapter 4 and 5) were undertaken following the Preferred Reporting Items for Systematic Reviews and Meta- Analyses (**PRISMA**) framework (Moher et al., 2009). Search terms and search strategies specific to the research questions in each chapter were developed and applied to search databases including PubMed, Medline, Scopus, CINAHL, Informit and Web of Science.

Chapter 4 examines the evidence for the application of a health economics approach to the assessment of service delivery interventions and innovations in the community aged care sector. This systematic review highlights the paucity of economic evaluations in this sector and the variations in the methodologies applied. The review argues that, where practically possible, the application of cost utility analysis (CUA) is the preferred approach for assessing the value of new service interventions and innovations in the community aged care sector. CUA facilitates the promotion of efficiency for the aged care sector through its generic focus on quantifying the quality of life benefits that older people obtain from new service innovations and models of care.

Chapter 5 is a systematic review of published studies that aims to identify outcome measures that are suitable for application among older people in a CUA framework. Although the review identified the EuroQoL 5 dimensions (EQ-5D) as the most predominantly applied instrument, it is notable that the EQ-5D is largely focused on functional status and health, an aspect of quality of life that is generally declining in older age. Quality of life in older age is generally defined in a broader context and goes beyond health and functional status. Therefore, this review recommended the use of the EQ-5D which is commensurate with the quality adjusted life years (QALY) scale, in combination with a broader measure of quality of life e.g. the ICEpop CAPability measure for Older people (ICECAP-O) a measure of capability designed for use with older people or the Adult Social Care Outcomes Toolkit (ASCOT) (designed to measure social care related outcomes) that define quality of life using domains that are relevant to older people.

Two empirical studies were conducted to assess the impact of a CDC model of service delivery on quality of life and capability (chapter 6 and 7). A cross-sectional study design was adopted for both studies as practical limitations coupled with the rapidly changing policy environment for provider organisations during the time frame of data collection for this thesis meant that it was not possible to follow the same participants longitudinally. Study samples were obtained from a population of older Australians receiving community aged care services from five aged care service providers operating across New South Wales (2) and South Australia (3). Older people were invited to participate if they were 65 years or older, still living in their own home and sufficiently cognitively intact (according to the judgement of the aged care provider) to provide informed consent to participate. In the first study participants completed the self-administered questionnaires as a component of an interactive workshop to investigate their attitudes towards and preferences for CDC. The second study was administered as a postal survey. Quality of life was assessed using the EQ-5D-5L and capability was assessed using the ICECAP-O, instruments previously identified in the systematic review (chapter 5) as suitable for use with older people.

In Chapter 6 the quality of life and capability of older people receiving the newly initiated CDC model of services and those still receiving the traditional provider directed care was assessed. This cross-sectional study was conducted during the earliest stage of the transition to CDC, December 2013. The results revealed that quality of life was broadly similar for both models of service delivery. However, participants receiving a CDC service generally reported higher levels of control/independence on the ICECAP-O ($p=0.017$) relative to those receiving traditional provider directed care.

Chapter 7 is an assessment of quality of life and capability undertaken following the system-wide transition of all community aged care services to a CDC model that commenced in July 2015. Conducted between December 2015 and February 2016, it was aimed at determining the changes in quality of life associated with the duration of provision of services under a CDC model. Higher scores were observed for older people in receipt of a CDC model of service delivery for a shorter time (0-12 months) compared with a longer time (more than 12 months). This study demonstrated early evidence of the potential for improvements in these outcomes for older people receiving CDC.

Chapter 8 reports on the methods and results of a costing exercise applied to understand the costs to consumers associated with receiving services under a CDC model. The main cost drivers associated with the provision of CDC were care services, administration and care coordination/case-management. The proportion of expenditures allocated to care services was approximately 50% whilst about 40% was allocated to administration and case-management. Small variations were evident in these proportionate expenditure breakdowns according to home care package level. The key predictors of cost were the home care package level and the hours of formal care support received.

Chapter 9 summarises the key findings of this research, the main limitations and recommendations for future research. It will take some time for the full impact of CDC in relation to the key cost drivers and the key outcomes of health and quality of life for older people and carers to be realised in practice. It is therefore recommended that further research is undertaken as CDC becomes more established, involving more diverse populations and service organisations to provide a sector wide representation and longitudinal assessment of changes over time in consumer choice and control, cost and quality of life outcomes.

CONCLUSION

This chapter has introduced the global and national challenge of population ageing and has considered the impact of socio-demographic changes and population ageing on the demand and supply of aged care services in Australia. The quality of aged care service delivery has been analysed within the quality framework first proposed by Donabedian describing the inter-connected nature of structure, processes and outcomes. The importance and relevance of a theoretical economics perspective to the market for aged care (including market failure and product differentiation) has been highlighted. The chapter has also introduced the concept of CDC and its applicability to the Australian community aged care sector and has indicated why the novel research reported in this thesis is timely and important.

The next chapter focuses in more detail upon the structure of aged care services, i.e. funding and regulation frameworks governing the aged care sector in Australia, and the policy reform that led to the introduction of CDC in the community aged care sector.

CHAPTER 2

OVERVIEW OF THE AGED CARE SYSTEM IN AUSTRALIA

This chapter provides a descriptive summary of the aged care system in Australia and a theoretical analysis of the performance of this system. Commensurate with the focus of the thesis, this chapter focuses on the recent post reform period in the community aged care sector, characterising the operationalisation of delivering a consumer directed care model across the Australian community aged care sector.

2.1 INTRODUCTION

Whilst the majority (approximately 68%) of older Australians live independently in the community without the need for aged care services, a significant proportion of older Australians receive these services. Data from the Aged Care Financing Authority indicates that in 2015/16, approximately 25% of older Australians were in receipt of community aged care services and 7% received residential aged care services (Aged Care Financing Authority, 2017a). Those enrolled in the community aged care system are mainly persons above the age of 75 years with multiple and sometimes complex care needs, who are no longer able to live in the community without support. Older people who are highly dependent and in need of intensive care to support their activities of daily living tend to live in residential aged care facilities (Guberman et al., 2012, Richman, 2012, Robison et al., 2013).

As highlighted in chapter 1, market failure a suboptimal allocation and pricing of goods or services (Pearce, 1992, Morris et al., 2007c), is inherent in the aged care market. Consumers of aged care services are often vulnerable with insufficient knowledge and information to navigate the system. In order to prevent consumer exploitation and to ensure acceptable standards of quality and safety in the services delivered by aged care providers, the market for aged care is regulated and heavily subsidised by the Australian Federal Government who contribute over 65% of total revenue (Deloitte Access Economics, 2016). Government subsidies on aged care services amounted to $16.2 billion in 2015/16 with 17.5 billion projected for 2016/17 and 20.8 billion in 2019/20 (Aged Care Financing Authority, 2017a). Market stewardship by the government provides oversight by regulating basic standards, ensuring equitable access to services, filling market gaps and preventing non-competitive practices (Gash et al., 2014). As regulator, the government is responsible for setting the prices of the different levels of care services designed for individuals with varying care needs (Gash et al., 2014).

Government support for aged care services dates to the beginning of the 20th century. The Federal Government, together with the state and territory governments, are mandated to provide aged care services to Australian citizens identified as in need of these services under the *Aged Care Act 1997* and the *Home and Community Care Act 1985* (Productivity Commission, 2011a, AIHW, 2016). Under this mandate, the Department of Health provides funding as a government subsidy for aged care services in the different states and territories.

The Department of Health, in consultation with the respective state and territory health departments, approves organisations that provide either community or residential aged care services or both. These are referred to as 'Approved Providers'. Approved providers can be private, government (local and state government) or not-for-profit (NFP) religious, community-based and charitable organisations.

Section 2.2 of this chapter describes funding and regulation framework of the aged care system particularly the key reforms that commenced in August 2013 namely *Aged Care (Living Better Living Longer) Act 2013*. Section 2.4 provides analysis of these reforms within the theoretical framework of market failure and product differentiation.

2.2 FUNDING AND REGULATION FRAMEWORK OF AGED CARE

Funding and regulation is broadly classified according to (i) mainstream funding strategies where older people access support based on their citizenry (this support is available to all eligible Australian citizens) and (ii) the targeted funding strategies where support is provided by virtue of their age (Aged Care Price Review Taskforce and Cullen, 2003, AIHW, 2016).

There are three mainstream funding strategies:

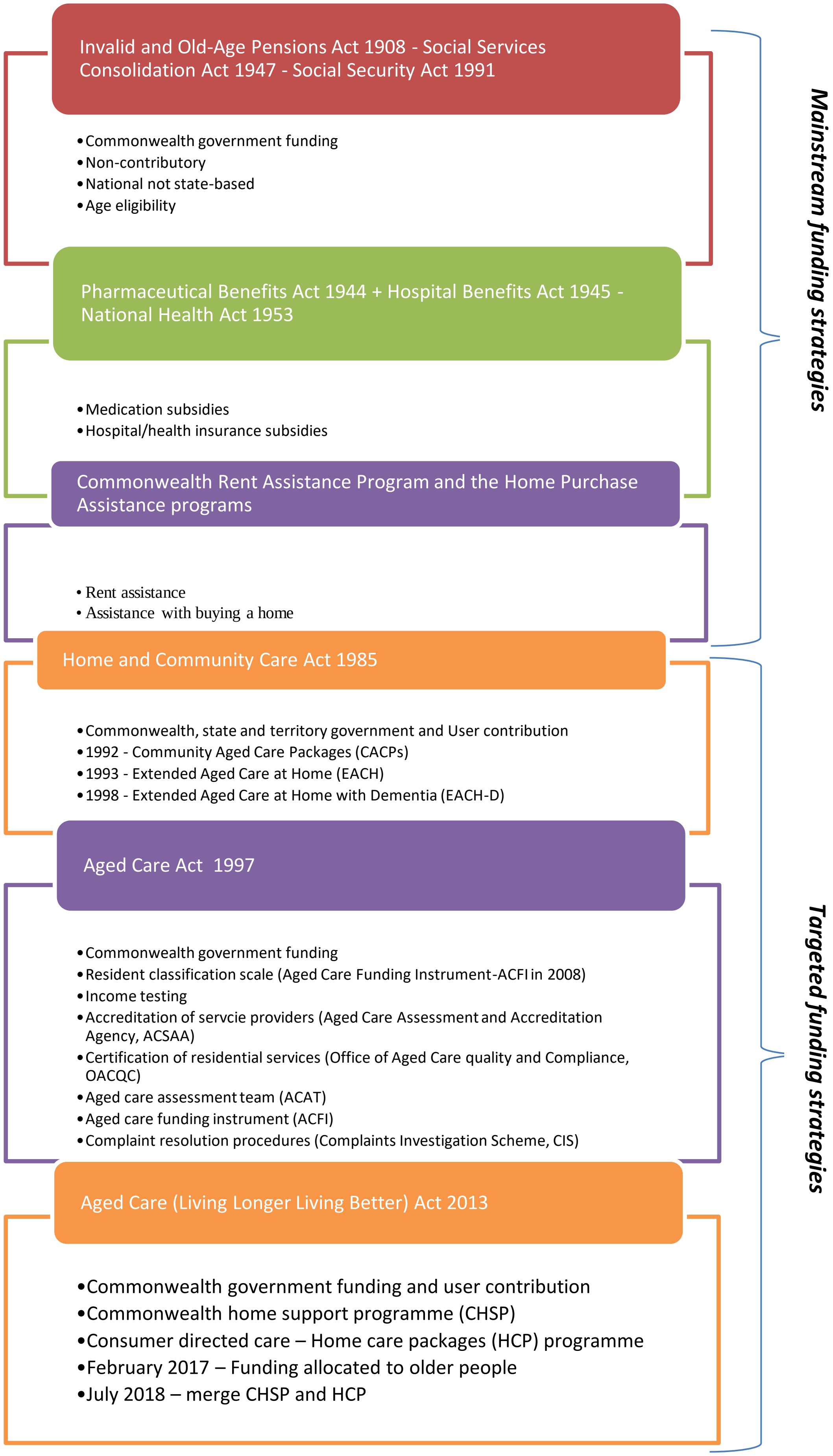
- Income support as pensions through the Social Security Act 1991;
- Subsidised health services through the National Health Act 1953; and
- Support for housing through the Commonwealth Rent Assistance Program and the Home Purchase Assistance programs.

The targeted funding strategies are:

- Support for aged care infrastructure;
- Subsidised residential care;
- Subsidised care at home and in the community; and
- Support for carers.

The evolution of the funding and regulation frameworks for older people is summarised in Figure 2.1 below. For this thesis, targeted funding and specifically the changes to funding and/or regulation frameworks since 1997 are particularly relevant.

Figure 2.1: Funding and Regulation of aged care in Australia



Mainstream funding strategies

Invalid and Old-Age Pensions Act 1908 - Social Services Consolidation Act 1947 - Social Security Act 1991

- Commonwealth government funding
- Non-contributory
- National not state-based
- Age eligibility

Pharmaceutical Benefits Act 1944 + Hospital Benefits Act 1945 - National Health Act 1953

- Medication subsidies
- Hospital/health insurance subsidies

Commonwealth Rent Assistance Program and the Home Purchase Assistance programs

- Rent assistance
- Assistance with buying a home

Targeted funding strategies

Home and Community Care Act 1985

- Commonwealth, state and territory government and User contribution
- 1992 - Community Aged Care Packages (CACPs)
- 1993 - Extended Aged Care at Home (EACH)
- 1998 - Extended Aged Care at Home with Dementia (EACH-D)

Aged Care Act 1997

- Commonwealth government funding
- Resident classification scale (Aged Care Funding Instrument-ACFI in 2008)
- Income testing
- Accreditation of servcie providers (Aged Care Assessment and Accreditation Agency, ACSAA)
- Certification of residential services (Office of Aged Care quality and Compliance, OACQC)
- Aged care assessment team (ACAT)
- Aged care funding instrument (ACFI)
- Complaint resolution procedures (Complaints Investigation Scheme, CIS)

Aged Care (Living Longer Living Better) Act 2013

- Commonwealth government funding and user contribution
- Commonwealth home support programme (CHSP)
- Consumer directed care – Home care packages (HCP) programme
- February 2017 – Funding allocated to older people
- July 2018 – merge CHSP and HCP

2.2.1 Regulation governing mainstream funding strategies

Social Security Act 1991

Direct government support for older Australians can be traced back to 1909 as an age pension or income support provided for pensioners under the *Invalid and Old-Age Pensions Act 1908*. This act was later transformed into the *Social Services Consolidation Act 1947* and later the *Social Security Act 1991* (Aged Care Price Review Taskforce and Cullen, 2003). Separate pensions were provided for eligible veterans under the *Australian Soldiers' Repatriation Act 1935*, which later became the *Veterans' Entitlement Act 1986*.

Support under the pensions act is a national non-contributory, age-based pension provided to all Australian citizens above 65 years of age. The amount received is subject to an income and assets test so as to encourage self-provision in this population (Department of Human Services, 2017). Older people receive further concessions in the community such as free health checks (for example free hearing tests), rent assistance, concession rates for public transport fares, utilities and motor vehicle registration (Department of Human Services, 2017). Age eligibility for the veterans' pension is 60 years (five years earlier than the regular pension) because of increased morbidity and mortality among ex-servicemen (Department of Veterans' Affairs, 2016).

National Health Act 1953

Government support for the health of all its citizens commenced in 1944 with the *Pharmaceutical Benefits Act 1944* and the *Hospital Benefits Act 1945* and later the *National Health Act 1953* (Australian Government, 1947, Australian Government CommLaw, 2013). With the introduction of insurance-based health financing in the Australian health care system, insurance companies were averse to recruiting chronically ill older Australians or pensioners (Aged Care Price Review Taskforce and Cullen, 2003). The government then introduced the Pensioners Medical Service in 1951 to support older Australians' health and pharmaceutical needs until the introduction of national health insurance Medibank (later Medicare) in 1975 (Aged Care Price Review Taskforce and Cullen, 2003). Through Medicare all Australians receive free access to treatment in public hospitals, subsidised access to medical services through the Medicare Benefits Schedule (MBS), pharmaceuticals through the Pharmaceuticals Benefits Scheme (PBS), and private health insurance through the 30% tax offset for private health insurance (Australian Government CommLaw, 2013).

Commonwealth Rent Assistance Program and the Home Purchase Assistance programs

Housing support is provided for citizens whose housing needs cannot be met by the private market such as low-income earners, through the department of social services under

Commonwealth Rent Assistance Program and the Home Purchase Assistance programs (Department of Social Services, 2017). Specific capital funding towards the construction of houses for older Australians was initially provided through the *Aged Persons Homes Act 1954* (became the *Aged or Disabled Persons Care Act 1954 and was repealed in 2011*) (Australian Government, 2009, Australian Government, 1954). Construction support was provided to state governments under the Commonwealth State Housing Agreement (CSHA) through the *States Grants Act 1969* over a period of 9 years after which this support was channelled into the Pensioner Rental Housing Program and back into the CSHA in 1997 under the *Housing Assistance Act 1996* (Aged Care Price Review Taskforce and Cullen, 2003). Currently housing support is provided to individuals through the Commonwealth Rent Assistance Program and the Home Purchase Assistance programs (Australian Institute of Health and Welfare, 2018).

2.2.2 Regulation governing targeted funding strategies

Home and Community Care Act 1985

A review of nursing homes and hostels undertaken in 1985 revealed that older persons were seeking nursing home and hostel care much earlier than they actually needed it because they lacked sufficient levels of support in their own homes (Aged Care Price Review Taskforce and Cullen, 2003). Cost sharing grants between states and Commonwealth governments to provide home and community care were initiated in 1985 through the *Home and Community Care Act 1985 (HACC)* (Australian Government, 1985). HACC was aimed at providing basic maintenance and support services to frail older people to continue living independently in their homes or community. It was also aimed at ensuring priority access to resources by persons most in need, equitable distribution of services between regions, cost effectiveness and the integration and coordination of aged care services with related health and welfare programs (AIHW, 2012a). A continuum of services including personal care and other personal assistance services were delivered in the home as a Community Aged Care Package (CACP). In 1993 subsidised extended aged care at home packages (EACH) were introduced to support older people who required nursing care at home and Extended aged care at home packages (EACH-D) to provide specialised care for older people with major disability such as dementia were introduced in 1998 (Aged Care Price Review Taskforce and Cullen, 2003).

Community care packages provided respite to the residential facilities or institutional care through the supply of basic care and maintenance services at home or in the community.

The Aged Care Act 1997

A comprehensive review of aged care regulation and funding was undertaken in the 1990s. This review was aimed at assessing the ability of the system to effectively, efficiently and sustainably meet the rising demand for aged care services and the changing needs of the aged care industry (Aged Care Price Review Taskforce and Cullen, 2003). With increased age, there were more frail residents in hostels who required high levels of care yet the existing funding mechanisms did not permit an increase in the government contribution to their facilities (Aged Care Price Review Taskforce and Cullen, 2003). The rigid classification of facilities and the need to move residents from low care to high care facilities when their care needs increased did not permit residents to 'age in place'.

The review also found gaps in regulation standards for the infrastructure and quality of care being provided. Regulation mechanisms were fragmented, complex and hard to navigate with the *National Health Act 1953* regulating nursing homes and health while the *Aged or Disabled Persons Care Act 1954* regulated capital funding and community care packages.

This review led to reforms and the introduction of the *Aged Care Act 1997* which aggregated legislation governing the provision of aged care services (Australian Government, 2017a). The act ushered in reforms in residential aged care service delivery including the resident classification scale to determine residents' eligibility for government subsidy based on their care needs and income testing, the accreditation and certification of residential services, as well as residents' access to anonymous complaint resolution procedures (AIHW, 2012a, AIHW, 2012c, Australian Government, 2017a). The resident classification scale (replaced by the Aged Care Funding Instrument – ACFI in 2008) was introduced (AIHW, 2016).

The act also allowed for greater government regulation of the infrastructure and standards of care in the nursing homes under the Aged Care Standards & Accreditation Agency (AIHW, 2016, Australian Government, 2017a). Through this, accreditation standards for residential care were enforced with the focus on continuous quality improvement, education and staff development. Quality improvement and physical building standards such as ventilation, fire safety of facilities were to be monitored through a certification process (Aged Care Price Review Taskforce and Cullen, 2003, AIHW, 2016). Under this act, hostels and nursing homes were merged into one system with each being able to offer both low and high level of care services, henceforth referred to as residential aged care services (Australian Government, 2017a).

Older people in residential facilities were to contribute towards their accommodation and care through basic daily fees, income tested fees, accommodation payments and extra service fees. The basic daily fee was a contribution towards basic accommodation and living expenses. The income-tested fee was charged above the daily fee for residents whose total assessable income - combined assets and annual income, were above the age pension (Aged Care Price Review Taskforce and Cullen, 2003, Productivity Commission, 2011a). Extra service and additional service fees were charged for additional services that residents desired such as higher standards of accommodation, hairdressing, newspapers etc.

Restructuring assistance or a Concessional Resident Supplement was provided to facilities whose residents could not afford the accommodation fees (Australian Government, 2017a). Facilities that could not raise their capital resources because of low client numbers and remoteness were to be further supported through establishment grants for physical infrastructure or initial capital purchases (Australian Government, 2017a).

The *Aged Care Act 1997* was further amended in 2011 through the *Aged Care Amendment Act 2011* (Australian Government). In this amendment, both the *Aged or Disabled Persons Care Act 1954* and the *Nursing Home 1994* were repealed and amendments specific to older people were made to the *National Health Act 1953*. It also permitted RAC service providers to utilise residents' accommodation bonds for capital investments and made provisions for the management and resolution of residents' complaints and concerns (Australian Government).

2.3 REGULATION AND SERVICE DELIVERY 2013 – PRESENT: AGED CARE (LIVING LONGER LIVING BETTER) ACT 2013

Following recommendations for reform by the National Health and Hospitals Reform Commission, an inquiry into the aged care sector was commissioned by the Commonwealth government department of Treasury in 2009. The main objective of the reform was to ensure that the aged care system would be able to meet the challenges it faced with the increasing population of older Australians, increased diversity of culture and needs, desire for choice, the need for improved effectiveness and efficiency in the system and coordination with the entire health care system (Productivity Commission, 2008). This inquiry was undertaken by the Productivity Commission in 2011 (Productivity Commission, 2011a). The review was a consultative process that involved aged care service providers, consumers (older people and their carers) and funders of the aged care system to investigate weaknesses or hindrances to the system and propose interventions to overcome these challenges.

Reported challenges and weaknesses of the aged care sector

This section briefly describes the challenges and weakness in the system as identified by the Productivity Commission review.

It was observed that the system was bureaucratic and difficult to navigate and access information, care and support. Bureaucracies in the system coupled with limitations in the number of aged care places available delayed access to services (Productivity Commission, 2011a). Also, consumer choice for services and provider choice for the packages that could be offered based on consumer needs was limited. This affected the continuity of care, service providers' ability to respond to the consumers' changing needs and was a dis-incentive to providers as they could not fully innovate and provide client specific services to improve client outcomes.

The committee identified irregularities in the pricing of RAC services by providers - the government subsidy and consumers' co-contributions were not consistent across the different care settings, which made the financing unequitable (Productivity Commission, 2011a). This affected equitable access to care by older people and did not stimulate provider investment to meet demand such as investment in extra services for high care residential facilities.

The regulatory mechanism of the system was found to be duplicative, excessive and in some cases unnecessary and costly to service providers (Productivity Commission, 2011a). For example, the provision of care involves both process and outcome indicators, however, the accreditation and quality assurance framework were more focussed on process measures as opposed to outcome measures. There were also significant shortages in the aged care workforce, mainly resulting from the low wages of workers in this sector and therefore lower ability to attract and retain skilled workers (Productivity Commission, 2011a).

Further, the aged care system was affected by frequent changes in policy and planning for other service areas such as availability of formal and informal carers, financing for aged care, housing and transport regulations, and health policy (Productivity Commission, 2011a). For example, the National Health and Hospitals network argued for the reduced access to acute care beds by older people because the care given in the acute care hospitals could otherwise be provided to them at home by palliative or sub-acute services.

The productivity commission also highlighted the fact that funding of the aged care system was primarily from the government, both Commonwealth and the state and territory governments, with minimal contributions from older people. With increasing demand for aged care services, this skewed funding approach presented a significant burden to the taxpayer. There was therefore need to expand the funding base through taxation and higher user contributions (Productivity Commission, 2011a).

Recommendations for reform

Following this review, the Commission proposed changes to the system that were aimed at:

- Ensuring equitable access to person-centred services for all older Australians in need of care and support
- Increasing older people's choice and control over their care through a consumer directed model of service delivery
- Improving transparency and access to information on what care and support is available and how to access those services
- Assisting informal carers to perform their caring role
- Ensuring that care is affordable to those in need and to society more generally
- Ensuring the efficient use of resources devoted to caring for older Australians and broadly equitable consumer contributions

Following this review, the *Aged Care Act 1997* was amended to incorporate the recommended changes to the system and the *Aged Care (Living Longer Living Better) Act 2013* was introduced in 2013 (Parliament of Australia, 2013). The Australian aged care system currently comprises three main service streams; community aged care, residential aged care and flexible aged care services. Community care is where aged care services are provided to older people with reduced functional capacity while still living in the community either in their homes with family members or in retirement villages (Productivity Commission, 2011a). Residential aged care on the other hand is where older people who are frail or otherwise incapable of living independently in the community any longer are admitted into residential facilities (not hospitals) that provide accommodation and aged care services combined with nursing care (Productivity Commission, 2011a). Flexible aged

care services are provided to older persons who ‘require a different approach to care than is provided in the mainstream residential and home care’ programs either in the community or in a residential facility for example respite care, transition care, and aged care services for indigenous and remote communities (Aged Care Financing Authority, 2017a).
Profound recommendations of this reform that have been implemented are summarised below.

2.3.1 Phase 1: 2012/13 – 2013/14

Following the CDC pilot phase in 2010/11 to 2011/12 and commencing August 2013, aged care service providers initiated the provision of all new community aged care places under a CDC model as home care packages (HCP). As highlighted in chapter 1 CDC is an approach to service delivery ‘that allows consumers to have greater control over their own lives by allowing them to make choices about the types of care and services they access and the delivery of those services, including who will deliver the services and when’ (DoHA, 2013a).

Approximately 68% of older Australians live independently in the community without government subsidised formal services (Aged Care Financing Authority, 2017a). Care and support at home is often provided by partners, family, friends or neighbours also referred to as informal carers. Informal carers provide a range of services including both activities of daily living and instrumental activities of daily living. As previously noted, informal carers receive a carer’ pension as well as support services through the National Respite for carers program (NRCP) and the National Carelink centres. One quarter (25%) of older people in Australia receive government subsidised aged care services at home as full pensioners, part-time pensioners or self-funded retirees (Aged Care Financing Authority, 2017a).

Older people in need of care are referred (by family members, health professionals or by their GP) for assessment of their eligibility for government subsidised aged care services through the My Aged Care portal (Australian Government, 2017b). The *My Aged Care* agency (includes a website and contact centres) was established in July 2013 as a gateway to the aged care sector to streamline access to information regarding eligibility and assessment system, how to access services, cost associated with aged care services and older people’s rights and responsibilities (Australian Government, 2017b). Assessment is undertaken at two levels: a needs assessment to determine the type and level of care to be received and a financial assessment to determine how much older people would contribute to their care. Needs assessment for entry level services under the Commonwealth home support program (CHSP) is undertaken by My Aged Care regional assessment services while assessment for home care packages (HCP), residential aged care (RAC) and flexible care services is undertaken by ACAT (Aged Care Financing Authority, 2017a). Financial assessment for CHSP applicants is undertaken by the respective service provider while older people applying for HCP and RAC services are assessed by the Department of Human services (Aged Care Financing Authority, 2017a). Following assessment, older people who are found to be eligible for care are placed on a national waiting list to receive a care package as soon as one becomes available.

Home Care Packages (HCP) Programme

Home Care Packages provide coordinated tailored and individualised package of services to older people with multiple and complex care needs that require a high intensity or volume of services on an ongoing basis at home. These services are delivered by approved providers with funding from the Australian government (Aged Care Financing Authority, 2017a). As previously mentioned, there are four levels of care in the HCP Programme:

i. Home Care Level 1 – provision of basic care;
ii. Home Care Level 2 – provision of low-level care equivalent to CACPs;
iii. Home Care Level 3 – for people with intermediate care needs;
iv. Home Care Level 4 – to support older people with significant and complex care needs equivalent to EACH and EACH-D

Older people across all levels of care who are assessed as in need of specialised support for example those with cognitive impairment receive specific supplements such as the dementia supplement to facilitate access to and provision of these specialised services (DoHA, 2013a). In addition, there is greater flexibility and universal access to nursing, allied health and other clinical services and to a wider range of aids and equipment (DoHA, 2013a).

Residential Aged Care (RAC)

This service provides accommodation and care to older people with moderate to severe reduction in functional capacity whose care needs cannot be sufficiently met at home through community aged care services. Older persons who require ongoing health and nursing care in addition to assistance with activities of daily living are admitted into residential facilities. Care in residential facilities can be temporary in the form of respite care or long term as permanent care.

Residential facilities are run by approved providers with funding from the Commonwealth government under the *Aged Care Act 1997*. On admission, the aged care service provider determines the level of government funding/subsidy permanent residents are eligible for based on their level of need using the Aged Care Funding Instrument (ACFI) (AIHW, 2012c). Care needs are categorised as nil, low, medium or high and the government subsidy is provided based on this categorization with routine reappraisals to adjust funding to residents' changing needs (DoHA, 2009). To ensure continuity of services and the seamless transition for older people with changing care needs, the distinction between low level and high-level residential care was removed in August 2013. This means that as older people become frailer and require more care, the service providers can adjust their funding requirements without the need for ACAT re-assessment.

2.3.2 Phase 2: 2014/15 – 2015/16

As of 1 July 2015, all home care services were delivered under a CDC model as HCP and consumers had an individualised budget (Department of Health, 2015b, Department of Social Services, 2016). In addition to promoting consumer control and empowerment, CDC was also aimed at reducing the budgetary pressure of aged care services on the public system by introducing income-tested consumer contributions (Australian Government Department of Health, 2017). Prior to July 2014, the government was responsible for the full amount of care fees charged by the providers. With the introduction of income testing in the HCP program, the government contribution towards the care fees is now reduced by the income-tested fee (ITF) (Aged Care Financing Authority, 2017b). The ITF is charged for all consumers with income above that of a full pensioner. Full pensioners (P) are assessed as having no other form of income and therefore do not pay the ITF while part-pensioners (PP) and self-funded retirees (SFR) pay a maximum of $5,276.08 and $10,552.18 per annum respectively with a lifetime cap of $63,313.28 (Aged Care Financing Authority, 2017b). This figure is independent of the level of care or HCP received and therefore individuals contribute a greater proportion towards the lower levels of care than the higher levels of care. The individualised budget therefore has three components: the ITF, basic daily fee (determined by the service provider), and the government subsidy (determined based on package level) (Aged Care Financing Authority, 2017a). The maximum value of the basic daily fee is set by the government at 17.5% of the basic single age pension ($3,686.50 per annum) (Aged Care Financing Authority, 2017b).

In residential care, market-based accommodation prices were introduced with higher prices charged for newer facilities. New means testing arrangements that include both income and assets in determining resident contributions were also introduced (Aged Care Financing Authority, 2017a). Service providers are now required to publish their accommodation prices and an Aged Care Pricing Commissioner was appointed to regulate these prices.

2.3.3 Phase 3: 2015/16 - 2016/17

The Commonwealth home support programme (CHSP) was introduced to provide entry level support services to older people in the community (Australian Government). The Short term restorative care program (STRC) incorporating transition care and restorative care services was also introduced (Department of Health, 2015b).

Commonwealth Home Support Programme (CHSP)

This is the entry-level tier into the aged care system and the provision of formal care services to older people in the community. The CHSP was introduced in July 2015 to consolidate and replace some aspects of the HACC program; the NRCP, the Assistance with Care and Housing for the Aged (ACHA) program and the Day Therapy Centre (DTC) program (Department of Health, 2015c). Through CHSP, older people receive a small amount of care and support for immediate needs which if addressed restore independence and enable them to continue living in their own homes. Services provided under CHSP range from the non-specialised services such as personal care, domestic care, house maintenance, to specialised services such as nursing care and allied health services (Department of Health, 2015c). These services are provided individually or in combination at a low intensity on an on-going basis or at high intensity for a short time. Older people in need of a higher volume of services are referred to the Home Care Packages Program (Department of Health, 2015c). The CHSP also provides support for informal carers, services previously provided under the NRCP.

Short term restorative care program

This post-reform program incorporates transition care and restorative care programs.

Transition care (TC)

This is short-term care provided to older people after a hospital stay. Assessment for eligibility is undertaken by ACAT based on the following criteria:

- in the concluding stage of an in-patient hospital episode

- medically stable
- has the potential to benefit from transition care
- in hospital at the time the assessment is undertaken and would be assessed as eligible to receive residential care if the person applied for residential care.

Transition care provides time-limited (84 to 126 days) goal-oriented and therapy focused acute, post sub-acute care to older persons at home or in a residential facility. It is aimed at restoring and optimising older people's functional capacity through services such as physiotherapy, occupational therapy, nursing care, personal care and social support (AIHW, 2012a).

Restorative care (RC)

This is short-term goal-oriented multi-disciplinary support provided at home focussing on improving physical and cognitive function to older people at risk. It is aimed at assisting older people adapt to functional loss, regain function after loss or avoid preventable injuries.

<u>Flexible Aged Care services</u>

Flexible care is defined as "care provided in a residential or community setting through an aged care service that addresses the needs of care recipients in alternative ways to the care provided through residential care services and home care services" (Department of Health, 2015a). Flexible aged care packages are provided to older persons with special needs such as those requiring temporary residential care, older persons living in remote areas and the indigenous communities with special cultural needs. Pre-reform, these included transition care, restorative care and the multi-purpose and innovative care programs for older people in remote areas and the indigenous communities. Flexible care packages post-reform include:

Multi-purpose services (MPS)

This is designed to provide combined health and aged care services to rural and remote communities where separate services are not available. Services provided in this category include:

- residential care
- and at least one of the following services – a health service; a home and community care service; a dental service; a transport service; a home care service; a service for which a Medicare benefit is payable; a service that provides a pharmaceutical benefit; and any other service nominated as appropriate by the responsible Minister of the State or Territory in which the service is located.

The Innovative Care Program

Services provided in this program include:

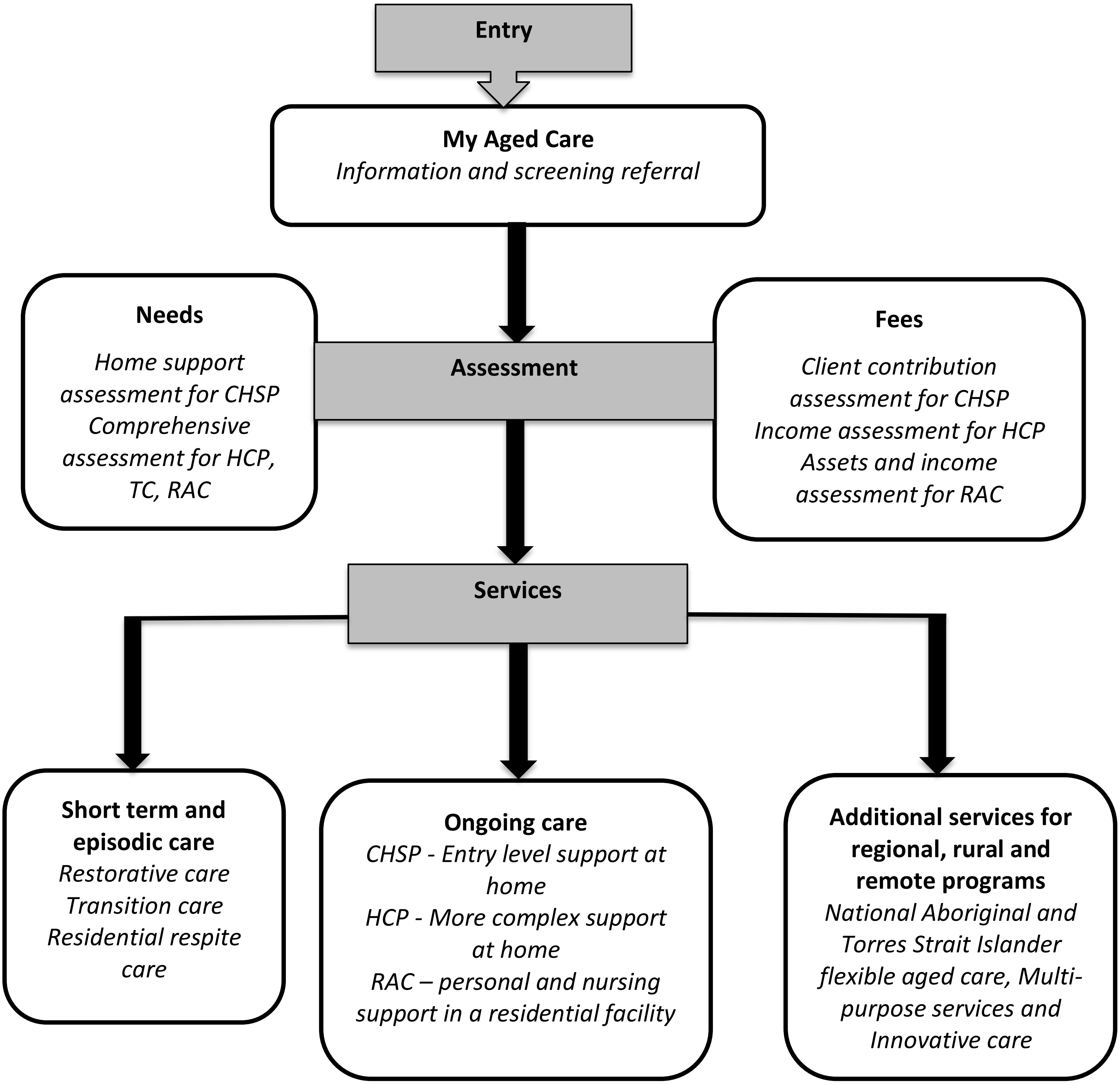
- care that includes alternative options such as for older people with complex conditions or who require coordination and integration of care;
- care provided in circumstances that require the delivery of alternative care options such as in an emergency
- care provided in remote and hard to reach locations
- care provided for people in need of alternative care options, such as the coordination and integration of aged care and health care services
- care provided for a limited period to pilot or trial alternative care options
- and all other kinds of care that, to the satisfaction of the Secretary provide alternative care options in the community or in residential care

Further reforms aimed at increasing competition in the sector and making it more market based were implemented in February 2017. In this reform aged care funding is now assigned to individual consumers who then choose their service provider or a mix of providers as opposed to previously when it was assigned to service providers as aged care places (Department of Health, 2017a).

Other reforms implemented regarding how services are delivered to older people are summarised in appendix 2.1.

Figure 2.2 below summarises the current structure of the aged care system

Figure 2.2: Structure of the Current Australian Aged Care System



2.4 THEORETICAL ANALYSIS OF AGED CARE IN AUSTRALIA

A consumer directed model of service delivery within aged care in Australia has only been in operation since July 2015, which implies that there has been insufficient time to robustly evaluate the performance of this model. An attempt is however made to assess the performance of this model within the context of two key economic concepts, market failure and product differentiation. Analysis of the outcomes of consumer directed care under the extra-welfarism theory in terms of quality of life and capability is also provided.

As highlighted in chapter 1, there is market failure in the provision of aged care services and government intervention is necessary to ensure optimal service provision. Some of the factors contributing to market failure due to monopolistic service providers in this sector include barriers to entry through high investments costs, government approval and accreditation of providers. There is price discrimination through income testing for consumer contributions (ITF) and most providers exist as large conglomerates (16%) or even monopolies especially in remote/rural areas (Aged Care Financing Authority, 2017a). In addition, the majority of service providers are not-for-profit (54% in the residential care sector and up to 74% in the community aged care sector) (Aged Care Financing Authority, 2017a) and therefore do not necessarily provide services at optimal prices and/or quantities. There is also information asymmetry, which may lead to supplier induced demand, as older people do not possess perfect knowledge of the amount of funds allocated to their care, the suite of services they are eligible to receive and service prices.

Market failure is experienced as a consequence of supply and demand inefficiencies resulting in moral hazard while information asymmetry leads to supplier induced demand and adverse selection (Morris et al., 2007c). As previously mentioned in chapter 1, adverse selection in the context of aged care occurs where only the frailest older people who are in most need of care apply for and are enrolled into care (Shi et al., 2017, Buchmueller and Dinardo, 2002) while moral hazard is the excessive utilisation of services by older people, especially experienced when services are free at the point of service or incur a fixed cost regardless of quantity consumed (Van den Berg, 2005). Fees at the point of service i.e. user fees and gap fees (Dijk et al., 2013) as well as waiting lists are introduced to prevent moral hazard. Supplier induced demand is addressed through mechanisms that equip consumers with information/knowledge necessary for decision making regarding services needed and service prices (Boone, 2014) and regulation/monitoring frameworks to safeguard consumers.

As also highlighted in chapter 1, there is evidence of product differentiation within the aged care service sector with providers marketing their services as distinct from those of competitors. A key hypothesis associated with client-assigned funding and demand driven CDC models of care is a stronger incentive for providers to seek to optimize their market share through horizontal product differentiation (Kessler and Geppert, 2005). Providers create a degree of variation in the suit of services they offer under each HCP to appeal to consumer preferences and differentiating themselves from other providers.

The proceeding sub-sections analyse the policy changes accompanying the implementation of a CDC model of services and how they mitigate the effects of market failure and promote competition through service/product differentiation in the delivery of aged care services. In relation to evaluating the performance of aged care services within the context of product differentiation, competition in the market is discussed. The impact of the new policy on cost-shifting, consumers quality of life, choice and control over their care is also discussed.

2.4.1 Market failure and performance of aged care services

<u>Supplier induced demand</u>

Prior to February 2017 where aged care funds were directly assigned to providers by the government, consumers had little ability to exercise choice or control as they, when compared to providers, had limited knowledge of the services they received. The services received were therefore largely pre-determined by the providers themselves. As such, there was little if any incentives in place for providers to improve the quality of their services or for competition between providers. There was also a high risk of supplier-induced demand or over-supply because service providers had to demonstrate utilization of all funds allocated under each package of care which led to provision of services that would have been deemed unnecessary under full disclosure. There was also an incentive for under-supply because funds left over at the end of the financial year would be retained by the provider. Supplier induced demand was suspected among older people receiving traditional aged care services who indicated that they had little or no information about available services and services were provided based on service provider’s menu with little consideration of whether the older person needed them at that point in time (McCaffrey et al., 2015, Productivity Commission, 2015).

Since February 2017 funding is now allocated to individuals who then choose their service providers, authorise how funds are spent and they receive monthly accountability statements. It can be argued that this knowledge of and control over finances reduces the possibility of supplier induced demand (Boone, 2014). It empowers consumers to purchase services based on need, pricing and quality of care creating a degree of contestability and competitive pressure among providers (Morris et al., 2007e).

Regulatory frameworks have also been set up to prevent supplier induced demand. These include the 'My Aged Care' portal that provides information on types of services available, how to access services, cost associated with aged care services and older people's rights and responsibilities. Regulatory mechanisms such as the Australian Aged Care Quality Agency responsible for quality review of home care service providers to ensure consumers obtain value for money in care received and the Aged Care Complaints Commissioner that addresses consumers' concerns about the services and quality of care received have also been set up.

Moral hazard

Prior to July 2014, the government was responsible for the full amount of care fees charged by the providers. To ensure long-term sustainability of aged care funding, income tested consumer contributions were introduced with CDC (Aged Care Financing Authority, 2017a). Consumer contributions act as a barrier to moral hazard, alleviating inappropriate and over use of services (Dijk et al., 2013). Early reports on CDC have not indicated moral hazard, rather on the contrary, income tested fees (ITF) have had a negative impact on the utilisation of services. Because ITF are independent of the HCP received, consumers with larger income reserves and assets are required to contribute a greater proportion towards the lower levels packages of care (31-100%) than towards the more expensive higher level HCPs (7-40%) (Aged Care Financing Authority, 2017a). Consequently some older people may be opting out of lower level HCPs, for which they are required to contribute a greater proportion in ITF instead electing for alternative less expensive care options e.g. informal care provided by family members (Aged Care Financing Authority, 2016).

Moral hazard is also minimised through ACAT's gatekeeper role. Prior to receipt of an HCP older people are assessed by the ACAT service to determine whether they need care and what level of care is needed. Once need is determined, an HCP is approved and the older person is placed on a waiting list to receive the next available HCP. As at 31 December 2017, 104,602 older people had been approved for but were waiting for allocation of a home care package compared to 76,905 in receipt of a package (Department of Health, 2018). The majority (78.7%) of older people on the waiting list had been approved for a high-level HCP while the majority (68%) of those in receipt of care were receiving a level 2 HCP. This process prevents indiscriminate access to HCPs and unnecessary use of services.

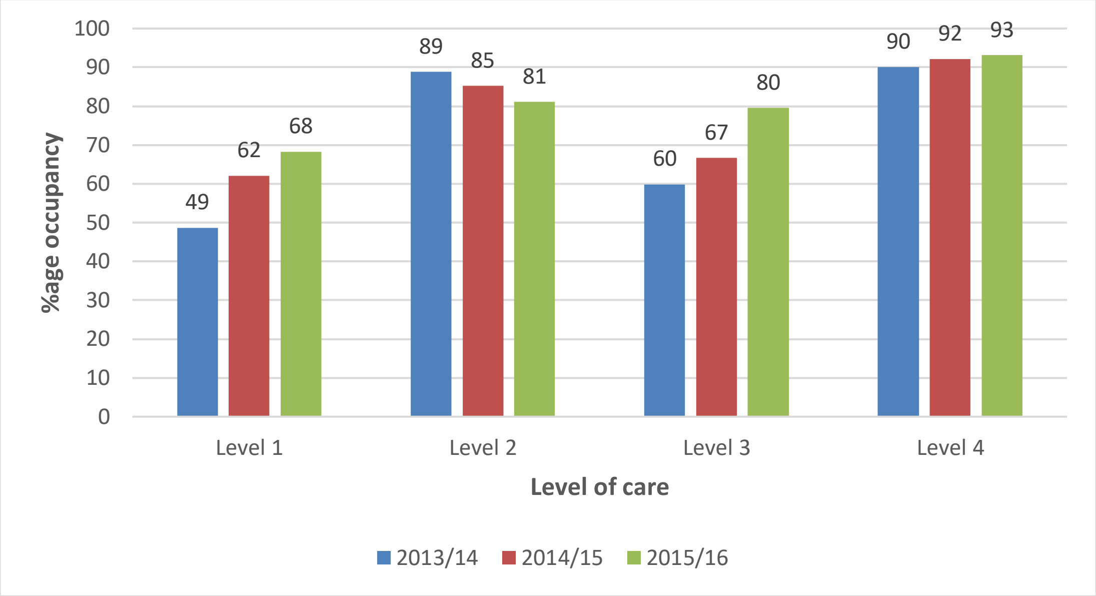
Another system-built mechanism to prevent moral hazard is the individualized budget as older people can only receive services equivalent to their budgets. Older people are also free to purchase only the services they need and retain unused funds in their package for future use, this is an incentive to prevent overuse of services. On the other hand, however, some consumers may opt not to purchase needed care in the interest of saving up monies for a rainy day. This may have a negative effect as they may become frailer at a more rapid rate resulting in a need for higher level home care package or earlier entry to institutional care.

Adverse selection

As mentioned above, early reports on the performance of CDC have indicated that more affluent older people who are required to make larger consumer contributions to their care through the ITF are choosing not to take up lower level HCPs because they are perceived as providing less value for money compared to the higher HCPs (Aged Care Financing Authority, 2017a). Because the same amount of ITF is contributed regardless of HCP level, such consumers tend to seek care when in need of higher-level HCPs which are deemed more value for money as they contribute a smaller proportion than the government. Without the appropriate care at the lower levels of need, such older people may deteriorate much faster and require higher HCPs much earlier. If this tendency becomes widespread, it will be analogous to adverse selection in the health insurance market where only the sickest individuals purchase health insurance policies. It may eventually lead to adverse selection through under consumption of lower level HCPs and over occupation of the higher-level HCPs and residential aged care which cater for the frailest older people in society by more affluent older people.

Occupancy rate, measured as ‘the total number of days a package was actually being used by a consumer (occupied place) as a proportion of the number of days a package was available to be offered to a consumer by a provider (available/operational place)' can be used as a proxy for the uptake of services (Aged Care Financing Authority, 2017a). The trend in occupancy for the different HCP levels pre- and post-reform is illustrated in figure 2.3 below.

Figure 2.3 Uptake of home care packages following introduction of CDC



Source: Fourth report on the Funding and Financing of the Aged Care Sector (Aged Care Financing Authority, 2016)

Figure 2.3 shows, as expected, a progressive increase in occupancy for the entry levels of care (HCP 1 and HCP 3) reflecting increasing demand for services but a particularly steeper increase in HCP 3 in 2015/16 following the system wide transition to CDC in July 2015 suggesting a greater demand for the higher HCPs.

In the previous system, older people could only access low level care (under CACPs equivalent to HCP 1) or high-level care (under EACH and EACH-D equivalent to HCP 4) so it has been argued that the introduction of HCP 2 and 3 has created opportunities for older people with intermediate care needs to access appropriate care and subsequently increased access to care overall (Aged Care Financing Authority, 2016). As indicated previously, the steeper increase in HCP 3 could also be a result of adverse selection, where more affluent older people (who contribute proportionately more of their own personal income to finance care packages relative to those older people on lower incomes) seek entry to the aged care system at the higher levels of care which they deem to provide greater value for money. In addition, as highlighted in chapter 1 (sections 1.2.1), the provision ratio for home care services has progressively increased since 2013 while that for residential care has reduced (Aged Care Financing Authority, 2016) which may make the higher-level home care places more readily accessible for older people with high level needs compared to residential aged care places.

It can also be argued that ACAT's role mitigates to prevent adverse selection occurring in the aged care market through experience rating as it assesses older people's level of care and allocates HCPs based on their needs. Service providers are obliged to provide services to older people for the HCP levels that they are approved for and for which the service providers have the appropriate accreditation.

2.4.2 Product differentiation and performance of aged care services

Competition in the market

Prior to February 2017 any unused funds attributable to an older person's HCP in a particular funding cycle were retained by the service provider, however, with the reforms, any unused funds move with the consumer (Department of Health, 2017a). Although it's still too early to quantify any impact, this initiative is likely to make the market more competitive as service providers have a new incentive to review their operating and business models so as to attract and retain consumers as well as discourage early exits (StewartBrown, 2017). Service providers need to focus on differentiating their care models to meet consumer preferences with efficient use of resources to maximise the care dollars under the scrutiny of consumers who are now privy to their budget and expenditures. Organisations aim to differentiate their services from their competitors which should drive improvements in the quality of services whilst also meeting their key objective of increasing market share (Hotelling, 1929, Brekke et al., 2010, White, 1972, O'Sullivan et al., 2012, Kessler and McClellan, 2000). Product differentiation has been observed in the residential aged care sector in recent years as some providers are offering hotel style accommodation, serviced apartments in care villages as opposed to regular bed accommodation in a facility (Agedcare101). In the community aged care sector, increased provider flexibility and consumer choice can be expected in terms of who provides care and when it is provided including the introduction of new and more flexible services moving above and beyond traditional care-plans to meet consumer preferences. Other modifications may include availability of multi-lingual carers, attention to religious and cultural preferences in care provision for older people from culturally and linguistically diverse populations as well as culturally sensitive services for Aboriginal Australians (Department of Health).

Since the introduction of CDC the home care market has attracted new service providers, with the number of applicants for home care service providers almost tripling in 2016/17 compared to 2015/16 (Aged Care Financing Authority, 2017b). Whilst it is still too early to assess the full impact, it is anticipated that the introduction of new entrants into the home care market will increase competition and will lower the cost of services in the long run. Price competition in the fees charged by providers for non-care services, including administration and care coordination may become an area of contention. In chapter 8, I present the methods and findings from a detailed costing study in which I identify that in 2016 approximately 40% of total HCP expenditures were allocated to administration and care coordination. It is reasonable to hypothesize that the introduction of client-assigned portable funding will drive providers to further differentiate through service initiatives that lower the costs associated with administration and care coordination thereby allowing a greater proportion of HCP expenditures to be allocated to the direct provision of care services which will be attractive to consumers.

A review of aged care quality regulatory processes in 2017 proposed the formation of the Aged Care Quality and Safety Commission which commences in January 2019 (to replace the Australian Aged care Quality Agency and the Aged Care Complaints Commissioner) (Carnell and Paterson, 2017, Department of Health, 2018b). With increased emphasis on quality of care and the more widespread availability of information e.g. in relation to quality indicators and the level of quality achieved by individual service providers to the public, consumers are more likely to seek out higher quality services which will further promote competition and product differentiation among service providers.

Overall, considering that providers are in the initial phase of transitioning to portable HCPS and the reforms being embedded into the sector, it is still early to model the level of product differentiation (quality of services, product variety and location) and its impact on competition in the aged care sector. This should be considered as an area of future research as these policy changes become more established.

2.4.3 Cost shifting

The 2016 ACFI report shows an increase in consumer contributions, as a proportion of total contributions, from 7% in 2014 to 10% in 2015 (Aged Care Financing Authority, 2016) with a reduction to 8.2% in 2016 (Aged Care Financing Authority, 2017b). The impact of consumer contributions on cost-shifting from the government to consumers to date has been small, primarily because most older people (82%) receiving HCPs are pensioners who are not required to make contributions towards their care through the ITF (see section 2.3.2). As previously highlighted, a flat rate ITF is charged regardless of the level of care received and older people with higher incomes are required to make larger consumer contributions (compared to the government subsidy) through higher ITFs for the lower level HCPs. Consequently, older people on higher incomes have been reported to self-select out of the lower levels of care as they are deemed poorer value for money and instead seek informal care which is free or cheaper (Aged Care Financing Authority, 2017a). Because they are receiving sub-optimal care from these alternative sources, it can be hypothesised that without the appropriate care at the lower level of need these individuals deteriorate much faster, swiftly become frailer and in need of the higher-level HCPs. This contributes to increased utilization of the higher levels of care that have a relatively lower proportion of ITF and greater government contribution, thereby increasing the cost of delivery of aged care services to the government and further affecting the financial sustainability of the sector. Mechanisms to encourage and maintain enrolment where there is an assessed level of need, in all HCP levels are required to encourage higher income older people to seek the appropriate level of care in a timely fashion e.g. by indexing ITF to the HCP received such that, lower ITF are charged for the lower level HCPs and higher ITFs are charged for higher level HCPs.

The ACFI report also highlighted pricing irregularities resulting from approximately 17% of providers who are not charging the full basic daily fee with consumers contributing only a small proportion of the required ITFs (Aged Care Financing Authority, 2017a). This means that even older people with adequate financial means are not contributing as much as they should. This further affects the overall goal to shift costs to the consumer. In addition, because they are paying the provider an amount that is less than what is required for their assessed level of care, such consumers do not receive the appropriate amount of care to meet their needs and therefore deteriorate faster and require the higher levels of care much earlier which is a greater cost to the government. A review of the *Living Longer Living Better Act 2013* aged care legislation recommended for government intervention to ensure that all service providers charge the full amount of the basic daily fee and the ITF and provide the appropriate services for the different levels of care (Department of Health, 2017b). To improve the sustainability of the sector, the legislative review also recommended that annual and lifetime caps to consumer contributions should be removed (Department of Health, 2017b).

2.4.4 Quality of life, consumer choice and control

Although still in its infancy, high levels of satisfaction have been reported by users of CDC in Australia compared with traditional provider directed care. A study conducted amongst older people who participated in a pilot study of CDC reported high levels of satisfaction with the CDC model implemented (KPMG, 2012). Also participants in a state specific direct-funded CDC pilot program among people with disabilities reported improvements in quality of life and wellbeing especially among consumers who received larger budgets and those who had prior experience with the traditional system (Fisher and Campbell-Mclean, 2008).

Increased choice, control and flexibility about goods and services was also reported under CDC, for example, some older people who participated in the 2010 CDC pilot chose to implement home modifications to increase their levels of independence, e.g. by modifying the bathroom to enable the older person to take their own shower as opposed to paying a carer to assist with bathing. Others opted to switch their grocery shopping to an online service as opposed to going to the shops directly which would require carer assistance (KPMG, 2012). It can be hypothesised that with client assigned funding that commenced in February 2017 (Department of Health, 2017a), control over finances and expenditures (which service provider and the mix of services purchased) promotes consumer choice and control as consumers have a greater understanding of how their budget is being expended, with the flexibility to spend more on those services that lead to the greatest improvements in their quality of life.

Prior to the reforms, high levels of specialised care were only provided as EACH and EACH-D packages or in residential care. Introduction of the four HCPs with supplements for specialised care provided across all levels allows for more choice as even consumers with basic care needs can access specialised care e.g. support for mental health and dementia related conditions, without needing to transition to high care services at home or residential care (DoHA, 2013a).

In addition, the increased supply of services through the increased home care provision ratio and changes to nationwide allocation mean that consumers have more choice in determining who provides the services that they need (Aged Care Financing Authority, 2016). Consequently, as highlighted in the policy analysis provided in chapter 2, it is expected that service provision and market structure of the community aged care sector in Australia will continue to evolve within the framework of product differentiation. Service providers will attempt to innovate by designing packages of services that are tailored to suit consumer preferences to increase their market share. This may involve market segmentation beyond assessed care needs to reflect consumer preferences in relation to socio-demographic characteristics e.g. according to differing income levels, geographical location, cultural background etc

CONCLUSION

This chapter has introduced the Australian aged care system, a historical time-line of how the system has been funded and regulated and the current structure of the system following major reforms in August 2013 has been described. It has also provided a theoretical analysis of the structure of current system within the framework of market failure and product differentiation and the outcomes within the extra-welfarism framework as quality of life and capabilities.

The next chapter provides a detailed description of consumer directed care, it describes the consumer directed care philosophy and, how it has been implemented globally. It also provides a theoretical analysis of these more established models within the context of market failure and product differentiation. It then describes the CDC model implemented in Australia highlighting its similarities to the more established models.

CHAPTER 3

CONSUMER DIRECTED CARE IN AN INTERNATIONAL CONTEXT

This chapter provides a detailed review of the concept of consumer directed care (CDC); its origins, the various definitions, application and how CDC models of care have evolved in different countries. It also looks at the evidence for effectiveness of CDC models and the impact of such models on quality of life, choice and control and competition in the aged care market. As was discussed in chapters 1 and 2, analysis of the performance of these models is also undertaken within the context of market failure and product differentiation.

3.1 INTRODUCTION

Consumer directed care (CDC) has been widely applied internationally among people with disabilities and is quickly developing as a new model of service delivery for community and home care services in Australia and internationally (Dejong et al., 1992, Simon-Rusinowitz and Hofland, 1993, Ottmann et al., 2009a, Ottmann and Laragy, 2010). Currently there is no single definition of CDC accepted universally. However, the key principles of CDC are to permit the consumer or their representatives to have 'choice' and 'control' over allocated services and funds received. In practice, operational models of CDC have ranged along a continuum from '**self-directed care'** through to '**cash for care'** schemes. Self-Directed Care is focused upon increasing recipients' control over care arrangements and flexibility of care provision through programs and services which meet the needs of the recipient (Simon-Rusinowitz et al., 2005, Alakeson, 2010). In contrast, cash-for-care schemes involve unrestricted provision of cash or service vouchers so that recipients may manage their own funds and directly purchase their care (Carlson et al., 2007, Arksey and Kemp, 2008).

CDC is proposed as an alternative to service delivery that promotes greater consumer choice and control, personal independence and empowerment for individuals who need long-term care services such as assistance with activities of daily living (ADL) and instrumental activities of daily living (IADL) (Litvak et al., 1987, Benjamin and Matthias, 2001, Gadsby, 2013, Doty et al., 1996). Activities of daily living (ADL) refers to actions undertaken to care for one's self and body such as personal care and hygiene, mobility, and eating while IADL include activities necessary for independent living in the community such as housekeeping and meal preparation, transport, managing finances, shopping and access to the social activities (KATZ, 1983). Although predominantly implemented to date in community aged care, CDC models are progressively being embraced as an alternative model of service delivery in institutional care (Boyd and Johansen, 2008, Ethel and Mitty, 2008, Rahman and Schnelle, 2008, KPMG, 2014). The underlying philosophy of CDC is that it promotes 'decisional' independence for the consumer/client and a market-based economy that facilitates competition amongst providers. It is anticipated that increased competition in the sector will eventually translate to promote better quality of services (Riddell et al., 2005, Simon-Rusinowitz et al., 2005, Priestley et al., 2007). CDC models of care are argued to be more consumer-focused than traditional provider-directed models of care. It has been suggested that CDC provides more flexibility for the consumer and empowers them to make their own decisions (including, for example, choosing their own care and support staff) thereby promoting consumer satisfaction and wellbeing (Litvak et al., 1987, Kennedy and Litvak, 1991, Eustis and Fischer, 2002, Gadsby, 2013).

Like most developed countries aged care services in Australia are heavily subsidised by the federal government. With an aging population, increasing demand for home and community-based long-term care services is inevitable. In an environment of economic pressures and constrained financial resources, CDC has been viewed by some commentators as a means of containing the costs of providing care whilst also achieving positive outcomes of satisfaction and improved quality of life for consumers (Alakeson, 2010, Gadsby, 2013, Doty et al., 1996). Consumer directed care models have been advocated as potential cost-containment measures for public expenditures because they encourage individuals to continue living in their homes for as long as possible as opposed to moving into institutional care, a more expensive option (Timonen et al., 2006, Brown et al., 2007, Kröger and Leinonen, 2012). In addition, the potential for reducing bureaucracy and the burden of administrative fees with CDC has also been advocated as an additional cost containment mechanism (Arksey and Kemp, 2008, Doty et al., 1996). It has also been suggested that the introduction of CDC may assist in stimulating the market for home care services and provide employment opportunities for people in the community who would otherwise be unemployed such as informal caregivers who previously provided services voluntarily (Timonen et al., 2006, Da Roit et al., 2007)

Consumer directed care models of service delivery have been implemented under different names or labels in different countries. These include 'cash and counselling' in the USA, 'individualised budgets' in England, 'individualised funding' in Canada, 'personal budgets' in the Netherlands and Germany, '*allocation personnalisée à l'autonomie'* in France, 'care allowances' in Austria, 'attendance allowance' in Italy, 'assistance allowance' in Sweden, 'supplement for dependency' in Portugal, 'Home-Care Grants' (HCG) in Ireland, 'personal assistance budgets' in Belgium, and 'service vouchers' in Finland (Alakeson, 2010, Da Roit and Le Bihan, 2010).

Consumer directed type models have taken on different forms and labels in various countries. A review by Alakeson (2010) examining self-directed care programs in England, Germany, the Netherlands, and the United States classified CDC type models into the 'open model' and the 'planned/budgeted model' of CDC (Alakeson, 2010), based on the level of control individuals have over the utilisation of funds. The 'open model' allows consumers to spend funds as they deem appropriate with no accountability to the funding authority but with regular monitoring/assessment of the client's wellbeing to ensure care needs are met. Cash payments are withdrawn and clients reverted to agency-provided care in case the assessment reveals that care needs are not sufficiently met. This model has been implemented in Austria, Italy and previously in Germany (moved to the planned model in 2004) where the funds are regarded as an income supplement (Da Roit et al., 2007, Da Roit and Le Bihan, 2010).

Countries such as the USA, England, the Netherlands, Finland, France and Australia have applied the 'planned /budgeted model' which is more rigorous in planning and implementation with a number of key steps (Alakeson, 2010). The initial step in this model is to pre-determine how much an individual is entitled to; this is estimated using various needs assessment criteria specific to each country such as the number of care hours required, level of income, and family support, carried out by a team of medical professionals or social workers or both. As the name suggests, this model involves an assessment/planning stage where the client's needs are assessed in conjunction with a team or case-manager from the funding authority to generate a care-plan against which the budget is to be spent (Arksey and Kemp, 2008, Alakeson, 2010). Funds are directly transferred to the consumer as cash payment or consumers nominate a third party fiscal agent to which the funds are transferred and individuals must spend and account for the funds as per the agreed/approved care-plan (Arksey and Kemp, 2008, Gadsby, 2013). In Australia, funds are administered by the service provider on behalf of the consumer.

Following the analysis of the introduction to CDC in the Australian aged care system presented in chapter 2, the performance of more mature models of CDC operating in other parts of the world is assessed in this chapter within the context of the economic concepts of market failure and product differentiation and their ability to improve quality of life and promote consumer choice and control. Section 3.2 describes the evolution of CDC models in other developed countries particularly those with population profiles and health systems that are like Australia. Section 3.3 describes the evolution of CDC in Australia. A detailed analysis of the policy frameworks governing the delivery of CDC in Australia within the context of market failure and product differentiation has been provided in chapter 2.

3.2 THEORETICAL ANALYSIS OF CDC MODELS OF AGED CARE IN OTHER PARTS OF THE WORLD

3.2.1 Cash and Counselling in the United States of America

Consumer directed care in the USA originated with the Independent Living Movement in the 1970s, an organisation that advocated for a good quality of life for people living with disabilities (DeJong, 1983, Litvak et al., 1987). Since 1975 individuals requiring long-term care in the community, including older people and people living with disabilities, were provided personal assistance services or home and community-based (HCB) long-term care services under the Medicaid personal care services (PCS) optional benefit (Litvak et al., 1987, Doty et al., 1996). Over the years the PCS benefit evolved into the Medicaid State Plan optional personal care benefit to encompass other population groups including people with mental health problems. The level of consumer control varied in different states with some states such as Michigan permitting the consumer to hire, train and supervise their personal carers including family members and to take on financial control and accountability (Litvak et al., 1987, Dejong et al., 1992, Doty et al., 1996). Other states such as Maryland and Texas limited financial control as they required that consumers employ staff from certified home health care agencies (Kennedy and Litvak, 1991, Doty et al., 1996).

In the mid-1990s, a new approach to Medicaid PCS benefit, the ‘cash and counselling’ model that laid more emphasis on consumer direction was introduced (Benjamin and Fennell, 2007). This was a ‘budgeted/planned model’ with funds disbursed to consumers on a monthly or quarterly basis for the purchase of care related goods and services (Brown et al., 2007). Individuals were allowed to choose a representative to take charge of their decision-making responsibilities, while the ability to hire and who could be hired (including family and relatives) varied from one state to another (Simon-Rusinowitz et al., 2005, Brown et al., 2007). In addition, individuals received counselling services to assist them with planning and proper utilisation of the allocated resources and a fiscal agent to manage and account for the funds. 'Cash and counselling' model was implemented in three states (Arkansas, Florida and New Jersey) commencing in 1998, 1999 and 2000 respectively and evaluated after five years (Brown et al., 2007).

Building on the 'Cash and counselling' model, the 'Independence Plus Initiative' was implemented in Florida, Louisiana, New Hampshire, and South Carolina beginning September 2003 (Crowley, 2003). In addition to all Medicaid services under the HCB and PCS benefit, more goods and services could be purchased including equipment and supports services, environmental adaptation services, home health services, homemaker services, transportation and respite care services to enable consumers continue to live at home. The main cap to the budget allocated per recipient was not to exceed the cost of institutionalisation or the cost of state-managed services to that individual although routine assessments to ensure the individual budget was adequate were permitted. Consumers still received direct cash payments, could hire and supervise care-workers but the state provided emergency back-up for services and supports, information necessary for proper consumer-centred planning of services and maintained the quality assurance role (Crowley, 2003). Consumers were also permitted to use unspent funds saved through efficient management to obtain additional services or purchase equipment/supports or placed in a saving account for later use although some states required that unspent funds were returned to the funding authority.

In January 2007 all states began to implement the 'individualised budgets' as a follow-on from 'cash and counselling' and 'Independence Plus Initiative' (Spillman et al., 2007). Although 'individualised budgets' are similar to their predecessors in eligibility, scope and the key tenets highlighted above, there are no requirements of the Medicaid waiver system governing the former which allows for increased flexibility in the populations to be served and utilisation of funds (Spillman et al., 2007).

Market failure and product differentiation within 'cash and counselling'

Although not explored or reported upon in the evaluation conducted by Brown et al. (2007), it can be hypothesised that the increased utilisation of services under Cash and Counselling was a result of moral hazard following the direct access to care funds. In their evaluation, Spillman et al suggested that budget caps coupled with saving of unspent funds under the newer ‘individualised budgets’ were mechanisms to prevent moral hazard which was most likely happening with ‘Cash and Counselling’ (Spillman et al., 2007).

Brown et al. (2007) reported lower cost of care for older people, a finding attributed to the ability to purchase services that enabled them to stay at home as opposed to admission into institutional care (Brown et al., 2007, Dale and Brown, 2007). As such the main findings from this evaluation were improved consumer wellbeing and effectiveness of the Medicaid HCB program because consumers were more likely to access care which was more tailored to and better met their individual needs. It can be argued that the ability to purchase only services they needed prevented supplier induced demand as consumers had control over what services should be purchased.

Similar to health care in the USA (Gaynor and Town, 2011), it can be hypothesised that there is a level of product differentiation in the provision of aged care services, however, no evidence was provided in the evaluations reviewed above or elsewhere in the literature.

Quality of life, consumer choice and control

The evaluations revealed improved access to and satisfaction with services and life in general attributed to the increased control and flexibility and reduced unmet needs with cash payments but there was no significant improvement in quality of life/health status (Brown et al., 2007, Clark et al., 2008). The cost of personal care services was much higher compared with the PCS program since with cash in hand and the flexibility to hire family members, consumers purchased all the services in their care-plans (including those that were not available in the traditional system) unhindered by bureaucracies and shortages in the traditional system.

3.2.2 Individualised Budgets in England

Like the USA, CDC was first introduced in the UK as government funded cash payments to people living with disabilities. Community care reforms in the mid-1990s led to the introduction of CDC type models as ‘direct payment’ (DP) mechanisms to individuals aged between 18 and 65 years receiving social care services (Barnes, 1997, Riddell et al., 2005, Glendinning et al., 2008). Individuals who were willing and deemed able to control and manage their care received cash payments to purchase and manage care services tailored to their needs, as determined by the individual with the help of a case-manager. This 18-65 years age bracket was widened in 2000 to include people above 65 years (Glendinning et al., 2008).

In 2005 ‘direct payments’ were transformed into ‘personal/individualised budgets’ (IB) that include a means-tested consumer contribution. The IB is a budgeted/planned model of CDC that integrates and aligns all government/public funding to an individual into one central fund or budget and is utilised to achieve the individual’s pre-determined goals and outcomes (Glendinning et al., 2008). The amount allocated per budget is determined based on a needs and income assessment and individuals can opt to self-manage or nominate a third party (such as a local authority or financial institution) for fiscal management whilst they maintain control over goods and services to be purchased (Timonen et al., 2006). Consumers receive support from a case manager in formulating a care-plan. In principle, IBs encourage consumers to achieve greater financial control as they are made aware of the amount of funds in the budget and the cost of services (Glendinning et al., 2008). Unlike ‘direct payments’ where funds were allocated to purchase pre-defined services, there is more flexibility in the usage of funds under IBs enabling individuals to purchase services from the open market (private or voluntary sector, but not relatives) or from the public sector including non-traditional goods/services although all purchases must not exceed the budget.

Market failure and product differentiation within IB

A major evaluation of IBs was undertaken in 2008 and revealed that IBs were accompanied by the opening up of services markets in terms of hiring and where to purchase services including the private market as opposed to relying solely on public/agency services (Glendinning et al., 2008). There was some evidence to indicate that this opening up of service markets improved access to care and promoted timely service delivery as consumers were able to control their own care by-passing the bureaucracies and time consuming administrative procedures undertaken by agencies (Glendinning et al., 2008). With consumer choice of services to be purchased and who should provide them, it can be argued that IBs reduce the effect of supplier-induced demand as consumers determined and purchased only services that they needed. However, service providers also reported an increased demand for services that were previously not requested or being utilised, this may be an indication of moral hazard among IB recipients but there was no explicit evidence in the evaluation to indicate whether this was the case.

The evaluation demonstrated that there was increased pressure for providers to differentiate their services based on consumer preferences so as to remain viable in the market (Glendinning et al., 2008). For example, IBs provided room for flexibility in terms of who could be hired, especially for recipients with complex high levels of support/need who could hire personal carers to undertake health-related tasks as well and older people from minority ethnic groups could purchase culturally appropriate services.

<u>Quality of life, consumer choice and control</u>

By facilitating a greater level of consumer involvement, IBs were found to be associated with improvements in quality of life and wellbeing although this was dependant on the level of expenditure with better outcomes being attributed to individuals with larger budgets (Netten et al., 2012b). However overall, in contrast to younger adults, quality of life was not found to improve amongst older people with IBs, a finding attributed to the smaller budgets that left little or no room for flexibility beyond services previously accessed under provider directed services (Woolham et al., 2016), but also the increased levels of anxiety and psychological distress associated with managing their own care (Glendinning et al., 2008, Moran et al., 2013, Netten et al., 2012b)

Unlike the findings from the USA, Glendinning et al. (2008) did demonstrate lower costs associated with IBs compared with conventional provider directed care (Glendinning et al., 2008).

The evaluation revealed improved consumer choice and control, flexibility of service delivery and opening up of the social care market (Glendinning et al., 2008). The unrestricted purchase of care related goods and services according to individuals' specific needs and preferences offered increased consumer choice and control (Stevens et al., 2011, Netten et al., 2012b).

3.2.3 Personal Budgets in the Netherlands

Under the '1968 Exceptional Medical Expenses Act (AWBZ)' insurance plan, people of all ages with physical or mental health problems, the disabled and older people (over 65 years of age) requiring and assessed as eligible for long-term care services (LTC) in the Netherlands received state-funded services (Da Roit and Le Bihan, 2010). This system was co-funded by the consumer (income-tested) and the government through monthly insurance premiums. Since 1996, individuals had the option of receiving care in kind or as a cash allowance (equivalent to in-kind services in value) also referred to as ‘personal budgets’ (PGB) to purchase services from government/local authority-approved service providers (Health Foundation, 2011, van Ginneken et al., 2012). In line with the CDC philosophy, PGB was aimed at empowering and giving consumers more control over their care. Universal rollout of PGB was implemented in 2001 and restrictions on the purchase of services from approved providers was removed in 2003 so as to stimulate a commercial market economy for care services (Huijbers, 2004).

‘Personal budgets’ is a ‘budgeted/planned model’ of CDC where an individual’s care needs are established by a multi-disciplinary team of experts and a care-plan developed in consultation with the individual (Health Foundation, 2011). A budget is then allocated bi-annually based on the individual’s care needs and income level. Funds are used to purchase services from the public or private market but 98% of purchases must be care-related and limited to the budget with any surplus covered by the consumer (Arksey and Kemp, 2008, Health Foundation, 2011).
Compared with services received in-kind, increased utilisation of readily available informal care rendered the PGB less costly and consumers reported high levels of satisfaction with the service model (Da Roit, 2013). However, the convenience of PGB generated an increase in demand and subsequently the cost of PGB rose exponentially. As such, new PGB applications were halted in 2010 and all LTC services were provided in-kind (Da Roit, 2013). The PGB program was reviewed in 2012 with the introduction of means-testing (including both income and assets) for consumer contributions and a change in the eligibility criteria to include only individuals living in the community who would otherwise be institutionalised (in nursing home or residential care home) (Health Foundation, 2011, van Ginneken et al., 2012). Main features of the new PGB included the restriction of purchases to services not provided by the health and social care systems; spending against the care-plan; no provisions for engaging a third party fiscal management agency and funds were to be deposited into a personal account specifically created for this purpose (Health Foundation, 2011). Consumers who were no longer eligible for PGB but in need of LTC could purchase tailor-made services from the open market then receive reimbursement from the government.

With soaring expenditure, the PGB was not financially sustainable and it was repealed in 2014 and re-introduced in 2015 with more controls to prevent misuse and increased emphasis on care at home as opposed to institutionalisation (Van Ginneken and Kroneman, 2015, Maarse and Jeurissen, 2016). Under the new system, budgets are managed by a government body, the Social

Insurance Bank (SVB), care is decentralised with nursing care services at home provided under health insurance and social care support (including help at home, house adjustments) is provided by municipalities (previously all services were provided under the AWBZ) (Maarse and Jeurissen, 2016). Social care support is provision-based where support is only provided after informal care is considered insufficient. It was hoped that the new emphasis on personal responsibility and unpaid informal care for social care support as opposed to professional care/payed care in the previous system would reduce costs, however, this is not the case as informal carers are in short supply and more funds have had to be allocated to PGBs (Van Ginneken and Kroneman, 2015, Maarse and Jeurissen, 2016).

Market failure and product differentiation within PGB

Reviews of the PGB prior to 2014 revealed that the system was faced with increasing demand for services by individuals who previously did not require them, an indication of moral hazard (van Ginneken et al., 2012, Le Bihan and Martin, 2012). The government sought to address this demand through the introduction of budget caps and waiting lists for receipt of a PGB (Health Foundation, 2011). Waiting lists did not deter demand for services as many recipients were happier to wait than choose the traditional care option.

The PGB did not achieve its goal of creating a formal care market as most recipients used the cash payment to compensate their informal carers' time as opposed to purchasing formal care services (Da Roit, 2013). In addition, competition among providers was marginal because there were monopolies already in place yet the entry of new and smaller providers was restricted (Kremer, 2006). However, there was evidence of product differentiation as providers became 'more client oriented but also helped providers make better distinctions between routine and extra care and thus deal with demanding clients' (Health Foundation, 2010).

Quality of life consumer choice and control

Review of the PGB prior to 2014 also indicated that it reduced consumer choice and flexibility as it offered less services, however, the ability to hire and purchase services from the open market would still promote control and increased access to care (van Ginneken et al., 2012, Le Bihan and Martin, 2012).

3.2.4 Allocation Personnalisée à l'autonomie in France

Until the mid-1990s, the provision of LTC for older people in France was government funded social assistance under the social care policy designed for people with disabilities, the 'ACTP; compensatory allowance for a third party' (Da Roit et al., 2007, Da Roit and Le Bihan, 2010). A temporary means-tested scheme, '*prestation spécifique dépendance'* (PSD), was then created in 1997 to specifically address the needs of older people including institutionalised care. This was reformed in 2002 into the '*allocation personnalisée à l'autonomie'* (Personalised allowance for autonomy - APA), so as to ensure universal coverage and reduce costs of LTC with consumer contributions of up to 90% of the benefit (Da Roit and Le Bihan, 2010).

The APA scheme is a 'budgeted/planned model' of CDC characterised by a cash-for-care benefit calculated in line with the recipient's level of dependency and income. The level of dependency and ultimately the amount of care required is determined based on a national assessment grid with a maximum payment per dependency level (Da Roit et al., 2007, Da Roit and Le Bihan, 2010). This benefit is restricted to the purchase of specific care services or a care package determined by a team of professionals and formulated into a care-plan (Da Roit et al., 2007). Consumers have the freedom to purchase services from the public or private market and can employ relatives but not live-in partners.

To address the increasing demand and financial sustainability of LTC further reforms led to establishment of the 'Fund for the frail elderly' ('*Caisse nationale de solidarité pour l'autonomie'*) in 2005. This was a social insurance based scheme with mandatory contributions from all working-class citizens, to fund personal care, home modification and LTC needs for older people and people living with disabilities in the community (Da Roit et al., 2007).

Market failure and product differentiation within the APA

It can be argued that the ability to hire and supervise care workers under APA may result in moral hazard as consumers decide what services to purchase and from whom (Le Bihan and Martin, 2012).

The impact of consumer contributions on cost-shifting and financial sustainability of the program was not evident as majority of consumers were below the means-tested income level and did not contribute to their care (Le Bihan and Martin, 2012). With zero contributions, there is a potential for moral hazard as consumers seek more services that they would otherwise utilise if they had to pay for them. Unlike the Australian system, for example, there were no caps to consumer contributions in the APA and as seen with ITF in the Australian context, it can be argued that this would have implications for uptake of the program as consumers with higher levels of need and therefore contributions would opt out from receiving care at home and instead seek institutionalised care resulting in adverse selection for institutionalised care. It could also create market for migrant informal care workers who provide cheaper alternative care at home.

To prevent the emergence of a black market for informal care, an employment agency *'Agence des services `a la personne'* to assist families in sourcing for qualified care workers was created in 2006 (Da Roit and Le Bihan, 2010). The resultant effect was an up-skilling of the care workforce and professionalization in the formal care services sector as carers were required to have appropriate qualifications and quality of care was closely monitored. It can be hypothesised that professional workers would provide better quality of care and the increased availability of specialised care workers would promote product differentiation and competition in the market. Providers would be in position to provide specialised care workers based on specific consumer needs.

Quality of life, consumer choice and control

The freedom to hire and supervise care workers under APA promotes consumer choice and control, flexibility and increased access to care resulting in improved effectiveness of the program in meeting care needs (Le Bihan and Martin, 2012).

3.2.5 Personal Budgets in Germany

'Long Term Care Insurance' (LTCI) levy was introduced in Germany in 1995 with mandatory social security contributions from all employed citizens (Arntz and Thomsen, 2011). To mitigate the impact of demographic changes leading to reductions in the employable population (the taxable base for LTCI contributions) yet an increasing demand for aged care services, the LTCI levy is indexed every few years to match revenue to the increasing demand (Arntz et al., 2007).

Under the self-financing LTCI individuals assessed by the 'Medical Review Board' as eligible for long-term care services regardless of their level of income, could opt to receive services in-kind from a registered agency or as a cash payment that enabled them to manage their care or a mix of both approaches (Arntz et al., 2008, Da Roit and Le Bihan, 2010, Arntz and Thomsen, 2011). The monetary value of agency-provided services was twice the amount received as cash payments for the same level of need, although services provided by the agency were limited to an approved list of care services. The cash payment was an ‘open model’ of CDC with no restriction on how the funds could be spent; the payment was viewed as an income supplement spent on any desired goods or services that positively contributed to quality of life. Consumers could also employ family members and friends. Quality control was achieved through semi-annual visits by a case-manager to assess the level of care and the health of the consumer.

With increasing demand and costs, the LTCI system was reviewed in 2002 and ‘personal budgets’ (*Pflegebudget*) were introduced in 2004 (Arntz et al., 2008, Alakeson, 2010). This differs from cash payments as the budgets are equivalent to entitlement under agency-provided services (which is also twice the amount under cash payments for the same level of need), and purchases are not restricted to a pre-determined list of services or service providers but consumers maintain the use of case-managers to plan and monitor the adequate provision of care. To deter consumers switching from cash payments to ‘personal budgets’, spending of ‘personal budgets’ is restricted to long-term care services with unspent funds returned at the end of the month (Arntz et al., 2008, Arntz and Thomsen, 2011). In addition, consumers cannot employ close relatives (Arntz et al., 2008, Arntz and Thomsen, 2011).

Market failure and product differentiation within personal budgets

Although CDC approaches were cost efficient compared with in-kind services, evaluation of the system demonstrated that ‘*Pflegebudget*’ was costlier than cash payments because of the ‘woodwork effect’ where support previously provided by informal caregivers had to be purchased from the formal care market which was more expensive (Arntz et al., 2008). It can be hypothesised that this coupled with regulations regarding unspent funds under *Pflegebudget* present a moral hazard where consumers may purchase ‘unneeded’ care so as increase their informal carers’ income and also to exhaust their budget allocation (Van den Berg, 2005).

Competition in the market was not achieved with the *Pflegebudget* because consumers pay for a care package whose prices are pre-negotiated by the LTCI and the service providers with no consumer input (Arntz et al., 2007). This approach promotes supplier-induced demand as service providers will determine how much of the services to provide to maximise their revenue. On the down-side however, it can be argued that since consumers have financial control, they seek cheaper and more flexible care from the informal sector encouraging an informal care market and a grey market for informal care provided by immigrant workers. This is a negative externality to the system as majority of these immigrant workers are illegal and do not pay taxes.

Like the other systems discussed above, product differentiation is expected in a CDC model of service delivery, however, the evaluations discussed above did not report any evidence to that effect in Germany.

Quality of life, consumer choice and control

Prior to the introduction of CDC, its advocates envisioned that increased consumer control and independence would improve consumers' quality of life and wellbeing while its opponents envisioned a deterioration; however, slight improvement or no change in quality of life/health status was observed between personal budgets and agency care in Germany (Arntz et al., 2008).

Although consumers could hire family members who could provide flexible care, choice and control over finances was not fully achieved as consumers did not have the freedom to directly negotiate service prices with providers (Arntz et al., 2007).

3.2.6 Care Allowance (*'Pflegegeld'*) in Austria

Government support for LTC for the frail elderly in Austria was initiated in the early-1990s with the introduction of cash benefits for frail elderly with specific needs, provision of residential care and social services in the community, mainly limited to nursing care (Da Roit et al., 2007). Prior to this, LTC was viewed as the family's responsibility although the municipalities provided residential care as means-tested social assistance (Da Roit and Le Bihan, 2010). Funding to all people in need of LTC and those eligible for social protection (such as war victims) was provided as a cash allowance under the 'Federal Long-Term Care Allowance Act (*Bundespflegegeldgesetz, BPGG*)' (Riedel and Kraus, 2010). All individuals ineligible for the federal allowance but eligible for social assistance received a cash allowance from the provincial government under the '*Landespflegegeld*' (Riedel and Kraus, 2010). The provincial government also provided services in-kind in residential care homes, nursing homes, community living facilities and respite care when needed. Eligibility for the cash allowance was based on a permanent need for personal care services for at least six months, need for at least 50 hours of care per month, Austrian citizenship and residency in Austria while services in-kind were provided to Austrian citizens in need of health-related services (Riedel and Kraus, 2010).

Reforms to ensure universal access to long-term care led to the nation-wide introduction of cash-for-care schemes through social insurance, based on individual need regardless of income level, the *'Pflegegeld'* in 1993 (Da Roit et al., 2007). This is a care allowance for long-term care services in the community or in residential care facilities, whose value is based on individuals' level of dependency as assessed by a team of professionals (Da Roit et al., 2007, Da Roit and Le Bihan, 2010, Riedel and Kraus, 2010). The *'Pflegegeld'* is an open model of CDC where individuals are free to spend on care services or to supplement their home budgets and they can hire, supervise or manage staff including close family members or friends (Da Roit et al., 2007, Da Roit and Le Bihan, 2010). The provincial government is responsible for providing information and counselling support to all recipients and quality assurance monitoring of service providers and care recipients' health needs. New regulations in 2005 aimed at improving the standards and quality of care introduced uniform educational requirements for care-workers (Riedel and Kraus, 2010).

3.2.7 Attendance Allowance ('Indennità Di Accompagnamento') in Italy

National government funding for the provision of long-term care in Italy was initiated as an 'attendance allowance', the '*indennità di accompagnamento'* (IdA), for people living with disabilities and expanded in the mid-1980s to include dependent older people living in the community along with the provision of institutional care in residential homes and nursing homes at the local level (Da Roit et al., 2007, Da Roit and Le Bihan, 2010). This is a flat rate allowance separate from the social care system and health care system, whose eligibility is based on inability to work (for the younger adults) and the need for assistance in activities of daily living for both younger and older people. Another cash payment, the 'care allowance' '*assegno di cura*' is a supplementary means-tested allowance provided at the local level to all people with disabilities deemed eligible based on a given criteria although the IdA remains the predominant form of LTC support (Naldini and Saraceno, 2008, Da Roit and Le Bihan, 2010).

The IdA is an 'open model' of CDC with no restrictions on what and how the allowance is to be spent. In contrast, the regulations regarding use of the 'care allowance' vary from one local authority to another with some incorporating monitoring systems, support and counselling on how the funds are spent or restricting employment to certified/trained carers, while others have no regulation/restrictions of any kind (Da Roit et al., 2007, Naldini and Saraceno, 2008). Unlike other European countries whose policies have progressively evolved, there were no major changes to the policy on care for older people in Italy since its inception in the 1980s (Da Roit and Le Bihan, 2010, Le Bihan and Martin, 2012).

Market failure and product differentiation in Austria and Italy

It can be hypothesised that the ability to pay informal carers who previously provided care without pay may result in moral hazard first to increase family income and secondly to utilise all allocated funds.

However, reviews of these systems have highlighted the meagre amount of the cash allowances and demand for non-family informal care workers who are relatively cheaper to employ than paying family members, subsequently creating a grey market for informal care which affects competitiveness of the formal care market (Ungerson, 2004, Da Roit et al., 2007, Da Roit and Le Bihan, 2010, Österle and Bauer, 2012). This market was largely populated by unregulated immigrant care workers whose services are tailored to consumer preferences and yet more affordable. Informal care from the grey market is highly differentiated as the immigrant workers are more flexible in terms of care hours, with some willing to provide 24-hour care including services beyond care such as general housekeeping. To curb the rapid growth of the grey market in Austria, a tax subsidy available to families that employed carers from the formal care market was introduced in 2007 while compulsory documentation of immigrant workers under a legal working framework was implemented in Italy (Da Roit et al., 2007). Similar to France, the need for skilled formal training for care staff was implemented in Austria to promote professionalization of the workforce, increased competition for care work and improved quality of care (Riedel and Kraus, 2010).

Quality of life, consumer choice and control

Evaluations of the models of care in Austria and Italy have reported high levels of satisfaction amongst older people and their informal carers because the models permit paying for informal care provided by family and friends or the purchase of these services (Clark et al., 2004, Ungerson, 2004, Da Roit et al., 2007).

This ability to hire and supervise care workers also promoted increased choice, control and flexibility for example recipients of the cash allowance in Italy could hire personal carers to provide 24-hour care services that were not available under the traditional systems (Le Bihan and Martin, 2012).

Table 3.1 below summarises the key features of each of the CDC type models discussed above.

Table 3.1: Key features of CDC type models in the different countries

Country	Personalised care plan?	Budget setting	Budget deployment	Level of consumer control over budget	Financial reporting
USA	Yes	Budget based on assessed level of need (number of care hours and cost of care).	Direct cash payment to recipients or nominated fiscal agent.	Spending restricted to services in care-plan and purchase of care-related equipment.	Budget holders or fiscal agent must account for expenditure.
England	Yes	Locally determined processes. Often use 'indicative budgets' based on best guesses, and/or previous care packages.	Direct cash payment to recipients or nominated fiscal agent/third party.	Spending on care services and care-related equipment.	Budget holders or fiscal agent must account for expenditure.
Netherlands	Yes	Level of dependency and level of income, budget determined according to nationally fixed tariffs *Always about 25% lower than equivalent agency-directed service costs.*	Direct payment to recipient's account with options to outsource some aspects (e.g. salary administration). Big budget holders must use a fiscal agent.	98.5% should be spent on care services.	Periodic accountability by individual or fiscal agent.
France	Yes	Level of dependence and disposable income, budget amount according to nationally set tariffs.	Direct cash payment to recipients or paid directly to the service provider.	Spending restricted to care package.	Recipients justify expenditure and provide accountability.
Germany	Yes	Determined by a needs-based assessment, budget equal to cost of alternative agency-directed care.	Direct cash payment to recipients or notional budget.	Spending restricted to care services.	Individual – Accounting varies according to locality; some areas have very strict procedures.
Austria	No	Monthly budgets calculated based on seven levels of need for care (expressed in hours).	Direct cash payment to recipients. Where individual is cognitively impaired, someone is appointed to manage the budget.	Unrestricted spending.	None
Italy	No	Standardised flat rate budgets based on levels of needs with no age limits.	Direct cash payments to recipients.	Unrestricted spending	None
Australia	Yes	Based on needs assessment by ACAT, individualised budget based on care package.	Agency managed fund.	Spending restricted to care related services and equipment.	Agency

This table was adapted from Gadsby et al.2013 and Le Bihan et al. 2012 (Le Bihan and Martin, 2012, Gadsby, 2013)

3.3 CDC IN AUSTRALIA

Similar to the USA, a CDC approach to the delivery of care services in Australia was first implemented among people living with disabilities under the ‘Disability Services Act’ of 1986 and later the ‘National Disability Long-term Care and Support Scheme’ (Productivity Commission, 2011b). A comprehensive review of the disability scheme in 2010 led to the introduction of the ‘National Disability Insurance Scheme’ (NDIS). The NDIS commenced in 2013 to provide insurance cover to all eligible and entitled persons under the age of 65 years living with a profound and permanent disability and in need of long-term care in the community (Productivity Commission, 2011b, NDIS, 2015). Through the NDIS individuals have the option of receiving cash payments or contract a third party fiscal agency and have direct control over how and who provided the services with access to information on available care and support options plus referrals/linkages to service providers (Productivity Commission, 2011b). Consumers can purchase services from the public, private and not-for-profit sectors; non-government organisations, disability service organisations, state and territory disability service providers, individuals and mainstream businesses (Productivity Commission, 2011b).

As highlighted previously in chapter 2, consumer directed care in the Australian aged care sector was initiated following a federal government review of the provision of community aged care services in 2010 (Productivity Commission, 2011a). In addition to the key tenets of choice, control and promoting individual autonomy, CDC was incorporated as a cost shifting mechanism through the introduction of income-tested consumer contributions and a cost containing mechanism that encourages older people to continue living in their homes. The pilot program commenced in 2010/2011 with 1000 community aged care places allocated to existing or new clients who were interested in and able to direct their own care. This pilot programme was evaluated in 2012. Findings of this evaluation revealed greater satisfaction with service delivery and improved wellbeing especially for recipients of the more funded higher level care packages, and also among consumers who switched from the provider-directed model to the CDC model compared with new enrolees; which suggests greater satisfaction with CDC compared with provider-directed care (KPMG, 2012).

Widespread implementation of CDC commenced for all existing and new individuals enrolled across all packages of care in July 2015 (Department of Health, 2015b). Home care packages are allocated by the ACAT based on individuals' care needs, with a stipulated menu of services that can be obtained under each package (chapter 2). It is important to note, however, that depending on one's capability and willingness, older people still have the option to choose between self-directing all or some aspects of their care with the service provider or an intermediate agency managing the other aspects in the latter case (KPMG, 2012, KPMG, 2015).

The type of CDC introduced into the Australian aged care system is a self-directed care approach with a 'budgeted/planned model' like individualised budgets in the UK. In this model HCP funding is allocated to individuals who then choose an aged care agency to manage their package but they are given access to information about the budget available for their care and have control over the management and coordination of their care, determining how, when and who provides the services. Similar to Germany, England and some states in USA, consumers cannot hire friends or family members, but can directly hire service providers or services are brokered through an aged care agency (Low et al., 2012, KPMG, 2015). Like some states in the USA but unlike personal budgets in Germany, all unspent funds in the budget are rolled-over to the next month, used to purchase more services, make one-off purchases such as for expensive equipment, or saved for future use. In the case that a client transitions from one HCP level to another, unspent funds are transferred to their new package. And in case they opt to change agencies, the consumer transfers with their package funds less any contract fees with the current agency. Financial control and accountability is undertaken by the aged care agency with monthly statements submitted to the client (KPMG, 2012, Low et al., 2012, KPMG, 2015). In addition, the agency is responsible for ensuring access to information, capacity building, quality control and monitoring of care received in line with the care-plan and client's goals as well as the monitoring and review of the care-plan according to the client's changing needs.

Evaluation of CDC in Australia using the theoretical framework of market failure and product differentiation and its impact on quality of life, consumer choice and control is provided in chapter 2.

CONCLUSION

This chapter has provided a comprehensive description of CDC in principle and in practice. The different models of CDC implemented internationally have been described and analysed within the context of market failure and product differentiation as well as their impact on consumer quality of life, choice and control. It has highlighted the mechanisms in place to address market failure such as user fees and budget caps as well as efforts by service providers to differentiate their products to obtain or maintain their market share. There is variation in the evidence relating to the impact of CDC models on consumer quality of life and wellbeing. However, overwhelmingly the introduction of CDC models in Australia and internationally has been found to be associated with increases in consumer choice and control.

The next chapter reports on the application of health economics methodology in the evaluation of service delivery interventions in the community aged care sector. It highlights the paucity of economic evaluations in this sector and the variability of methodologies applied to evaluate service delivery interventions for older people.

CHAPTER 4

ECONOMIC EVALUATIONS IN COMMUNITY AGED CARE - A SYSTEMATIC REVIEW

This chapter explores the application of economic evaluation methodology to assess service delivery interventions in the community aged care sector. It reports on the methods and results of a systematic review of published studies applying economic evaluation methodology. Studies were included if they [1] compared both costs and outcomes of two or more interventions [2] in study population of people aged 65 years and over [3] dependent older people living in the community [4] alternatives being compared were care models or service delivery interventions [5] published in the English language between 2000 and November 2016. This systematic review provides a discussion and recommendations for the most appropriate economic evaluation methodology for innovations in care models and service delivery in the community aged care sector. It also highlights the importance of ensuring that instruments used to measure and value quality of life within cost utility analysis in community aged care accurately represent those quality of life domains that are most important to older people.

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4.1 BACKGROUND

In 2011/12 the Australian government expenditure on aged care services equated to $12.9 billion rising to 14.8 billion in 2013/14 and $16.2 billion in 2015/2016 with a projected increase at a rate of 4.9% annually over the next decade to over $26 billion by 2023/24 (National Commission of Audit, 2014, Productivity Commission, 2015, AIHW, 2016). The increased demand for aged care coupled with scarce and constrained resources requires a review of existing policies and new approaches in service delivery to ensure the efficient allocation of resources. Economic evaluation offers a systematic and transparent approach to assessing allocative efficiency and provides a framework for comparing the costs and benefits of competing interventions to ensure value for money. Traditionally, economic evaluations have been widely used to guide decision and the allocation of resources in health care. Advisory bodies including the National Institute for Health and Care Excellence (NICE) in the United Kingdom, the Pharmaceutical Benefits Advisory Committee (PBAC) and Medical Services Advisory Committee (MSAC) in Australia, and the Ontario Ministry of Health in Canada require cost effectiveness evidence when assessing applications of drugs or new health care technologies to be listed on their national formulary (Harris and Bulfone, 2004, Ontario Ministry of Health and Long-term care, 2006, Corbacho and Pinto-Prades, 2012, National Institute for Health and Care Excellence, 2013). However, to date economic evaluations have not been harnessed to the same degree in assessing service delivery interventions in the aged care sector (Morris et al., 2007b, Ratcliffe et al., 2012b).

The remaining part of this section provides an overview of the different types of economic evaluations and their application among older people. Section 4.2 describes the methodology applied in this review, the results are described in section 4.3 followed by a discussion of the findings in section 4.4.

4.1.1 What are economic evaluations?

Economic evaluation has been defined as ‘the comparative analysis of alternative courses of action in terms of both their costs and consequences’ (Drummond et al., 2005a). Economic evaluations generally assess the economic efficiency of a given set of competing alternatives by comparing their costs (inputs) and consequences (outputs) (Drummond et al., 2006). Economic evaluation evidence facilitates the efficient allocation and equitable distribution of health care resources as the results of economic evaluations can provide decision-makers with important information to assist in managing the demand for new health care technologies or interventions (Morris et al., 2007f).

There are various types of economic evaluations which can be differentiated according to how outcomes or outputs are measured. These include cost minimisation analysis (CMA), cost effectiveness analysis (CEA), cost utility analysis (CUA), cost consequences analysis (CCA) and cost benefit analysis (CBA) (Morris et al., 2007b, Drummond et al., 2005a).

Cost minimisation analysis

This type of economic evaluation is appropriate to use where the interventions compared have been demonstrated to be equivalent in terms of the main outcomes of interest e.g. through the conduct of a randomised controlled trial. The analysis compares the costs of the interventions, choosing the intervention with the least cost (Drummond et al., 2005a, Brazier et al., 2007b). Drummond et al. (2005) have argued that CMA is not a full economic evaluation as it is focused upon a comparison of costs only (Drummond et al., 2005a). In practice, CMA is not as useful and is seldom applied as it is rare that there are no differences in outcomes between interventions under consideration (Briggs and O'Brien, 2001).

Cost effectiveness analysis

This is a type of economic evaluation where outputs are measured in natural units or physical units of effect that are typically clinically or bio-medically focused such as number of infections averted, units of blood pressure reduced or more generally as the number of life years gained (Drummond et al., 2005a). Cost effectiveness analysis is used when comparing interventions with similar type of effects and a fixed budget, e.g. within a particular health care specialty or programme in order to maximise technical efficiency (Drummond et al., 2005a, Morris et al., 2007d). Results in CEA are expressed as the incremental cost per unit of effect referred to as the incremental cost effectiveness ratio (ICER).

Cost utility analysis

When comparing interventions in CUA, outcomes are expressed using a generic outcome measure, the quality adjusted life year (QALY) (Drummond et al., 2005a). The QALY combines the quantity of life attributed to an intervention and the value individuals place on that life (Brazier et al., 2007d). Quality of life is valued in several ways; the most common approach is using multi-attribute utility instruments (MAUIs) or preference-based instruments. Several popular MAUIs are currently in existence including the EuroQol EQ-5D (EQ-5D), the health utilities index (HUI), the Short Form 6 dimensions (SF-6D) and the Assessment of Quality of Life instrument (AQoL) (Brazier et al., 2007b, Brazier et al., 2007a). These comprise a health state classification system and a scoring algorithm to express the level of utility attached to living in each particular health state (Brazier et al., 2007d, Brazier et al., 2007a). Quality adjusted life years provide a generic measure of outcome, which facilitates the promotion of allocative efficiency by comparing the costs and outcomes of interventions across disparate conditions and programs. Results of CUA are expressed as the incremental cost per QALY gained.

Cost consequence analysis

This type of evaluation analyses both costs and outcomes but does not combine them to form an ICER and the results are reported separately as costs and a series of different outcomes. The outcomes are presented in their most appropriate units and not aggregated into a single measure. Drummond and colleagues have classified CCA as a variant of CEA, which has been discussed above (Drummond et al., 2005a). Some commentators have argued that CCA should be applied as a stand-alone methodology because its presentation of outcomes is more meaningful, easy to understand and allows the decision maker to decide what outcomes are important in the different contexts in their value judgment as opposed to CEA and CUA that present outcomes as an aggregate measure, however, others have argued that decisions based on decision-makers' value judgements would lack consistency and promote uncertainty in decision making (Coast, 2004, Mauskopf et al., 1998).

Cost benefit analysis

Cost benefit analysis is a type of economic evaluation where both costs and outcomes are measured and valued in monetary terms (Drummond et al., 2005a, Morris et al., 2007d). A positive net benefit indicates that an intervention is worthwhile as the costs associated with the intervention are outweighed by the benefits generated. Money being a universal outcome measure, CBA facilitates, in principle, comparison of programs across different sectors such as the health care sector and transport or education sectors. It informs decision makers on the absolute benefit and relative performance of competing alternatives (Morris et al., 2007d). Unlike CUA and

CEA that are undertaken within an already determined budget framework, CBA determines which interventions or programs are worthwhile based on the alternative uses of available resources (Morris et al., 2007d, Drummond et al., 2005a).

In the Australian context, cost utility analysis is the type of economic evaluation most preferred by the PBAC , although CEA and CMA approaches are also permitted depending on the context of the submission (PBAC, 2016). MSAC is relatively less prescriptive and permits different approaches depending on the comparative outcomes demonstrated in the clinical studies (MSAC, 2017).

4.1.2 Systematic reviews of applications of economic evaluation methodology in the aged care sector

A review conducted in 2004 by Ramos and colleagues sought to critically appraise economic evaluations conducted in home care for older people aged 65 years and over (Ramos et al., 2004). All studies, indexed in the MEDLINE database and published between 1980 and 2004, that applied economic evaluation methodology were identified and extracted. Of the 142 studies identified as possible economic evaluations, 73 (51%) included older people but only 24 analysed cost and outcomes for older people. The findings of this review highlighted disparities in levels of adherence to standard economic evaluation methodology/principles (Ramos et al., 2004).

Mason et al. (2007) conducted a systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people (above 60 years of age) and their informal carers (Mason et al., 2007). Both published and unpublished studies undertaken on the topic from 1980 (or inception of the database) to July 2005 were identified from 37 databases including grey literature. Of the 379 studies assessed for eligibility, only five economic evaluation studies were identified (Mason et al., 2007).

In 2012, Tappenden and colleagues undertook a systematic review to identify studies relating to the clinical and/or cost effectiveness of home-based, nurse-led health promotion for older people (> 75 years) (Tappenden et al., 2012). This review was limited to studies undertaken within the UK from a National Health Service (NHS) and/or Personal Social Services (PSS) perspective. Twelve key health and medical databases including Medline and Embase as well as Google Scholar for unpublished literature were searched for studies published between 2001 and March 2011. Forty-nine studies were assessed for eligibility but only three were classified as economic evaluation studies (Tappenden et al., 2012).

A more recent systematic review of literature by Graybill and colleagues investigated the cost effectiveness of using assisted living technologies among older people (aged 65 years and over) to support ‘Aging in Place’ (Graybill et al., 2014). The NHS Economic Evaluation Database (NHS EED) and the Health Economic Evaluations Database (HEED) were searched for relevant literature from inception to July of 2012. Only five economic evaluations were identified out of the 34 studies assessed for eligibility. This review highlighted the poor quality of data used and inconsistencies with regard to measurement of HRQoL as an outcome (Graybill et al., 2014). The review authors advocated for the use of quality of life instruments that include domains that are relevant to older people such as independence as opposed to instruments focused more narrowly on health status. This is because the benefits provided to older people by interventions in the aged care sector may extend beyond health status to broader aspects of quality of life (Graybill et al., 2014).

The reviews highlighted above emphasize the minimal application to date of economic evaluation methodology in the community aged care sector. In addition, the reviews indicate the variability in the methodological rigour applied (Ramos et al., 2004, Graybill et al., 2014). The review reported upon here differs from these previous reviews in several respects. Firstly, this systematic review is focused upon the application of economic evaluation methods to assess the costs and outcomes of care models and service delivery interventions for older people who are dependent i.e. need support in ADL and or IADL to continue living in the community. The critical appraisal of all economic evaluation studies identified will provide guidance on the appropriate type of analysis and standard methodology/principles to be followed when undertaking future economic evaluations in the community aged care sector. Secondly, this review updates previous reviews as it considers literature published between 2000 and November 2016.

Objectives

The main objectives of this study were:

- To identify economic evaluation methodologies that have been utilised to assess the costs and outcomes of care models and service delivery interventions *in* community aged care
- To provide recommendations for appropriate methodology to guide the design and conduct of future economic evaluations of care models and service delivery interventions in the community aged care sector

4.2 METHODS

A systematic review was conducted and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009). A search strategy was developed based on the study objectives, the strategy used in Medline, which was then translated to other databases is provided in *Appendix 4.1*

4.2.1 Databases

PubMed, Medline, Scopus, CINAHL, Informit and Web of Science

4.2.2 Search terms

Three key concepts were considered and incorporated:

i) the **population** was defined by subject headings such as aged, frail elderly and keywords such as elder or geriatric or old age or older person or people or adult

ii) **economic evaluation methodology** was defined by headings including economics; Quality-adjusted life years; costs and cost analysis; health care costs and keywords economic analysis or evaluation or model, cost effectiveness or cost utility or cost benefit, quality adjusted life years or QALY

iii) **community aged care sector** was defined by subject headings such as Homes for the Aged; Community Health Services; Independent Living and keywords such as community care, home care, community aged care, home living, community living.

4.2.3 Eligibility criteria

Five criteria were used to determine eligibility of studies to include. These are:

- studies comparing both the costs and outcomes of two or more interventions undertaken as stand-alone studies or alongside a clinical trial or other types of study design
- study population exclusive to people aged 65 years and over
- dependent (need support in ADL and or IADL) older people living in the community
- alternatives being compared were care models or service delivery interventions in the aged care sector
- published in the English language in peer reviewed journals between 1st January 2000 and 15th November 2016

Studies were excluded if:

- both costs and outcomes were not considered and compared e.g. a cost analysis with no outcome measurement, effectiveness studies with no cost measurement, studies with no comparators, burden of disease or cost of illness studies
- Theory papers, letters, editorials, reviews, theses or dissertations and studies where full texts could not be obtained.

A second reviewer independently assessed 20% of the articles for eligibility and overall agreement between reviewers was calculated using Cohen's kappa statistic (Cohen, 1960).

4.2.4 Data extraction

Full text articles of included studies were read to obtain the following categories of information: study design and type of evaluation, key comparators, perspective/viewpoint of the study, the cost categories considered, type of costing used and the source of costing data, definition of outcomes and how they were measured, and the key results and conclusions of the study.

4.2.5 Quality assessment

The methodological quality of included economic evaluations was assessed using the critical appraisal checklist developed by the University of Glasgow (University of Glasgow, 2015) that is based on the guidelines established by Drummond (Drummond et al., 2005c). The checklist is attached in *appendix 4.2*

4.2.6 Data synthesis

The data in included studies was synthesised narratively to identify key methodological principles applied.

4.3 RESULTS

4.3.1 Study selection process

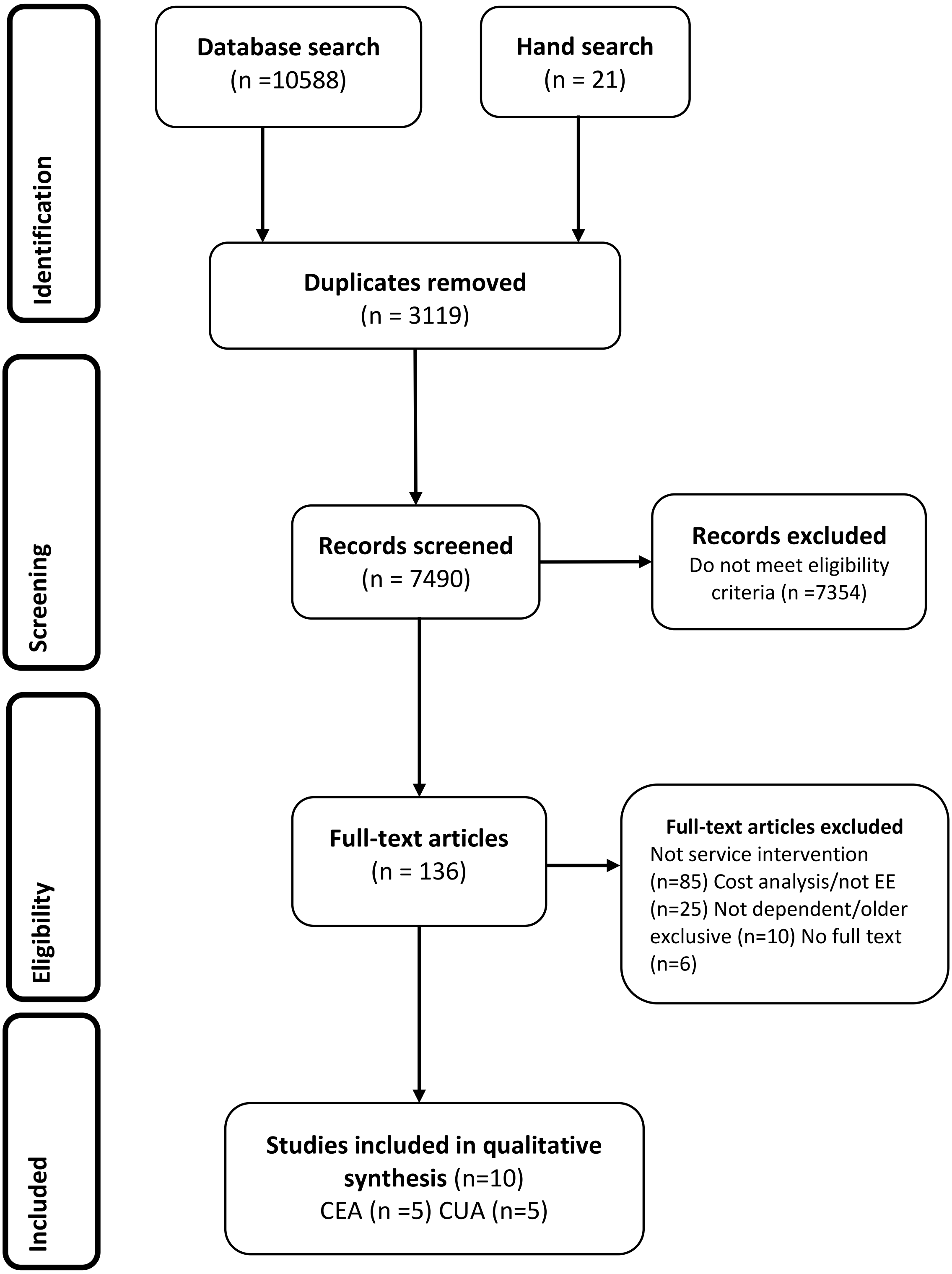
Figure 4.1 below is an illustration of the study selection process following the PRISMA guidelines (Moher et al., 2009). Study selection was divided into four stages:

i. **Identification:** 10,588 papers were identified from the database search and an additional 21 from backward and forward searching the reference lists of the final studies accepted for the review, 3,119 duplicate articles were removed.
ii. **Screening:** 7,490 titles and abstracts were screened for eligibility; 7,354 papers did not meet the eligibility criteria.
iii. **Eligibility:** 136 full texts articles were read and further assessed; 85 studies did not compare care models or service delivery interventions in community aged care, 25 were cost analysis studies while the population in 10 studies was not exclusive to older people and the full text could not be obtained in six studies.

iv. **Included:** 10 economic evaluation studies were included in the qualitative synthesis and narrative review. Five studies were CEAs and five CUAs.

The level of agreement relating to study exclusion and inclusion between the two reviewers was very high/almost perfect with a kappa statistic of 0.82 (Viera and Garrett, 2005).

Figure 4.1: Study selection process



4.3.2 Data extraction

The table below is a detailed description of the study identified

Table 4.1: Main characteristics of the studies

Title	Population Sample size and Country	Comparators	Perspective	Time horizon	Measure and Source of effectiveness data	Costs (Currency-Year)	Source of cost data	Measure of Outcome	Conclusions
Cost utility analysis									
Cost-Utility Analysis of Preventive Home Visits program for Older Adults in Germany (Brettschneider et al., 2015)	Over 80 years N=304 Germany	Preventive home visits vs usual care	S	18 months	Nursing home admissions RCT	Health care, Client/family, Informal care (Euro-2008)	Hospital, Nursing home and pharmacy Records, Self-report	QALY (EQ-5D-3L)	Intervention unlikely to be cost effective
Cost utility analysis of case management for frail older people: effects of a randomised controlled trial (Sandberg et al., 2015)	65+ years N=153 Sweden	Case management vs usual care	S	12 months	Healthcare utilisation RCT	Health care, Other sectors, Client/family, Informal care, Intervention (Euro-2011)	Hospital register, Community care records, Self-report	QALY (EQ-5D-3L)	Intervention was cost neutral and did not seem to have affected health-related quality of life
Occupational therapy compared with social work assessment for older people. An economic evaluation alongside the CAMELOT randomised controlled trial (Flood et al.,	65+ years N=321 UK	Occupational therapist led vs social worker led assessment	PS	8 months	Dependency using the Community Dependency Index (CDI) RCT	Health care, Social care, Client/family (Pound sterling-2001)	Clinical records, Self-report	QALY (EQ-5D-3L)	No difference in clinical and cost effectiveness

Title	Population Sample size and Country	Comparators	Perspective	Time horizon	Measure and Source of effectiveness data	Costs (Currency-Year)	Source of cost data	Measure of Outcome	Conclusions
2005)									
Cost-effectiveness of integrated care in frail elderly using the ICECAP-O and EQ-5D: does choice of instrument matter? (Makai et al., 2014a)	Over 75 years N=352 Netherlands	Integrated care vs usual care	S	3 months	ADL-functions, experienced health, mental well-being, social functioning, QES	Health care, Social care, Client/family, Intervention costs, Informal care (Euro-2011)	Patient health records, Self-report	Capability (ICECAP-O) QALY (EQ-5D-3L)	Intervention maybe cost-effective based on capability QALYs
Cost effectiveness of the Walcheren Integrated Care Model intervention for community dwelling frail elderly (Looman et al., 2016)	Over 75 years N=377 Netherlands	Integrated care vs usual care	S	12 months	Functions, experienced health, mental well-being, social functioning QES	Health care, Social care, Client or family, Intervention costs, Informal care (Euro-2011)	Patient health records, Self-report	QALY (EQ-5D-3L)	The WICM is not cost-effective
Cost effectiveness analysis									
Effects on health care use and associated cost of a home visiting program for older people with poor health status: A randomized clinical trial in the Netherlands (Bouman et al., 2008)	Aged 70–84 years N=330 Netherlands	Home visiting vs usual care	S	24 months	Health care use RCT	Health care, Intervention costs (Euro-2003)	Health use databases	Self-Rated Health (SRH)	Home visiting program did not appear to have any effect on the health care use of older people with poor health and had a low chance

Title	Population Sample size and Country	Comparators	Perspective	Time horizon	Measure and Source of effectiveness data	Costs (Currency-Year)	Source of cost data	Measure of Outcome	Conclusions
									of being cost-effective
Cost effectiveness of a multi-disciplinary intervention model for community-dwelling frail older people (Melis et al., 2008)	70 years or older N=151 Netherlands	Multi-disciplinary intervention vs usual care	HS	6 months	Functional performance in ADL and IADL (GARS-3) and mental well-being (SF-20 MH scale) RCT	Health care, Social care (Euro-2005)	Primary care physician's information system, Patient self-report	Successful treatment	Intervention is an effective addition to primary care for frail older people at a reasonable cost
Economic Evaluation of a Multifactorial, Interdisciplinary Intervention Versus Usual Care to Reduce Frailty in Frail Older People (Fairhall et al., 2015)	70 years or older N=241 Australia	Multi-factorial inter-disciplinary intervention vs Usual care for frailty	P S	12 months	Degree of frailty and disability RCT	Health care, Social care, Intervention costs (Australian dollar -2011)	Within trial service use database, Literature, Self-report	Transition out of frailty	A 12-month multifactorial intervention provided better value for money than usual care
Cost effectiveness of a chronic care model for frail older adults in primary care: economic evaluation alongside a stepped-wedge cluster randomised trial (van Leeuwen et al., 2015b)	65 years and older N=1147 Netherlands	Geriatric care model vs usual care	S	24 months	HRQoL (SF-12), and Functional limitations (Katz index) RCT	Health care, Social care, Intervention costs, Informal care (US dollar-2011)	Participant cost diaries	HRQoL (SF-12), QALY (EQ-5D-3L) and Functional limitations (Katz index)	Geriatric care model was not cost-effective compared to usual care after 24 months of follow-up

Title	**Population Sample size and Country**	**Comparators**	**Perspective**	**Time horizon**	**Measure and Source of effectiveness data**	**Costs (Currency-Year)**	**Source of cost data**	**Measure of Outcome**	**Conclusions**
Cost effectiveness of a home-based intervention that helps functionally vulnerable older adults age in place at home (Jutkowitz et al., 2012)	70 years or older N=319 USA	Advancing Better Living for Elders (ABLE) vs Usual care	SP	2 years	Reduction in functional difficulty and mortality RCT	Intervention costs (US dollar-2010)	Within trial database, Literature	Life years saved	Investment in ABLE may be worthwhile depending on society's willingness to pay

Study design: RCT=Randomised Control Trial, QES=Quasi experimental study, Perspective: S=Societal, HS=Health system, PS=Public sector (Health sector and social care sector), SP=Service provider (home care agency)

Geographical distribution: Geographical distribution of the studies varied widely with nearly three quarters (80% or 8 studies) undertaken in Europe.

Study design: Majority (80%) of the economic evaluations were undertaken alongside randomised controlled trials. Two economic evaluation were undertaken based on data from a quasi-experimental study. All identified evaluations were empirical studies.

Sample size: Sample sizes varied greatly from a minimum of 153 to a maximum of over 1,000 participants.

Type of evaluation: Half the studies identified were cost effectiveness analysis (50%) and the other half were cost utility analysis (50%).

Type of interventions: The interventions assessed pertained to structures and processes of care/service delivery: four studies assessed the cost effectiveness of preventative home visits for monitoring the level of frailty and delaying entry into institutional care and five studies compared integrated multidisciplinary care to usual care management by a general practitioner (GP). One study compared interventions relating to the organisation of care; comparing different models of assessment for eligibility of aged care services.

Perspective of evaluations: 55% or six studies were undertaken from a societal perspective, one study each was undertaken from a health system and service provider's perspective. Two studies (18%) considered the public sector (both health and social care) perspective.
Considering that majority of studies were undertaken in Europe where most countries have universal health and social care, it is not surprising that most studies were undertaken from a societal perspective.

Time horizon: Most evaluations were conducted under one year (45%) and between one and two years (36%).

4.3.3 Quality assessment

This section reports on the results of the critical appraisal. Methodological issues identified were the exclusion of informal care costs when using a societal perspective (Bouman et al., 2008) and absence of sensitivity analysis to establish robustness of the base case analysis (Sandberg et al., 2015). Majority of economic evaluations were undertaken alongside clinical trials demonstrating the effectiveness of the intervention/s for the specified study periods (Flood et al., 2005, Bouman et al., 2008, Melis et al., 2008, Jutkowitz et al., 2012, Brettschneider et al., 2015, Fairhall et al., 2015, Sandberg et al., 2015, van Leeuwen et al., 2015b). Effectiveness of the intervention in two studies was demonstrated by a quasi-experimental study (Makai et al., 2014a, Looman et al., 2016). Costs and outcomes were identified, measured and valued then discounted at the appropriate rates (based on country where the study was undertaken) for all studies with time horizons beyond one year except one (Brettschneider et al., 2015). The ICER was not calculated in one study because there was no difference in costs and outcomes between the intervention and comparator (Sandberg et al., 2015). None of the included studies formally considered the impact upon carers either in relation to costs (time spent providing informal care (such as personal care and household tasks) or in relation to outcomes (carer's quality of life) (Goodrich et al., 2012).

Results of the critical appraisal assessment are presented in table 4.2.

Table 4.2: Critical appraisal of economic evaluations

Study reference	**Is the EE likely to be usable**			**How were costs and outcomes assessed and compared**						**Will the results help in purchasing for local people**		
	Q1 Well-defined question	**Q2** Comprehensive description of alternatives	**Q3** Evidence of effectiveness	**Q4** Important/ relevant outcomes and costs identified	**Q5** Outcomes and costs measured accurately in appropriate units	**Q6** Outcomes and costs valued credibly	**Q7** Discounting	**Q8** Incremental analysis of the outcomes and costs	**Q9** Sensitivity analysis	**Q10** Discussion of the results include issues that are of concern to purchasers	**Q11** Conclusion justified by the evidence presented	**Q12** Results applicable to local population
(Brettschneider et al., 2015)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
(Sandberg et al., 2015)	Yes	Yes	Yes	Yes	Yes	Yes	N/A	No	Yes	Yes	Yes	Yes
(Flood et al., 2005)	Yes	Yes	Yes	Yes	Yes	Yes	N/A	Yes	Yes	Yes	Yes	Yes
(Makai et al., 2014a)	Yes	Yes	Yes	Yes	Yes	Yes	N/A	Yes	Yes	Yes	Yes	Yes
(Looman et al., 2016)	Yes	Yes	Yes	Yes	Yes	Yes	N/A	Yes	Yes	Yes	Yes	Yes
(Bouman et al., 2008)	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
(Melis et al., 2008)	Yes	Yes	Yes	Yes	Yes	Yes	N/A	Yes	Yes	Yes	Yes	Yes
(Fairhall et al., 2015)	Yes	Yes	Yes	Yes	Yes	Yes	N/A	Yes	Yes	Yes	Yes	Yes
(van Leeuwen et al., 2015b)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
(Jutkowitz et al., 2012)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

The University of Glasgow economic evaluation checklist in appendix 4.2 was used. N/A=Not applicable

4.3.4 Data synthesis

Because of the disparity in the perspectives, health care systems, time horizons and interventions compared in the identified studies, a quantitative synthesis or meta-analysis was not possible. A narrative synthesis was undertaken and is provided in this section.

<u>Studies applying CUA methodology</u>

Five economic evaluations applied cost utility analysis methodology. One study evaluated the cost effectiveness of preventive home visits for community-dwelling older people in Germany (Brettschneider et al., 2015). Preventive home visits are designed to preserve functional ability and subsequently delay admission to nursing homes or residential aged care facilities. Another preventative program in Sweden was aimed at ensuring that older people's care needs are met through access to appropriate healthcare (Sandberg et al., 2015). The intervention in this program was case management; a comprehensive person-centred approach to care that involved the use of case managers to assess the older people's routine needs, develop care plans, care coordination and service provision. Both economic evaluations were undertaken alongside RCT using a societal perspective and time horizon of 18 months and 12 months respectively. Cost categories included were health care costs, costs from other sectors (community care costs including home care services, home health care services, respite care, personal safety alarm services, grocery delivery services), client and family costs as well as informal care costs (using opportunity cost method). The measure of outcome was the QALY based on the EQ-5D-3L and the UK adult general population scoring algorithm was applied. Both studies demonstrated that the intervention was not cost effective. Preventive home visits only had a 39% probability of cost effectiveness at a WTP value of €250,000/QALY (Brettschneider et al., 2015). Sandberg et al, 2005 found no significant differences in costs or quality of life between the intervention and usual care but the need for informal care declined in the intervention group (Sandberg et al., 2015).

Flood and colleagues conducted a CUA alongside a RCT to compare the cost effectiveness of occupational therapist led (OT) and social worker led (SW) assessment of the needs of older people in the UK (Flood et al., 2005). This study was conducted from a public-sector perspective (both health and social care costs were incorporated) with a time horizon of eight months. Quality of life (using the EQ-5D-3L) and levels of dependency were the measures of outcome. Occupational therapist led assessment was costlier than SW but both OT and SW assessments were equally effective. There was <50% probability that OT was cost effective at a WTP value of £14,000/QALY.

The final two studies in this category analysed the cost effectiveness of the Walcheren Integrated Care model (WICM) in the Netherlands (Makai et al., 2014a, Looman et al., 2016). Both studies were conducted alongside a quasi-experimental study over a 3-month period (Makai et al., 2014a) and 12-month period (Looman et al., 2016) using used a societal perspective; costs included were health care costs, social care costs, intervention costs and informal care costs. The outcomes in the first study were quality of life assessed using the EQ-5D-3L and the ICEpop CAPability measure for Older people (ICECAP-O). The second study applied the EQ-5D-3L at 0, 3 and 12 months. The Dutch population scoring algorithm was used in both studies. These two studies highlight the effect of the outcome measure on the results of an evaluation. There was no significant differences between WICM and usual care using the EQ-5D-3L, a measure of HRQoL but there was a higher probability of cost effectiveness based on the capability QALYs using the ICECAP-O, an older-person-specific measure of capability (Makai et al., 2014a). Even with a longer time horizon (12 months), no differences were observed in HRQoL using the EQ-5D-3L and WICM was found not to be cost effective (Looman et al., 2016).

Studies applying CEA methodology

As highlighted above, five studies applied CEA methodology for the economic evaluations. In the first study, Bouman et al. (2008) investigated the effects of a home visiting program where home nurses assessed older people for problems and risk factors for increased disability/frailty, offering referral to relevant professional and community services (Bouman et al., 2008). This program was compared with usual care where the clients self-referred to available services when needed. Clients were followed up for 24 months. Costs included health care costs and social care costs to reflect a broader perspective, although the costs attributable to informal caring were not included. Using self-rated health (on ten-point Likert type scale ranging from poor to excellent) as a measure of outcome, Bouman et al. (2008) found no difference between costs and outcomes for the intervention and usual care.

Two separate studies evaluated multidisciplinary interventions to reduce frailty among older people in the Netherlands (Melis et al., 2008) and in Australia (Fairhall et al., 2015). Both studies adopted the health system perspective and time horizon of 6 months and 12 months respectively.

Cost components included health and social care costs as well as direct intervention costs. The measures of outcome were successful treatment defined by improvement of functional performance in instrumental activities of daily living and mental wellbeing in the first study, and the level of frailty coupled with HRQoL measured using the EQ-5D-3L in the second study. The interventions were cost effective in both studies: at a WTP of €34,000/successful treatment and $50,000/extra person out of frailty respectively. Although Bouman et al. (2008) above and Melis et al. (2008) evaluated similar interventions in the same setting (population and country), these two CEA studies cannot be compared because different measures of outcome were applied. Similar to Makai et al. (2014) under CUA above, Fairhall et al. (2015) demonstrated the insufficiency of HRQoL measures when applied in assessing interventions for older people as they did not find any significant change in HRQoL between the intervention and control group using the EQ-5D-3L, and quality of life was not considered as an outcome measure in the analysis (Fairhall et al., 2015).

One study assessed the cost effectiveness of integrated care models aimed at improved coordination of older people's care between health and social care services, the Geriatric Care Model, alongside a randomised control trial in the Netherlands (van Leeuwen et al., 2015b). A societal perspective was applied. Four measures of outcome were considered; HRQoL based on the physical component and mental component scales (PCS and MCS) of the SF-12; QALYs based on the EQ-5D-3L (using a Dutch population value set) and functional limitations in activities of daily living based on the Katz basic activity of daily living scale. All measures were administered every 6 months over a 24-month period. There were no differences in all outcomes between the two alternatives but the intervention was costlier with program costs and informal care as key cost drivers. The nature of this intervention is like that assessed by Sandberg et al. (2015) who applied a CUA methodology and identified informal care as a key cost driver, but the intervention led to reduced use of informal care.

The last study evaluated the cost effectiveness of a home-based program, Advancing Better Living for Elders (ABLE) in the United States of America (USA). This program was aimed at reducing functional difficulties and mortality to help vulnerable older adults age in place through occupational and physical therapy as well as home modifications (Jutkowitz et al., 2012). The follow-up period for this study was two years using the service provider's perspective (only intervention/direct costs included) and life years saved (LYS) as a measure of outcome. Cost effectiveness was analysed under two scenarios: using actual program costs from data collected alongside the trial and where costs were elevated by 10% to reflect the real-world setting; ABLE was cost effective at WTP of $13,000/LYS in the trial and $14,800/LYS in the real-world setting.

4.4 DISCUSSION

In contrast to the large proliferation of economic evaluation studies conducted in health care, this systematic review has highlighted the paucity of economic evaluation studies conducted to date in the community aged care sector. The most prevalent types of economic evaluation methodologies applied were CEA and CUA. Measurement of outcomes in natural units is a limitation of CEA as this affects the comparability of results between studies. For instance, although the interventions were similar and the population of study was comparable in the two studies that evaluated multidisciplinary interventions to reduce frailty, the results could not be compared because the measures of outcome were different (Fairhall et al., 2015, Melis et al., 2008).

Unlike other types of analysis, CUA applies a generic measure of outcome the QALY, incorporating both quality of life and life years gained that reflects benefits beyond natural units and facilitates comparability between studies. As highlighted previously, a key issue for the conduct of economic evaluation for service delivery interventions in the aged care sector is identification of appropriate utility instruments that reflect the breadth of quality of life as defined by older people and benefits of the interventions beyond health status such as increased choice and control (Flood et al., 2005, Graybill et al., 2014, Makai et al., 2014b). Makai et al. (2014) in their evaluation of the cost effectiveness of integrated care among the frail elderly, found no change in quality of life using the EQ-5D-3L but significant positive change when measured using the ICECAP-O (Makai et al., 2014a). Similarly Flood et al. (2005) and Fairhall et al. (2015) observed no change in quality of life using the EQ-5D-3L (Flood et al., 2005, Fairhall et al., 2015). Specifically, none of the CUA studies demonstrated cost effectiveness of the intervention except one where the ICECAP-O was applied (Makai et al., 2014a). These authors commented on the low sensitivity of the EQ-5D, a measure of health-related quality of life, to changes in those domains of quality of life most highly valued by older people. It has been argued that to comprehensively reflect quality of life and benefits of service delivery interventions in older people, an instrument that not only measures health and physical functioning but also includes dimensions that are important to older people and that are affected by service delivery interventions is required (Hickey et al., 2005, Grewal et al., 2006, Coast et al., 2008a, Jutkowitz et al., 2012). Such an instrument defines health as a resource to help older people achieve their goals and facilitate social and physical participation and includes dimensions such as psychosocial functioning, feelings of independence, choice and control (Bowling, 1998, Bowling et al., 2002, Bilotta et al., 2010). Currently there is no guidance on the most appropriate instrument for this context. However, the systematic review of instruments suitable for use in economic evaluations involving older people following on in chapter 5 recommended the inclusion of health status and dimensions important to older people using broader older people-specific instruments such as the ASCOT and the ICECAP-O in combination with measures of HRQoL/health status such as EQ-5D.

A recent review of the inclusion of informal care in applied economic evaluation found that only a small proportion formally included informal care (Goodrich et al., 2012). Our findings were consistent with this review. Most studies applied the broader societal perspective although half of them did not include the costs associated with the provision of informal care. Informal care is integral to community aged care, its economic value is estimated at over $6.5billion (the equivalent of all high-end residential aged care paid for by the Australian Government) in Australia in 2010 (Deloitte Access Economics, 2015, Kehusmaa et al., 2013). Informal carers have an important, yet ambiguous, role in economic evaluation. The time spent providing informal care (such as personal care and household tasks) is a resource that is used up because of caring, and so carers should arguably be considered as a cost in economic evaluation. The carer’s quality of life, however, may also be affected by a person’s condition, and so outcomes for carers may also be relevant in an economic evaluation.

Omitting the costs associated with the provision of informal care when evaluating interventions in the aged care sector from a societal perspective may undervalue the cost of the service (Brouwer et al., 2005, Bouman et al., 2008, Ratcliffe et al., 2012b, Ratcliffe et al., 2013, Weatherly et al., 2014). However, the theory and methods for incorporating informal care have not yet been significantly researched and therefore this cost category is not systematically included in most economic evaluations (Goodrich et al., 2012). Within the CUA framework, a new instrument the Carer Experience Scale (CES) which has been specifically designed for carers to measure and value the impact upon caring associated with the introduction of new interventions may be particularly helpful (Al-Janabi et al., 2011, Goranitis et al., 2014). Another possible option is to move beyond assessment of quality of life within CUA and incorporate the wider impacts of an intervention upon the caring role in monetary terms within the framework of cost benefit analysis (Drummond et al., 2005a).

For studies investigating the cost effectiveness of care models such as integrated care models, the intervention was not found to be cost effective in the majority of cases (Brettschneider et al., 2015, Sandberg et al., 2015, Looman et al., 2016, van Leeuwen et al., 2015b). This was attributed to the short time horizon of between 12 to 24 months applied in these studies. A longer time horizon is recommended for service delivery interventions that involve the integration of various sectors and building of networks in service delivery such as in the community aged care sector. The time horizon should be sufficient to permit the intervention to go beyond the teething problems and adjustment phases to then observe the benefits attributed to the intervention (Simoens, 2009, McIntosh, 2011, Sandberg et al., 2015, Looman et al., 2016).

CONCLUSION

In contrast to the high prevalence of economic evaluations conducted in the health care sector, this systematic review identified that relatively few economic evaluations have been conducted to date in the community aged care sector. Although CEA was equally employed as CUA, the application of CEA is limited due to measurement of outcomes as natural units, which do not comprehensively reflect the quality of life benefits that older people may obtain from service delivery innovations in aged care. The exclusion of carer impacts has also been highlighted as an important omission. CUA is recommended as the preferred type of economic evaluation in the community aged care sector with the appropriate choice of instrument for the measurement and valuation of quality of life addressing quality of life domains that are important to older people. Future research should be directed towards developing methods and applications to facilitate the inclusion of carers effects in the economic evaluation of interventions for the community aged care sector.

Following on from identifying the preferred methodology for economic evaluation in this chapter, the next chapter investigates the most appropriate instrument/s to be applied in the measurement of quality of life outcomes among older people receiving community aged care services.

CHAPTER 5

A SYSTEMATIC REVIEW OF OUTCOME MEASURES FOR ECONOMIC EVALUATION IN AGED CARE

This chapter was aimed at identifying instruments that are suitable for measuring quality of life outcomes among older people receiving community aged care services. Firstly, it describes the different approaches used to measure and value quality of life with a specific focus on generic and population preference based and non-preference-based instruments. Secondly, it describes the methods and results of a systematic review to identify instruments used to measure quality of life outcomes in older people. Studies that met the following criteria were considered: 1) study population exclusively above 65 years of age; 2) measured quality of life outcomes as indicators of health status or HRQoL through use of an instrument; and 3) published in journals in the English language after 2000. The most commonly applied generic preference-based instrument was the EQ-5D-3L. Of the older people-specific instruments, the ICECAP-O was the most commonly applied instrument. In the absence of an ideal instrument, which considers the breadth of quality of life as defined by older people and suitable for application in a cost utility analysis framework, this review recommended the application of a generic preference-based HRQoL instrument (e.g. the EQ-5D) commensurate with the QALYs scale, together with the ICECAP-O or the ASCOT. The ASCOT was specifically designed for evaluating quality of life outcomes for social care interventions while the ICECAP-O is a measure of capability specifically designed for older people.

This chapter contains material from BULAMU, N. B., KAAMBWA, B. & RATCLIFFE, J. 2015. A systematic review of instruments for measuring outcomes in economic evaluation within aged care. Health and Quality of Life Outcomes, 13, 1-23

5.1 INTRODUCTION

Quality of life is defined by the World Health Organisation (WHO) as ‘an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns’ (WHOQOL Group, 1998). Largely, quality of life is multi-dimensional encompassing physical health and functioning, psychosocial and emotional wellbeing, independence, personal beliefs, material wellbeing and the external environment in terms of how it impacts on the individual’s development and activity (WHOQOL GROUP, 1993 , Felce and Perry, 1995). Quality of life outcomes in older people cannot be singularly attributed to improvements in health status because of the technical success of a surgical procedure or intervention but are also highly dependent upon the process of service delivery in both health and aged care settings. Aged care services and how they are delivered contribute greatly towards older people’s self-worth, independence and quality of life (Shekelle et al., 2001, Donabedian, 2005, Sangl et al., 2005).

The definition and perception of quality of life for older people is typically broad. It often goes beyond work, finance, physical abilities and health status to encompass psychological and social factors such as physical and cognitive independence, social interaction with family and community, feeling of self-worth and security (Bowling et al., 2002, Milte et al., 2014). In measuring the impact of interventions for older people, researchers are progressively recognising the central importance of the social realm of the individual and the importance of incorporating this aspect alongside the traditional key clinical outcomes of survival, physical health and functional ability (Bowling, 1998, Bowling et al., 2002, Bilotta et al., 2010). Potential social realm aspects of importance to older people include personal and neighbourhood social capital, social comparisons and expectations, personality and psychological characteristics such as levels of optimism-pessimism, and feelings of safety and security in their environment coupled with the ability to maintain their independence (Bowling et al., 2002, Milte et al., 2014, Sorenson, 2007). Instruments measuring health outcomes in older people should therefore not only focus on health as a product of receiving health and aged care interventions but incorporate measurement of the improvements in the social realm or increased role of health as crucial to their participation in activities of daily living and social interactions (Barker et al., 2005, Milte et al., 2014).

Since the early 1970s, researchers in many countries have developed a plethora of both generic and condition-specific instruments designed for measuring quality of life in adults, including older people. Instruments for measuring health status and/or quality of life outcomes are differentiated into preference-based and non-preference-based. Preference-based instruments combine a description of health and/or quality of life states and a scoring algorithm of the general population's "weighted" valuation of these states (based upon an aggregation of individuals' preferences for one state over another) (Neumann et al., 2000, Drummond et al., 2005d, Brazier et al., 2007c). Because non-preference-based instruments do not facilitate the calculation of QALYs, they are not suitable for application in CUA. However, non-preference-based instruments may be applied in other types of economic evaluation including CEA and CCA where the calculation of QALYs is not required.

The remaining part of this section describes the different instruments used to measure quality of life and the methods applied to elicit individual preferences for the multi-attribute utility or preference-based instruments. Section 5.2 describes the methods applied for the systematic review of literature while section 5.3 shows the results of the review. Section 5.4 is a discussion of the results and provides recommendations for the most suitable quality of life instruments to be applied among older people.

5.1.1 Preference-based instruments

These are often referred to in the health economics and health services research literature as multi-attribute utility instruments (MAUIs). Preference-based instruments are further differentiated into generic, condition-specific and population-specific instruments. Generic MAUIs are broadly focused and therefore suitable for application across all conditions. Examples of generic MAUIs include the EQ-5D, HUI, SF-6D, AQoL, the Quality of Wellbeing scale (QWB) and the 15-Dimensions (15D) (Drummond et al., 2005d, Brazier et al., 2007c, Brazier et al., 2007a). All generic MAUIs are comprised of two main elements. Firstly, a descriptive system for classifying all possible health states defined by the instrument and secondly an off the shelf scoring algorithm or value set comprising values (on the 0-1 dead full health QALY scale) for all possible health states defined by the instrument. The values are typically elicited from large general population surveys where individuals are asked to value a series of health states using one or more of the valuation methods detailed below.

Eliciting individual preferences or levels of utility for health states

a. **Visual Analogue Scale (VAS)** also referred to as the rating scale is typically represented by a vertical or a horizontal line with intervals from 0 to 1 or 0 to 100, upon which respondents indicate their level of value or feeling about a health and/or quality of life state. The two endpoints, 0 and 1 (or 0 and 100) represent the worst imaginable state and the best imaginable state respectively or death and full health as defined by different VAS scales (Brazier et al., 2007d, Drummond et al., 2005d, Brazier et al., 2007c). For example, QWB scale defines the VAS endpoints as dead (0) and full health (1) whilst the EQ-5D defines the endpoints as worst (0) and best imaginable state (100) to reflect the potential for some states to be considered as worse than death. The intervals between points are assumed to be equal and therefore the distance between states is interpreted as a representation of respondents' relative preferences for the given states.
   The VAS is relatively simple, easy to complete and cheaper to administer compared to the standard gamble (SG) or time trade-off (TTO) (Froberg and Kane, 1989, Drummond et al., 2005d). It has also been found to have inter-rater reliability and test-re-test reliability (Loudon et al., 2002, Gloth et al., 2003, Wagner et al., 2007). Criticism of the VAS is centred around its ability to elicit utilities or preferences. Robinson et al. (2001) has argued that it is direct, choice-less and risk neutral, where respondents express preference under conditions of certainty, contrary to the definition of utility where preferences are expressed under conditions of uncertainty (Robinson et al., 2001). The VAS is also susceptible to context effects where the value of a given state is influenced by other states being valued and not necessarily measured against the 0 and 1 end points (Robinson et al., 2001). Brazier et al. (2007) contend that using the VAS may predispose respondents to response spreading where health and/or quality of life states are placed across the entire scale or only on a given portion of the scale irrespective of their differences or similarities. They also argue that overall, the VAS measures changes in health and/or quality of life status as opposed to the satisfaction or utility obtained as a result of changes in health and/or quality of life status and therefore it elicits percentages as opposed to preferences (Brazier et al., 2007d).

b. **Standard Gamble (SG):** With the SG, respondents determine their preference between two possible scenarios. Scenario 1 is the certainty of living in an impaired state of health and/or quality of life (*h*) for a given period (*t years*) while scenario 2 is uncertain: a gamble with a probability (*P*) of returning to full health for that period (*t years*) and a probability (*1-P*) of death. The probability is varied until the respondent is indifferent between scenario 1 (the certain health state) and 2 (the gamble). Preference is determined at this point and the probability *P* is the utility for the certain health and/or quality of life state (Torrance, 1986, Neumann et al., 2000, Brazier et al., 2007d, Drummond et al., 2005d). For chronic conditions considered worse than death, scenario 1 is the certainty of dying or death and the gamble in scenario 2 is a probability *P* of regaining full health for the remainder of a respondent's life (*t years*) and probability *1-P* of remaining in the chronic health and/or quality of life state for the *t years* (Brazier et al., 2007d). Preference for the chronic state is obtained at the point of indifference as *–P/(1-P).*

Since health conditions are characterised by risk and uncertainty, the standard gamble has been advocated as the preferred method for elicitation of utilities in health care (Patrick et al., 1994, Drummond et al., 2005d). It has been used to generate utilities for a number of instruments such as the HUI3 and SF-6D. Good response and completion rates have been reported for the SG, it is feasible and acceptable for use in various patient groups and disease areas and its reliability has also been reported (Ross et al., 2003, Brazier et al., 2007d). Its theoretical basis in expected utility theory qualifies the SG for use in eliciting preferences and subsequent calculation of QALYs in economic evaluations (Brazier et al., 2007d).

c. **Time Trade-Off (TTO):** This approach on the other hand has preferences of one health state over another expressed based on time spent in each of the states. In the TTO respondents choose between a paired comparison; living in a given impaired health state for a period t or in full health for a period x, where x is less than t. Time x is varied to the point of indifference between the alternatives and the utility is calculated as x/t (Torrance, 1986, Neumann et al., 2000, Brazier et al., 2007d, Drummond et al., 2005d). For states considered worse than dead, the alternatives are immediate death and living in that state for a given period (*y*) followed by full health for a limited time (*x*). The times *x* and *y* are varied until the point of indifference (Torrance, 1986, Brazier et al., 2007d).

The TTO is argued to be practical, reliable and acceptable (Torrance, 1982, Torrance, 1986, Neumann et al., 2000, Brazier et al., 2007d). However, its applicability in medical decision-making has been questioned due to the certainty of the alternatives being compared (Mehrez and Gafni, 1991, Green et al., 2000). It is argued that an individual's values using the TTO are affected by time preference where a greater value is given to time in the near future than in the distant future (Brazier et al., 2007d). In addition, health states may have a maximum endurable time after which respondents' utility become negative or a minimum survival time within which respondents will not choose them over their remaining life expectancy. As such, utility values obtained for a condition with a time duration *t* may not be the same when the time duration is different. Just like SG, there is no lower limit to values that can be obtained for conditions that are considered worse than death (Torrance, 1986, Neumann et al., 2000, Drummond et al., 2005d). To address this anomaly, Torrance proposed a rescaling of values obtained for states worse than death by the TTO to assign a value of -1 to the worst possible state (Torrance, 1984, Patrick et al., 1994). More recently, other researchers have suggested the use of other variants of TTO, lead-time or lag-time TTO for health states that are worse than dead to allow for values which extend beyond -1 (Robinson and Spencer, 2006, Devlin et al., 2011, Augustovski et al., 2013).

d. **Discrete Choice Experiments (DCE):** Preferences for health states can also be elicited using DCEs (Lancsar and Louviere, 2008, Gu et al., 2013, Bansback et al., 2012). Traditionally, DCEs have been used to measure and value characteristics associated with the process of health or aged care service delivery but increasingly they are being used to value health states (Chakraborty et al., 1994, Jan et al., 2000, Morgan et al., 2000, Hall et al., 2004). A DCE is a technique for eliciting individual preferences in the absence of revealed preference data. In the context of health state valuation, respondents choose between two or more multi-attribute alternatives/scenarios/health states in a choice set (Mangham et al., 2009). Choice sets are groups of alternatives that are defined by their salient characteristics or attributes and respondents indicate their preferred alternative in each choice set. Using the DCE methodology encourages respondents to reflect upon the trade-offs they are willing to make between attributes and their respective levels and their relative importance. It is assumed that individuals choose the alternative that maximises benefit or utility (Hall et al., 2004, Mangham et al., 2009). To reduce the cognitive burden associated with the valuation of health states using DCE’s when used in vulnerable population groups such as older people and children, a particular type of DCE known as profile case best-worst scaling has been proposed (Flynn et al., 2008, Ratcliffe et al., 2012a). In this approach, respondents choose the best and worst attribute levels of a single given health state rather than choosing between competing health states. Compared to the TTO and SG approaches to health state valuation, DCEs are arguably more straight forward and more easily relate to real world decision making and are therefore potentially easier for respondents to understand and complete (Mangham et al., 2009, Bansback et al., 2012, Gu et al., 2013).

Generic preference-based instruments

a. The **EQ-5D** is a multi-attribute utility instrument that measures health status and HRQoL according to five principal dimensions; mobility, self-care, usual activities, pain/discomfort and anxiety/depression (EuroQol Group, 2014). There are two main versions of the instrument. The EQ-5D 3 levels (EQ-5D-3L) was developed in the early 1990's and comprises three levels for each of the five dimensions (no problems/limitations, some problems, and severe problems), generating a total of 243 possible health states. The EQ-5D 5 levels (EQ-5D-5L) was developed more recently and comprises five levels for each of the five dimensions (no problems, slight problems, moderate problems, severe problems and unable to/extreme problems) generating a total of 3125 health states (Herdman et al., 2011). The EQ-5D-3L has been translated into many languages and several different scoring algorithms are available for the instrument (*refer to table 5.1*). It has been valued by a general population sample in a number of countries including the UK and Spain (using a variant of the VAS and TTO), the Netherlands (using the VAS) and USA (using the TTO) (Brazier et al., 2007a). To date, scoring algorithms for the EQ-5D-5L have been developed based on populations in Uruguay, Netherlands, England, Canada, Korea and South Australia (Augustovski et al., 2015, Kim et al., 2016, Xie et al., 2016, Versteegh et al., 2016, Devlin et al., 2018, McCaffrey et al., 2016).

b. The **Health Utilities Index** is a measure of HRQoL developed in three versions: the HUI Mark 1 (HUI1) was originally developed for use in neonatal intensive care but was succeeded by HUI Mark 2 (HUI2) for use in childhood cancer and now more generally used for the economic evaluation of interventions in childhood (Horsman et al., 2003). The HUI Mark 3 (HUI3) was developed from HUI2 for application with adults. The HUI2 has seven dimensions: sensation, mobility, emotion, cognition, self-care, pain and fertility, with 3-5 levels and defines 24,000 health states (Brazier et al., 2007a). The HUI3 on the other hand has eight dimensions: vision, hearing, speech, ambulation, dexterity, emotion, cognition and pain, with 5-6 levels and defines 972,000 health states (Furlong et al., 2001, Horsman et al., 2003). Scoring algorithms exist for HUI2 based on a general population adult sample in the UK (using the VAS then mapped onto the SG) and for HUI3 based on adult population samples from Canada and France using the VAS (Horsman et al., 2003). Both the HUI2 and the HUI3 have additionally been valued by general population samples in Australia, USA and Uruguay (Horsman et al., 2003).

c. The **SF-6D** is a preference-based form of the Short Form-36 designed to measure six dimensions of health status: physical functioning, role limitation, social functioning, pain, mental health and vitality (SF-36.org, 2014, Brazier et al., 2002). There are two versions of the SF-6D, one developed from the SF-36 defining 18,000 health states and one from the SF-12 defining 7500 health states. Using the SG approach, the SF-6D has been valued by a UK general population sample and scoring algorithms have also been obtained from populations in Japan, Hong Kong, Australia and Brazil (Brazier et al., 2002, Brazier et al., 2007a). The SF-6D cannot be used as a stand-alone instrument, it is used to generate QALYs from patient level data obtained using the SF-36 or SF-12 (Ferreira et al., 2013) by applying an algorithm developed by Ara and Brazier (Ara and Brazier, 2008, Mangham et al., 2009)

d. The **AQoL** is a generic preference-based instrument developed to measure and value HRQoL for application in economic evaluation. There are four versions of the AQoL developed to date, distinguished by the number of dimensions or attributes included within each version of the instrument (as illustrated in table 5.1) (Hawthorne et al., 2000). The eight dimensions version or AQoL-8D measures independent living, happiness, mental health, coping, relationships, self-worth, pain and senses. The version with seven dimensions or AQoL-7D measures independent living, mental health, coping, relationships, pain, senses and visual impairment; while the six dimensions version or AQoL-6D measures all the above except visual impairment. The four dimensions version or AQoL-4D measures independent living, mental health, relationships and senses (Assessment of Quality of Life, 2014). The AQoL instrument contains the most comprehensive descriptive system of all existing generic preference-based instruments and produces several millions of health states regardless of the version (Hawthorne et al., 2000). Scoring algorithms based on an Australian general population sample have been generated using TTO (Hawthorne et al., 2000).

e. **Quality of wellbeing scale (QWB**) is one of the oldest MAUIs developed in the 1970s. It has three multilevel function dimensions: mobility, physical activity and social activity and a list of 27 symptom and problem complexes. The function dimensions produce a total of 46 functional levels which when combined with the symptom complexes generate 945 health states (Brazier et al., 2007a). This instrument is administered by an interviewer and was valued by a general population sample in San Diego, USA using the VAS (Kaplan et al., 1997). A shorter and self-administered version, QWB-Self-administered (QWB-SA), was developed in 1996 (Kaplan et al., 1997, UCSD

Health Services Research Center, 2014).

f. A health state descriptive questionnaire, the **15D**, measures 15 dimensions of health status; health-mobility, vision, hearing, breathing, sleeping, eating, speech, elimination, usual activities, mental function, discomfort and symptoms, depression, distress, vitality and sexual activity (Sintonen and Pekurinen, 1993). Each dimension of the 15D has five levels to generate over a billion health states. This instrument is self-administered and has been valued using the VAS by an adult general population sample in Finland (Brazier et al., 2007a).

Population-specific preference-based instruments

These have been designed for use with a single population group e.g. children or older people. Examples of population-specific preference-based instruments include the HUI2 (Furlong et al., 2001) and the Child Health Utility 9D (CHU-9D) (Stevens, 2009, Stevens and Ratcliffe, 2012) for children and adolescents, the ASCOT designed to measure quality of life for individuals receiving social care in community and institutional settings (Netten et al., 2012a) and the older people-specific measure of capability ICECAP-O (Coast et al., 2008b). Only the ASCOT and the ICECAP-O, instruments that are suitable for use in older people, will be emphasised in this section.

a. The **ASCOT** is a preference-based multi-attribute utility instrument developed in the UK. It has 8 domains or attributes namely; Personal cleanliness and comfort, Accommodation cleanliness and comfort, Food and drink, Safety, Social participation and involvement, Occupation, Control over daily life and Dignity (Netten et al., 2012a). Each attribute has three to four levels depending on the version applied representing increasing decrements: (1) the attribute was experienced at the level the person wanted, (2) the attribute sometimes falls below the wanted level, and (3) the attribute is always at a low level. Utility weights for the ASCOT were obtained from a UK general population sample of older people. Variants of the ASCOT used in different settings include the four-level self-completion tool (SCT4 – a four-level self-report version for use in community settings), four-level interview schedule (INT4 – a four-level interview version used in community settings), the four-level self-completion tool for family/friend (unpaid) carers (Carer SCT4) and four-level interview schedule for family/friend (unpaid) carers (Carer INT4) (Netten et al., 2011).

b. The **ICECAP-O** is an older people-specific preference-based instrument that measures different attributes of capabilities in older people (Flynn et al., 2011, University of Birmingham, 2014). The ‘capability approach sees human life as a set of “doings and beings”–we may call them “functionings”–and it relates the evaluation of the quality of life to the assessment of the capability to function’ (Sen, 2003). The ICECAP-O measures capability across five key domains; Attachment (love and friendship), Security (thinking about the future without concern), Role (doing things that make you feel valued), Enjoyment (enjoyment and pleasure) and Control (independence) (Flynn et al., 2011, University of Birmingham, 2014). Unlike other instruments that are mainly focused on health status, the ICECAP-O explores older individuals’ ability to perform or function and its influence on quality of life (Coast et al., 2008b). General population values have been obtained for the ICECAP-O using a population of older people in the UK and in Australia based on the best-worst scaling approach anchored on a 0-1 scale, with 0 for no capabilities and 1 for full capability with death as a state of no capability (University of Birmingham, 2014, Coast et al., 2008b). Translations of the ICECAP-O are available in German, Spanish, Dutch, Welsh and Swedish (University of Birmingham, 2014). Although the ICECAP-O generates preference scores, these are not anchored on the death-full health scale and therefore cannot generate QALYs for use in economic evaluations. Rowen et al. (2015) have proposed mapping and hybrid models that can generate QALYs from preference data elicited using DCEs such as that of the ICECAP-O (Rowen et al., 2015).

Table 5.1 summarises the most commonly applied preference-based instruments internationally and the countries for which scoring algorithms have been generated for each instrument.

Table 5.1: Preference-based instruments

Instrument	Dimensions	Levels	Valuation	Scoring algorithms
Generic preference-based instruments				
EQ-5D*	mobility, self-care, usual activities, pain/discomfort and anxiety/depression	3/5	TTO and VAS	Adult general population samples from several countries including Australia
HUI2	sensation, mobility, emotion, cognition, self-care, pain and fertility	3-5	VAS and SG	Canada (age groups 5-37, 12-16, 8-16), USA (18-89), Australia (15+), UK (general population) and Uruguay (8-17 age group)
HUI3	vision, hearing, speech, ambulation, dexterity, emotion, cognition and pain	5-6	VAS	
SF-6D	physical functioning, role limitation, social functioning, pain, mental health and vitality	4-6	SG	Adult general population samples from UK, Japan, Hong Kong, Australia, Brazil.
AQoL**	independent living, happiness, mental health, coping, relationships, self-worth, pain and senses.	4-6	TTO	Australia (adult general population sample).
QWB	mobility, physical activity and social activity	Multi-level	VAS	USA (adult general population sample).
15D	health-mobility, vision, hearing, breathing, sleeping, eating, speech, elimination, usual activities, mental function, discomfort and symptoms, depression, distress, vitality and sexual activity.	5	VAS	Finland (adult general population sample).
Population-specific preference-based instruments				

Instrument	Dimensions	Levels	Valuation	Scoring algorithms
ASCOT***	Personal cleanliness and comfort, Accommodation cleanliness and comfort, Food and drink, Safety, Social participation and involvement, Occupation, Control over daily life and Dignity.	3	BWS and TTO	UK (adult general population sample)
ICECAP-O	Attachment, Security, Role, Enjoyment and Control	4		UK

**A new 5 level version of the EQ-5D was launched in January 2014 (Herdman et al., 2011).*
***Four instruments based on the number of dimensions: AQOL-4D, -6D, -7D and -8D (Assessment of Quality of Life)*
****Variants of ASCOT include SCT4, INT4, the Carer SCT4 and Carer INT4 (Netten et al., 2011)*
TTO=Time trade-off, VAS=Visual analogue scale, SG=Standard gamble BWS=Best worst scaling

5.1.2 Non-preference-based instruments

These instruments provide descriptions or classifications of different health and/or quality of life states but do not attempt to capture individuals' preference for one health state over another. These are instruments whereby simple summative scores are assigned to the different health and/or quality of life states (Brazier et al., 2007b, Drummond et al., 2005e).

Generic non-preference-based instruments

Generally, non-preference-based instruments are not recommended for measuring outcomes in economic evaluation where utility is a primary outcome, as they simply describe the individual's condition with no indication of the level of preference for one health and/or quality of life state over another. Therefore, they cannot be used to calculate QALYs (Drummond et al., 2005e, Brazier et al., 2010). Results are generated as attribute specific scores that cannot be compared across different interventions or programs (Drummond et al., 2005e, Brazier et al., 2010).The most commonly/widely used generic non-preference-based instruments include the Short Form 36 items (SF-36), Short Form 12 items (SF-12), World Health Organisation brief quality of life instrument (WHOQoL-Bref) and the Nottingham Health Profile (NHP) (Brazier et al., 2010).

a. The **SF-36** measures health status or health profile across eight attributes: physical functioning (10 items), Role - physical (four items), Bodily pain (two items), General health (five items), Vitality (four items), Social functioning (two items), Role - emotional (three items) and Mental health (five items) (SF-36.org, 2014, Quality Metric, 2014). The **SF-12** is a shorter version of the SF-36 that includes 12 items. Both the SF-36 and SF-12 can be aggregated into two summary scales, the Physical Component Summary (PCS) and the Mental Component Summary (MCS) (SF-36.org, 2014).

As noted above, it is possible to convert SF-36 and SF-12 responses into utilities and subsequently generating QALYs by applying the SF-6D scoring algorithm (Ara and Brazier, 2008, Mangham et al., 2009). This algorithm utilizes already generated dimension scores converting them into preference-based scores, enabling its use in the absence of patient level data and retrospectively for published studies/results.

b. The **WHOQoL-Bref** contains 26 multiple-choice questions, measuring four attributes of quality of life: physical characteristics (activities of daily living - ADL, dependence on medicines and medical aids, energy and fatigue, mobility, pain and discomfort, sleep and rest, working capacity), Psychological aspects (self-image of body and appearance, negative feelings, positive feelings, thinking, learning, memory and concentration), Social relationships (personal relationships, social support, sexual activity), Environmental circumstances (financial resources, freedom, physical safety and security, health and social care: accessibility and quality, home environment opportunities for acquiring new information and skills, participation in and opportunities for recreation/leisure activities, physical environment, transport) (WHOQOL Group, 1998, World Health Organisation, 1999).

c. The **NHP** consists of two sections that can be self-completed by the individual; the first section focuses on health and consists of 38 items and six subheadings (energy, pain, emotional reactions, sleep, social isolation, and physical mobility). The second section, which is often omitted in other measures of health status, focuses on general life and comprises seven items (occupation, housework, social life, family life, sexual function, hobbies and holidays) (Hunt et al., 1980, Wiklund, 1990, IN-CAM Outcomes Database, 2014).

Table 5.2 is a summary of some of the mostly commonly used non-preference-based instruments.

Table 5.2: Generic non-preference-based instruments

Instrument	**Dimensions**	**Levels**
SF-36	Physical functioning, Role - physical, Bodily pain, General health, Vitality, Social functioning, Role - emotional and Mental health	2-6
SF-12	Physical functioning, role limitations, bodily pain, general health perceptions, vitality, social functioning, role limitations because of emotional problems, general mental health or psychological distress and psychological wellbeing	3-6
WHOQoL-Bref	Physical characteristics, Psychological aspects, Social relationships and Environmental circumstances	6
NHP	Health; energy, pain, emotional reactions, sleep, social isolation, and physical mobility and General life; occupation, housework, social life, family life, sexual function, hobbies and holidays	2

Population (older people)-specific non-preference-based instruments

These are non-preference-based measures of quality of life designed specifically for use among older people.

a. The **WHOQOL-Old** is a quality of life questionnaire developed from the generic WHOQoL-100 questionnaire specifically for use in older people (aged 60 years or above). WHOQoL-Old has been translated into various languages and is applicable in several cultures (WHOQOL Group, 1998, Power et al., 2005). It has six domains or facets with four items in each facet (24 items); sensory functioning, autonomy, past-present-future activities, social participation, death and intimacy. Respondents score themselves using five levels with higher scores indicating a higher quality of life. The developers recommend that it is used in combination with the WHOQoL-BREF or the World Health Organization Quality of life instrument (WHOQoL-100) (Power et al., 2005). Three shorter versions of the WHOQoL-Old have been developed, each having only six items, one item per domain, as opposed to the original 24 items (Fang et al., 2012). All three versions are recommended and researchers are free to choose the version of the instrument which best fits their study needs.

b. The **OPQOL** was developed based on a quality of life survey among community dwelling and ethnically diverse older people in Britain as a 50-item questionnaire which was then reduced to 35 items after a pilot study to assess its validity and acceptability (Bowling, 2009). It consists of questions/statements relating to an individual's life overall (four items), health (four items), social relationships and participation (eight items), independence, control over life, freedom (five items), and area: home and neighbourhood (four items), psychological and emotional wellbeing (four items), financial circumstances (four items), and religion/culture (two items). Each of the questions has five levels or possible response categories "strongly disagree", "disagree", "neither agree nor disagree", "agree" and "strongly agree", with a score of 1 to 5. As such, the OPQOL has a best possible QoL score of 175 and a worst possible QoL score of 35. The developers of the OPQOL have indicated that it is suitable for use in cognitively normal older people and in those with mild to moderate dementia (Bowling, 2009). A shorter 13 item version, the OPQOL-Brief was developed by asking older people in the UK to choose the most important items out of the 35 in the longer version (Bowling et al., 2013). OPQOL-Brief is suitable for assessing the quality of life of older people where a brief measure is required.

c. The **CASP-19** (Control Autonomy Self-realization and Pleasure) is a 19-item Likert-scaled index measure of subjective wellbeing in old age based on the needs-satisfaction model (Higgs et al., 2003, Hyde et al., 2003). It was first developed for use in social care in the UK. CASP-19 has 4 domains, 'control' (items C1-C3), 'autonomy' (A1-A5), 'pleasure' (P1-P3) and 'self-realization' (SR1-SR5). Scores obtained range from 0–57 with higher scores indicating a better QOL (Higgs et al., 2003, Hyde et al., 2003). A shortened version which combines the 'control' and 'autonomy' domains, the CASP-12 was developed in 2008 (Wiggins et al., 2008).

Table 5.3 summarises older person-specific instruments described above.

Table 5.3: Older people-specific instruments

Instrument	Dimensions	Levels
WHOQoL-Old*	Sensory functioning, autonomy, past-present-future activities, social participation, death and intimacy	5
OPQOL**	life overall, health, social relationships and participation, independence, control over life, freedom, and area: home and neighbourhood, psychological and emotional wellbeing, financial circumstances, and religion/culture	5
CASP 19	Control, Autonomy, Self-realization and Pleasure	4

** Three shorter versions exist, each having only six items, one item per domain ** OPQOL-Brief is a shorter 13 item version*

5.1.3 Instruments suitable for use among older people in different contexts

To date, quality of life has been measured among older people in many different contexts including e.g. before, during and after the receipt clinical and surgical interventions, in rehabilitation and aged care settings as well as epidemiological type studies which have measured the impact of ageing and living conditions on quality of life. However, little guidance is currently available as to which instruments are most appropriate and in what contexts.

In 2005 Hickey and colleagues conducted a systematic review to identify instruments used to measure HRQoL in older people (Hickey et al., 2005). Studies undertaken to measure HRQoL in populations described as older or elderly (no age limits were set) and published between 1992 and

August 2003 were sourced from MEDLINE, PsycInfo, CINAHL and web of Science. The most commonly used instrument was the SF-36. None of the studies identified in this review used older person specific instruments. The authors noted that existing instruments for measuring HRQoL emphasized physical functioning, which may not be accurate and sensitive to the needs of older people with reduced physical functioning, leading to a poor assessment of their quality of life. Although cognisant of the generalizability of results obtained by generic instruments across population groups, the review argued for the development of instruments that incorporate items that are relevant to older people as these would be more sensitive in the measurement of older people's quality of life (Hickey et al., 2005).

Another review conducted in 2003 evaluated the measurement and practical properties of multi-attribute generic measures of health used in evaluations conducted among older people (60 years and over) between 2002 until September 2003 (Haywood et al., 2005b). This search was conducted in the PHI database (includes Embase, Medline and the System for information on grey literature-SIGLE). Several instruments were applied in the different settings of care for older people: community, primary care, hospital, day care and residential institutions. Most evidence for reliability, responsiveness and validity was found for the SF-36, the EQ-5D-3L and the NHP respectively.

A similar review to identify older people-specific instruments with measurement and practical properties suitable for the measurement of HRQoL in older people identified 18 instruments (Haywood et al., 2005a). Most evidence for reliability, validity, responsiveness, precision and acceptability was found for the OARS Multidimensional Functional Assessment Questionnaire (OMFAQ), Comprehensive Assessment and Referral Evaluation (CARE), Functional Assessment Inventory (FAI) and Quality of Life Profile – Seniors Version (QOLPSV). However, the authors established that the evidence found was not sufficient for them to recommend any of the instruments as highly reliable and responsive for use in older people (Haywood et al., 2005a).

More recently, a systematic review was undertaken to identify generic outcome measures of HRQoL and wellbeing suitable for application in economic evaluations of interventions in older people in long-term care (Makai et al., 2014b). Databases including Pubmed, Embase and CINAHL, Psycinfo, Econlit and Web of Science were searched for studies published between 2000 and June 2012. Instruments were assessed for their feasibility in this population as well as their psychometric properties. They identified four wellbeing instruments that measure benefits of both health and social care in older people; the Ferrans and Powers Quality of Life Index and the WHOQoL-OLD, ICECAP-O and the ASCOT (Makai et al., 2014b). Although not as widely validated due to their relatively recent development, and not very strong in measuring health consequences compared to the other two, only the ICECAP-O and ASCOT were found suitable for use in CUA in long-term care because they have preference weights attached to them. However, the authors recommended their use in combination with either the EQ-5D-3L or SF-6D to capture the health benefits.

This current systematic review was undertaken to build upon work done by Makai et al. (2014), considering the two-year period beyond June 2012 and emphasizing the contexts in which quality of life was assessed in addition to the measurement properties of the instruments used. The context was relevant in this review to guide selection of the of the most appropriate instrument to be applied in subsequent studies conducted in this thesis (chapter 6 and 7) that assessed quality of life of older people receiving services in the community aged care sector.

The three objectives of this review were to:

- identify instruments applied in the measurement of quality of life outcomes for older people
- identify the different contexts in which the instruments have been used
- discuss appropriateness and suitability of the different instruments for use in assessing quality of life outcomes of service delivery innovations in community aged care.

5.2 METHODS

5.2.1 Database sources

Online databases searched were CINAHL, Embase, informit, Medline, Proquest, PsycInfo, PubMed, Scopus and Web of science.

5.2.2 Search terms

Five major concepts were considered to generate appropriate subject headings and keywords based on the objectives of this review: the population (older people aged 65 years and over), quality of life, the contexts in which quality of life was assessed, and validity of the instruments. The full search strategy applied in Medline is available in *Appendix 5.1*.

5.2.3 Selection criteria

Studies included met the following criteria:

- measured quality of life and/or health status and/or HRQoL as a primary or secondary outcome, cross-sectional or longitudinal/change over time
- used a generic preference-based measure or older people-specific preference-based or a non-preference-based quality of life measure or both
- in a population of dependent older people (exclusively aged 65 years and over), receiving community aged care services or in residential aged care facilities, and
- published between 2000 and November 2016 in peer reviewed journals in the English language.

Commentaries, conference papers, review articles and dissertations were not included.
Articles (20%) were independently assessed by two other reviewers and overall agreement was calculated using Cohen's kappa statistic (Cohen, 1960).

5.3 RESULTS

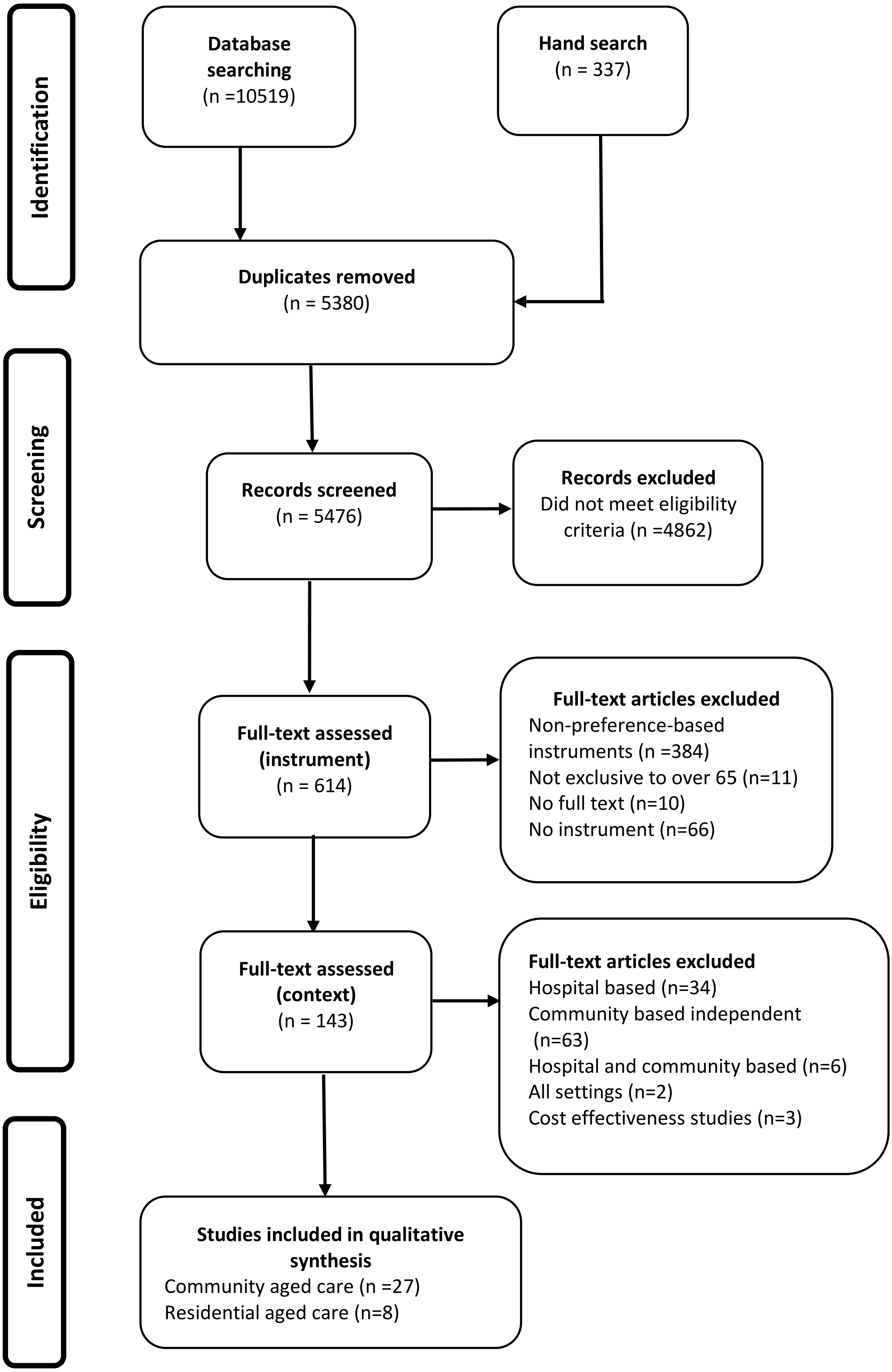
5.3.1 Study selection process

Figure 5.1 below illustrates the four stages of the study selection process:

i. **Identification:** 10,519 studies were identified from the online databases; 337 studies were identified from backward and forward search and basic internet search using the key words. 5,380 duplicate studies were eliminated.
ii. **Screening:** 5,476 titles and abstracts were screened for eligibility; 4,862 titles and abstracts were excluded
iii. **Eligibility:** 614 full text articles were assessed for eligibility. Full text could not be obtained for 10 studies and 461 studies did not meet the eligibility criteria. A further 107 studies were eliminated based on the context in which they were undertaken. An average kappa statistic of 0.81 was obtained for the level of agreement between reviewers.

iv. **Included:** Thirty-six studies met the inclusion criteria and were considered in the qualitative synthesis. Of these, 27 were studies undertaken in a population of dependent older people receiving community aged care services and eight studies were undertaken among older people receiving residential aged care services.

Figure 5.1: Study selection process

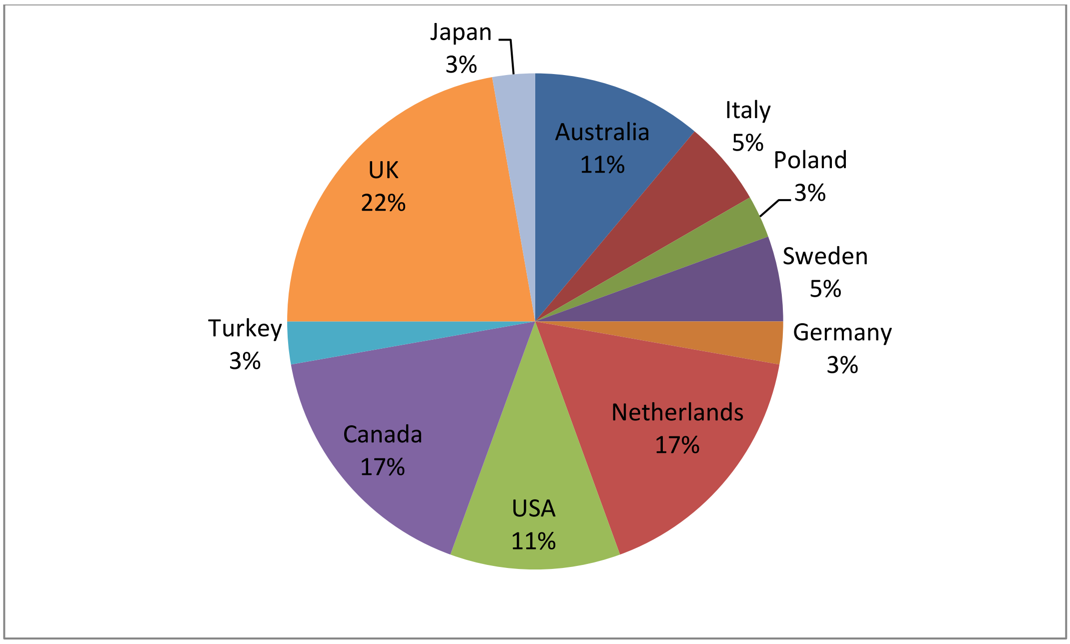


5.3.2 Study characteristics

Geographically, the research areas were diverse with eight studies from the UK, six each from Canada and the Netherlands and four studies each from Australia and USA. Figure 5.2 below shows the geographical distribution of the studies.

Details of the studies included in this review are provided in Appendix 5.2

Figure 5.2: Geographical distribution of identified studies



Twenty-two (61%) studies were undertaken using a cross-sectional design, six (17%) were randomised control trials, three (8%) were prospective studies and another three (8%) explorative surveys. There was one longitudinal study and one case control study. There was substantial variation in the sample sizes, varying from 10 to a maximum of 29,935 older people. Table 5.4 summarises the sample size distributions of the included studies.

Table 5.4: Sample size distribution

Sample size	**Frequency**	**Percentage**
1-100	7	20
101-200	7	10
201-300	5	14
301-400	7	20
401-500	3	9
501-1000	4	11
>1000	2	6
Total	**35**	**100**

5.3.3 Key findings 1: Contexts and settings

The context of the studies was determined based on the characteristics of the study population and the service or intervention under consideration. Four study contexts were identified: the health care sector; residential aged care sector; community sector/independent older people and community sector/dependent older people. In consideration of the main objectives previously highlighted, this review focused upon studies among community-dwelling dependent older people (needing some assistance to perform activities of daily living through the receipt of informal care and/or community aged care services) and those receiving residential aged care services.

a. **Community living dependent older people:** Twenty-seven studies were identified in this context; ten studies conducted in dependent older people who did not report any prevailing condition (Borowiak and Kostka, 2004, Maxwell et al., 2009, McPhail et al., 2009, Malley et al., 2012, Makai et al., 2013, van Leeuwen et al., 2014, Woolham et al., 2016, Kaambwa et al., 2015a, Comans et al., 2013, Forder and Caiels, 2011), nine among older people with cognitive impairment (Andersen et al., 2004, Kavirajan et al., 2009, Kleiner-Fisman et al., 2010, Kunz, 2010, Naglie et al., 2011a, Naglie et al., 2011b, Oremus et al., 2014, Orgeta et al., 2015, Davis et al., 2016) and eight studies were conducted among frail older people but cognitive status was not specified (Zhang et al., 2006, Bilotta et al., 2010, Bilotta et al., 2011, Theeke and Mallow, 2013, van Leeuwen et al., 2015a, van Leeuwen et al., 2015d, Kojima et al., 2016, van Leeuwen et al., 2015c). One study was conducted in a sample of older people with a history of stroke (Vahlberg et al., 2013).

b. **Residential aged care context:** Nine studies were conducted in this context; three studies included residents with cognitive impairment (Makai et al., 2012, Devine et al., 2014, Yamanaka et al., 2013) and in four studies participants were recruited from the general resident population at the facility (Sitoh et al., 2005, Netten et al., 2012c, Top and Dikmetas, 2015, Torma et al., 2015).

5.3.4 Key findings 2: Instruments used to measure quality of life in the aged care sector

Generic preference-based instruments were applied in 69% of the studies. The most prevalent instrument was the EQ-5D-3L used alone in 31% of studies and in combination with other instruments in 36% of the studies. Other generic instruments used were the ASCOT, HUI2/3 and SF-6D. Older people-specific instruments were used in the remaining studies; the most prevalent being the preference-based ICECAP-O used in five (17%) of studies. The OPQOL was applied in four (11%) of the studies. Table 5.5 summarises the instruments applied.

Table 5.5: Instruments used in the identified studies

Instruments used	**Number of studies**			
Instrument	**Community**	**Residential**	**Total**	**Percentage**
EQ-5D-3L	7	4	11	31
ASCOT	2		2	6
HUI2/3	4		4	11
EQ-5D-3L+ASCOT	3	1	4	11
EQ-5D-3L+QWB+HUI3	2		2	6
EQ-5D-3L+ASCOT+ICECAP-O	2		2	6
EQ-5D-3L+ASCOT+OPQOL	1		1	3
EQ-5D-3L+ICECAP-O	3	1	4	11
CASP-12/19	1		1	3
OPQOL	3		3	9
WHOQOL-OLD		1	1	3
Total	**28**	**7**	**35**	**100**

As highlighted above the most commonly used generic preference-based instruments in both community and residential aged care was the EQ-5D-3L and the most popular older people-specific instruments were the ICECAP-O and OPQOL in community aged care and the ICECAP-O in residential aged care. Several reasons could explain the popularity of the EQ-5D-3L including its brevity, the availability of translations and scoring algorithms from several different languages, cultures and countries (EuroQol Group, 2014). It is also recommended for use in obtaining QALYs by NICE in the UK (NICE, 2013). Although relatively newer, NICE also recommends the ASCOT for the measurement of social care related outcomes and the ICECAP-O for measurement of outcomes in terms of capabilities and functioning (NICE, 2013). Majority (60%) of identified studies were undertaken in Europe, with health and aged/social care systems as well as population profiles like those of the UK, which probably explains the popularity of these instruments. The following section describes studies that applied each of the different instruments.

<u>Generic preference-based instruments</u>

a. **EQ-5D-3L**

The EQ-5D-3L was used in 24 studies; used alone or in combination with a generic non-preference based or disease-specific instrument in 11 studies, and in combination with other instruments in 13 studies (*refer to table 5.5*). This section will discuss studies that applied the EQ-5D-3L alone; studies that have used the EQ-5D-3L in combination with another instrument will be discussed under the later instrument.

Community dwelling dependent older people

Four of the studies in this category were undertaken among dependent older people with cognitive impairment. Depending upon the severity of the cognitive impairment, the EQ-5D-3L was completed by the older person with the help of their caregivers or entirely by the caregiver. A study by Andersen et al. (2004) found that being dependent upon others to perform activities of daily living was the main detriment to quality of life in this population (Andersen et al., 2004). Another study compared EQ-5D-3L scores for individuals diagnosed with Alzheimer’s disease in Canada, calculated by using preference weights from general population samples in Canada and the USA (Oremus et al., 2014). Individual and mean utility scores were affected by the preference weights used. Oremus et al. (2014) argued that to avoid biased results, preference weights from the research sample’s country of origin should always be applied where possible (Oremus et al., 2014). Kunz (2010) analysed the psychometric properties of the self- and proxy-rated EQ-5D-3L among older people with mild to moderate dementia (Kunz, 2010). Proxy ratings were significantly lower compared to self-ratings at both the dimension and total score level, although higher levels of agreement were observed for older people with better functioning in activities of daily living. This study also reported higher completion rates of the interviewer administered instrument for people with mild dementia compared to those with moderate dementia (Kunz, 2010). Another study also assessed the acceptability, validity and level of agreement between self- and proxy rating of the EQ-5D-3L among older people with dementia (Orgeta et al., 2015). Orgeta et al. (2015) argue that a brief instrument like the EQ-5D-3L could be applied among people with mild to moderate dementia in an interviewer-administered format. They also found significant differences between self- and proxy ratings (self-ratings being higher) and that the caregiving relationship influenced the proxy-ratings; spouse caregivers rated the care-recipients higher compared to adult children acting as caregivers (Orgeta et al., 2015).

Of the three other studies, Borowiak and Kostka (2004) undertook a study to determine the predictors of quality of life in older people living at home and those in institutions. Depression, health promoting behaviour and both social and physical participation were found to predict older people's HRQoL (Borowiak and Kostka, 2004).
McPhail et al. (2009) investigated the equivalence between EQ-5D-3L scores obtained when the instrument is administered over the phone or during face-to face interviews (McPhail et al., 2009). Their findings indicated high levels of agreement between the two modes of administration.
Vahlberg et al. (2013) applied the EQ-5D-3L to investigate whether quality of life was a determinant of low mobility and physical activity in older people after stroke, (Vahlberg et al., 2013). The level of self-reported mobility and performance-based mobility were independently related to the HRQoL.

Residential aged care

Four of the studies that used the EQ-5D-3L were conducted in the residential aged care sector.
To identify the determinants of HRQoL in institutionalized older persons, Sitoh et al. (2005) conducted a study among older people (including those with mild to moderate cognitive impairment) living in nursing homes and in hostels in northern Sydney (Sitoh et al., 2005). Their findings suggested a strong and independent association between health conditions that cause

loss of independence, dignity and those that cause pain such as urinary incontinence, Parkinson’s disease and increased frailty, and lower HRQoL as measured by the self-administered EQ-5D-3L. Devine et al. (2014) examined the levels of inter-rater agreement between proxy and self-reported EQ-5D-3L scores among care home residents (Devine et al., 2014). Increased levels of agreement were observed between proxies and self-report data in individuals with depression and lower cognitive impairment. Overall, they argued that proxy data was acceptable for index scores and QALYs but less reliable for domain-specific scores. This argument differs from that put forward by Ortega et al. (2015) who found differences between self- and proxy rated scores in a community dwelling sample.

To investigate the impact of cognition stimulation therapy on quality of life, Yamakanka et al. (2013) applied the EQ-5D-3L in a sample of nursing home residents with dementia (Yamanaka et al., 2013). Like other studies among respondents with cognitive impairment both proxy- and self-rated scores were obtained. The findings in this study revealed improvements in quality of life based on proxy-rating but not for self-rated EQ-5D-3L scores. Lastly, Torma et al. (2015) applied the EQ-5D-3L in a study that compared the impact of two approaches to the implementation of nutritional guidelines; external facilitation and education outreach visits, on quality of life of older adults in nursing homes (Torma et al., 2015). There were no statistically significant differences in quality of life for the two groups.

b. ASCOT

The ASCOT was used in four studies among community dwelling dependent older people and two studies in the residential aged care sector.

Community dwelling dependent older people

In a study to improve local authorities’ policy targets for older people, van Leeuwen et al. (2014) applied the ASCOT to measure SCRQoL in older adults and its relationship with social policy interventions pertaining to accessibility of information and advice, design of the home and accessibility of the local area in the UK (van Leeuwen et al., 2014). Quality of life was negatively associated with difficulty in finding information and advice about services and providers, inappropriate home design for those with functional disabilities and difficulty in getting around the local area or the external environment. Van Leeuwen et al. (2015) also translated and validated a Dutch version of the ASCOT in a community dwelling sample of older adults in the

Netherlands (van Leeuwen et al., 2015c). Their findings demonstrated that the instrument was valid, reliable and comparable to the English version; however, revisions were suggested for items under the dignity dimension, as respondents did not properly understand them.

In a study to assess the construct validity of the ASCOT in measuring SCRQoL in community dwelling dependent older people, Malley et al. (2012) applied the ASCOT to measure SCRQoL and the EQ-5D-3L to measure HRQoL (Malley et al., 2012). The ASCOT was found to exhibit good construct validity in this population. The researchers also highlighted the need for the development of a version of the ASCOT designed specifically for proxy respondents as it was noted that 10% of the older people included in this study needed proxy support to complete the ASCOT.

Forder and Caiels (2011) compared the ASCOT and the EQ-5D-3L in measuring outcomes of long-term care. Like Malley et al. (2012) who applied the ASCOT in a community dwelling sample of older adults, they argued that the ASCOT had greater construct validity and was more suited than the EQ-5D-3L for the assessment of quality of life in a population of community dwelling dependent older people. Forder and Caiels (2011) further noted that unlike the EQ-5D-3L which focuses on personal ability derived from one's own health, the ASCOT focuses on the impact of services on functioning in everyday life and is therefore likely to be more sensitive to outcomes of social care interventions (Forder and Caiels, 2011).

In a more recent study, Woolham et al. (2016) applied the EQ-5D-3L in combination with the ASCOT to compare outcomes of older people receiving two CDC models of care; direct payments (cash-for-care) and managed personal budgets (self-directed care model) (Woolham et al., 2016). Although recipients of direct payments felt they had more control, there were no differences in outcomes between recipients of the two forms of CDC. However, unlike the EQ-5D-3L the ASCOT was able to identify older people with greater social care need; a statistically significant negative relationship between the ASCOT score and the size of the budget was observed.

Residential aged care

Netten et al. (2012) used the ASCOT in combination with the EQ-5D-3L to investigate the relationship between quality ratings of care homes and care outcomes of the residents (Netten et al., 2012c). Positive association was observed for quality ratings and residents' SCRQoL outcomes in residential aged care homes but not for residents in nursing homes. The researchers seemed to attribute this to the levels of focus in the different settings with nursing homes focusing more on health outcomes and not on SCRQoL outcomes. However, no argument was provided for the nursing homes rating and EQ-5D-3L scores.

c. HUI2/3

All studies that applied the HUI2/3 were undertaken among community-dwelling dependent older people, with three studies applying the instrument(s) among older people with cognitive impairment.

Zhang et al. (2006) measured the longitudinal changes in health status of older people at risk of institutionalisation (Zhang et al., 2006), while Maxwell et al. (2009) assessed the contribution of social and clinical factors to the quality of life of dependent older people in the community by gender (Maxwell et al., 2009). Both studies found that worsening depressive symptoms, multi-morbidity and increasing age were associated with declines in HRQoL. Maxwell et al. (2009) did not identify any gender differences in HRQoL.

Kleiner-Fisman et al. (2010) applied the HUI3 to measure and identify predictors of quality of life in a population of older people with Parkinson’s disease (Kleiner-Fisman et al., 2010). Poor self-care and performance in activities of daily living was associated with low levels of HRQoL.

Kavirajan et al. (2009) evaluated the validity of the HUI2 and HUI3, rated by a proxy or caregiver in a community dwelling sample of older people with dementia (Kavirajan et al., 2009). Proxy ratings were responsive to behaviour disturbances and clinical decline in quality of life but poorly responsive to improvements in behaviour. They suggested that the HUI2 was preferred to the HUI3 in this population. In another sample of older people with cognitive impairment Naglie et al. (2011) applied the HUI in combination with the EQ-5D-3L and the QWB in two studies that investigated the predictors of self-rated (Naglie et al., 2011b) and proxy-rated (Naglie et al., 2011a) quality of life. Depression was a significant predictor of self-rated quality of life while functional status and depression were predictors of proxy-rated quality of life on all the instruments.

Older people-specific preference-based instruments

a. ICECAP-O

Community dwelling dependent older people

Van Leeuwen et al. (2015) compared the measurement properties of the ICECAP-O, EQ-5D-3L and the ASCOT in a sample of community dwelling older people (van Leeuwen et al., 2015a). Findings in this study highlighted the difference in domains measured by the EQ-5D-3L being health related compared to the broader aspects of quality of life measured by the ASCOT and ICECAP-O. They revealed that the ASCOT was more responsive to change in quality of life than the ICECAP-O. Van Leeuwen et al. (2015) also explored the content validity and feasibility of the Dutch versions of the ICECAP-O, EQ-5D-3L and ASCOT in a smaller sub-sample of the population reported in a previous study (van Leeuwen et al., 2015d). This explorative qualitative study revealed that older people's preference for one instrument over another was determined by the extent to which it reflected the domains that were relevant to their present quality of life. The EQ-5D-3L was understood as intended but the role attribute of the ICECAP-O was poorly understood. Similar to a previous study that validated the Dutch version of the ASCOT in a relatively larger sample (van Leeuwen et al., 2015c), the Dignity dimension was poorly understood.

Comans et al. (2013) applied both the ICECAP-O and EQ-5D-3L to investigate quality of life gains for older people receiving a post-discharge program. Their findings indicated greater quality of life improvements with the ICECAP-O compared to the EQ-5D-3L. Similar to van Leeuwen et al. (2015), it was argued that the ICECAP-O measures broader aspects of quality of life and is able to capture improvements including and beyond health compared to the EQ-5D-3L (Comans et al., 2013).

In a study to validate the ICECAP-O in post-hospitalised older adults, Makai et al. (2013) applied both the EQ-5D-3L and the ICECAP-O (Makai et al., 2013). The results of this study demonstrated good convergent validity of the ICECAP-O with wellbeing measures [(Instrument for Level of Well-being (SPF-IL), Katz-15 Instrumental Activities of Daily Living (IADL) scale, Geriatric Depression Scale (GDS) and the Medical Outcomes Study Short form (SF-20) social functioning dimension)] and with the EQ-5D-3L. They therefore argued that the ICECAP-O is suitable for the measurement of both health and wellbeing outcomes. This argument is similar to that put forward by other studies discussed above that applied the ICECAP-O (Comans et al., 2013, van Leeuwen et al., 2015a).

Lastly, to examine the level of agreement between self and proxy ratings of quality of life in a sample of community-dwelling older adults with cognitive impairment, Davis et al. (2016) applied the ICECAP-O in combination with the EQ-5D-3L (Davis et al., 2016). A high level of agreement was observed with the EQ-5D-3L (with perfect agreement on the self-care dimension) but not with the ICECAP-O. These findings with regard to the EQ-5D-3L are similar to those observed by other studies where this instrument was applied (Devine et al., 2014, Orgeta et al., 2015).

Residential aged care

Makai et al. (2012) translated and validated a proxy version of the ICECAP-O in a psycho geriatric elderly Dutch population of restrained and unrestrained residents in nursing homes (Makai et al., 2012). Nursing home staff and family members were interviewed as proxies Restrained residents had lower quality of life than the unrestrained. Results of this study demonstrated the convergent and discriminant validity of the ICECAP-O, with significant correlation between capabilities and HRQoL measured by the EQ-5D-3L. Like Comans et al. (2013) and Makai et al. (2013), they argued that the ICECAP-O measures broader aspects of quality of life than health alone. Their findings also suggested that nursing home staff are more appropriate proxy respondents in this setting as they provide a more precise quality of life assessment than family members.

<u>Older people-specific non-preference-based instruments</u>

a. OPQOL

All studies that applied the OPQOL were conducted among older people who living in the community.

One study applied the OPQOL to investigate the correlation between dimensions of quality of life and frailty status in a sample of community dwelling older adults (Bilotta et al., 2010). Bilotta et al. (2010) found that ‘functional independence’, ‘psychological wellbeing’, ‘home and neighbourhood’, ‘leisure activities’ and ‘religion’ were negatively associated with frailty. Better emotional status and higher body mass index were correlated with quality of life among older people of advanced age and the robust older subjects respectively. These findings are similar to Maxwell et al. (2009)’s argument that poor health and increased disability, which are synonymous with frailty, are associated with worse quality of life as measured by HUI3 (Maxwell et al., 2009). In another study, Bilotta et al. (2011) demonstrated that the OPQOL total score can predict adverse health outcomes such as falls and admission to the emergency department while the health sub-score predicted admission to nursing homes or death in community-dwelling older adults (Bilotta et al., 2011).

Kojima et al. (2016) used the OPQOL in a longitudinal study to investigate quality of life in a sample of community dwelling older adults and its relationship to frailty status (Kojima et al., 2016). Similar to other studies (Bilotta et al., 2010, Maxwell et al., 2009), they observed variations in quality of life according to frailty; the least frail older adults show improvement in quality of life over time while quality of life declines with increased frailty.

The convergent validity and level of agreement between the newer version of the OPQOL, OPQOL-brief was compared to the EQ-5D-3L and the ASCOT in a community dwelling sample of older people in Australia (Kaambwa et al., 2015a). Moderate levels of agreement were observed between the three instruments, with more agreement between the ASCOT and the OPQOL-brief, which both measure broader aspects of quality of life compared to the EQ-5D-3L.

b. CASP-19

Theeke and Mallow (2013) used the CASP-12 to assess the effect of loneliness on the quality of life of chronically ill community dwelling rural older people. Their findings demonstrated that loneliness is associated with poor health and lower quality of life in this population. They argued that interventions to avert loneliness could reinforce positive health behaviour and reduce the negative impact of chronic illness on quality of life (Theeke and Mallow, 2013).

c. WHOQoL-OLD

The original 24-item version of this instrument was applied to investigate the relationship between attitudes towards ageing and quality of life nursing home residents in Turkey (Top and Dikmetas, 2015). A positive attitude towards ageing was associated with higher levels of quality of life.

5.3.5 Domains identified as important to older people

This multi-dimensional definition of quality of life for older people was highlighted by this review. Important quality of life dimensions amongst dependent older people living in the community include physical and cognitive functioning (Borowiak and Kostka, 2004, Maxwell et al., 2009), independence in activities of daily living (Andersen et al., 2004, Bilotta et al., 2010), social relationships (Borowiak and Kostka, 2004, Maxwell et al., 2009, Bilotta et al., 2010), health or absence of morbidity or health impairments (Borowiak and Kostka, 2004, Zhang et al., 2006, Maxwell et al., 2009) and pyscho-social wellbeing (Borowiak and Kostka, 2004, Zhang et al., 2006) and accessibility in their home and surroundings (Bilotta et al., 2010, Theeke and Mallow, 2013, van Leeuwen et al., 2014). For older people in residential care, dimensions of quality of life that are important include sense of dignity and physical freedom/functioning, independence in activities of daily living (Sitoh et al., 2005, Makai et al., 2012, Netten et al., 2012c, Makai et al., 2014c), health or absence of morbidity or health impairments (Sitoh et al., 2005) and happiness coupled with social participation (Netten et al., 2012c, Top and Dikmetas, 2015).

Table 5.6 below maps the domains identified in this review and in literature that are important to older people onto the existing preference-based instruments. Seven dimensions were identified as being important to older people living in the community. Similarly, nine dimensions were identified as being important to older people in residential care. Although some commonalities are evident, the dimensions differed in some respects in these two contexts for example peace and contentment, dignity and sense of security were only identified as important to older people in residential care. These dimensions were matched against the domains of the seven preference-based instruments identified in this study to assess conceptual overlap between them (table 5.5). The EQ-5D, SF-6D, AQOL-4D and 15D had the most overlap with the dimensions important to community living older people, each matching 6/7 of these dimensions. Domains for the ICECAP-O and ASCOT were matched to the least number of dimensions (4/7) important to older people in the community but only these two instruments matched the control/independence dimension. None of the seven instruments could be matched to all the dimensions important to older people living in residential care. All instruments were matched to 5/9 dimensions except the QWB (3/9) but the ICECAP-O and ASCOT were matched to the sense of dignity and only the ASCOT matching the security dimension. None of the instruments was matched to the spiritual wellbeing dimension. Overall, the EQ-5D and SF-6D had 100% of their domains (5/5 and 6/6 respectively) matched to the important dimensions for older people in both community and residential care.

Table 5.6: Cross-matching older people's dimensions of quality of life onto existing preference-based instruments

Dimensions important to older people	Instruments EQ-5D	SF-6D	AQoL-4D	15D	HUI3	QWB	ICECAP-O	ASCOT
Community living dependent older people								
Physical functioning	Mobility	Physical functioning	Independent living	Mobility	Ambulation	Physical activity	_	_
Cognitive functioning/ Psychological wellbeing	Anxiety/ depression	Mental health	Mental health	Mental function, Depression, Sleep, Distress,	Cognition, Emotion	Acute and chronic symptoms	Security	_
Independence in activities of daily living	Self-care	Role limitations	Independent living	Eating, Excretion	Dexterity	Self-care	Control/ Independence	Control over daily life, Personal cleanliness and comfort
Social relationships	Usual activities	Social functioning	Relationships	Usual activities, Sexual activity	_	_	Attachment, Enjoyment	Social participation and involvement, Occupation
Absence of morbidity or health impairments	Pain/ discomfort	Pain, Vitality	Mental health	Discomfort and symptoms, Vision, Hearing, Breathing, Eating, Speech, Excretion, Sleeping, Vitality	Pain	Acute and chronic symptoms	_	_
Accessibility within the home and community	Usual activities	Role limitations	Independent living	Usual activities	Ambulation	Mobility	_	Accommodation cleanliness and comfort
Independence or control over their life	_	_	_	_	_	_	Control/ independence	Control over daily life

Dimensions important	Instruments							
to older people	EQ-5D	SF-6D	AQoL-4D	15D	HUI3	QWB	ICECAP-O	ASCOT
Older people in residential aged care								
Independence in activities of daily living	Self-care	Role limitations	Independent living	Eating, Excretion	Dexterity	Self-care	Control/ Independence	Control over daily life, Personal cleanliness and comfort
Physical freedom	Mobility, Usual activities	Physical functioning, Vitality	Independent living	Mobility	Ambulation	Physical activity, Mobility	_	_
Absence of morbidity or health impairments	Pain/ discomfort	Pain	Mental health	Discomfort and symptoms, Vision, Hearing, Breathing, Eating, Speech, Excretion, Sleeping, Vitality	Vision, Hearing, Speech, Pain	Acute and chronic symptoms	_	_
Peace and contentment	Anxiety/ depression	Mental health	Mental health	Distress	Emotion	_	Security	Social participation and involvement
Social participation	Usual activities	Social functioning	Relationships	Usual activities	_	_	Attachment, Enjoyment	Social participation and involvement, Occupation
Happiness	_	_	_	_	Emotion		Enjoyment	_
Sense of dignity	_	_	_	_	_	_	Role	Dignity
Security	_	_	_	_	_	_		Personal safety
Dimensions not matched								
Spiritual wellbeing	_	_	_	_	_	_	_	_

5.4 DISCUSSION

When considering instruments that are suitable for evaluating quality of life outcomes of interventions in the aged care sector, the ability (or otherwise) of each instrument to assess the dimensions of quality of life that are most important to older people within the framework of economic evaluation is fundamental.

The findings of this review are in line with several commentators who have argued that social participation (Nilsson et al., 1998, Gabriel and Bowling, 2004, Levasseur et al., 2009, Borglin et al., 2005), health (Nilsson et al., 1998, Gabriel and Bowling, 2004, Milte et al., 2014), home and community environment (Gabriel and Bowling, 2004, Borglin et al., 2005, Levasseur et al., 2008, Levasseur et al., 2009, Milte et al., 2014), and well-being indicators such as independence or control over their life (Gabriel and Bowling, 2004, Levasseur et al., 2009, Milte et al., 2014, Ratcliffe et al., 2017) are important for assessing quality of life in dependent older people living in the community. For older people in residential care, these dimensions include social participation in family and leisure activities (Kane, 2001, Tester et al., 2004, Hall et al., 2011), independence (Kane, 2001, Tester et al., 2004, Hjaltadóttir and Gústafsdóttir, 2007, Hall et al., 2011), peace and contentment (Hjaltadóttir and Gústafsdóttir, 2007, Hall et al., 2011), security (Kane, 2001, Hjaltadóttir and Gústafsdóttir, 2007) and spiritual well-being (Kane, 2001, Tester et al., 2004).

Of the generic preference-based instruments, the EQ-5D, SF-6D, AQOL-4D and the 15D had the most overlap with the dimensions important to older people living in the community and those in residential care (table 5.6). As mentioned previously, the majority of these HRQoL instruments are primarily focused on health status as they were developed for application in a health care context. These instruments may not be the most representative of quality of life in older people especially those in residential care who are frailer and do not value physical health as highly as the less frail older people in the community (Puts et al., 2007, Lutomski et al., 2017). Empirical research has also demonstrated that the relative importance of dimensions differs between younger people and older people (Ratcliffe et al., 2017). Some commentators imply that older people interpret dimensions of quality of life differently for example physical functioning is not merely the level of mobility but may be linked to the ability to take part in activities that demonstrate their relevance to family and society, their independence and the ability to preserve their dignity (Nilsson et al., 1998, Sitoh et al., 2005, Puts et al., 2007). However, this has not been tested formally and should be subject to further research.

Several researchers have further argued that generic HRQoL instruments may not be appropriate for assessing quality of life outcomes of interventions in aged care because the benefits of such interventions go beyond health to include broader quality of life and well-being dimensions that are important in this context (Borowiak and Kostka, 2004, van Leeuwen et al., 2015d, Ratcliffe et al., 2017).

The AQOL has been demonstrated as suitable for assessing HRQoL in older people who are hospitalized or those with chronic illnesses (Osborne et al., 2003, Giles et al., 2009) but compared to other generic preference-based instruments, AQOL is relatively new and not as widely validated. Head-to-head comparison with the EQ-5D revealed that the EQ-5D was more suited for use in older people as it 'was easier to administer, had a higher completion rate, and appeared more sensitive to change' (Holland et al., 2004).

The main challenge with the SF-6D is that although brief, for greater validity and consistency it's utilities must be derived from the SF-36 (Ferreira et al., 2013) The SF-36 has more questions and higher respondent burden and low completion rates have been reported when used in older people (Parker et al., 2006, Hayes et al., 1995). This similar argument can be applied to the 15D which, compared to EQ-5D, is longer with low completion rates among older people.

As highlighted above, the EQ-5D is relatively easy to administer with a high completion rate, including among people with mild to moderate dementia (Gerard et al., 2004, Holland et al., 2004, Davis et al., 2012, Makai et al., 2014c, Orgeta et al., 2015, van Leeuwen et al., 2015d, Kunz, 2010, Davis et al., 2016). The EQ-5D-3L also has practical advantages when respondent burden is considered as it is relatively brief with only five dimensions each with three levels. However, research has also shown that the EQ-5D-3L has high ceiling effects and is unable to discriminate when applied among older people with few or no chronic conditions compared to other instruments such as the SF-6D (Brazier et al., 2004, Wu et al., 2014, van Leeuwen et al., 2015d, Lutomski et al., 2017). It's been argued that the newer five-level version of the EQ-5D (EQ-5D-5L) may minimize this ceiling effect (Janssen et al., 2008, Janssen et al., 2013). Epidemiological studies indicate that one in four older people exhibit symptoms of mild cognitive impairment (Purser et al., 2005). Interviewer assistance (Coast et al., 1998, Hulme et al., 2004) or proxy respondents (Naglie et al., 2011a, Devine et al., 2014, Makai et al., 2014c) have been advocated as suitable to assist respondents with reduced cognitive function or the oldest old in completing the EQ-5D. However, it is important to highlight that some studies have demonstrated little or no agreement between self- and proxy-rated scores (Kunz, 2010, Yamanaka et al., 2013, Orgeta et al., 2015).

Although the ASCOT and ICECAP-O were matched to the least number of dimensions overall, only these two instruments were matched to control/independence and dignity, key dimensions for older people receiving aged care services, particularly under a CDC model of service. The ASCOT is a preference based measure specifically designed to assess SCRQoL with a broader focus on dimensions that are important to people receiving social care services (Netten et al., 2012a). Such quality of life dimensions include control over daily life and community and environment (occupation, safety and accommodation dimensions) which have been demonstrated in the literature summarised above for older people in the community and those in residential care. As such, the ASCOT may be considered appropriate for assessing quality of life outcomes in relation to service innovations in the aged care sector.

The ICECAP-O incorporates quality of life dimensions beyond health and has been validated in several European countries for use in both health and the aged care context (Coast et al., 2008a, Flynn et al., 2011, Makai et al., 2012, Makai et al., 2014c, van Leeuwen et al., 2015d). Good construct validity has also been reported when the ICECAP-O was used in the significant cohort of older people with mild to moderate cognitive impairment (Purser et al., 2005, Makai et al., 2012, Makai et al., 2014c, van Leeuwen et al., 2015a). Although the ICECAP-O is preference-based and potentially suitable for use in economic evaluations, it is focused on capabilities and does not enable the calculation of QALYs, however, Rowen and colleagues developed econometric models which may be applied to facilitate conversion of capability based preferences onto the QALYs scale (Rowen et al., 2015).

The OPQOL is considered the most comprehensive older people-specific instrument developed to date because it incorporates both health status and broader quality of life dimensions highlighted as important for older people in the community and those in residential care (Bowling et al., 2002, Hendry and McVittie, 2004, Bowling, 2009). However, the OPQOL is non-preference based and therefore has limited use in an CUA framework.

Overall, in both the community and residential aged care contexts, the broader of dimensions that define older people’s quality of life should be emphasized. Although the ASCOT and ICECAP-O lack a health dimension, it can be argued that they are more sensitive the benefits of interventions in the aged care context because of their broader focus on quality of life beyond health. This review argues that when assessing interventions in the aged care sector, the choice of instrument should depend on the objective of the intervention being assessed; the EQ-5D is recommended for interventions aimed at maintaining or improving health while the ASCOT and ICECAP-O are recommended when assessing interventions with benefits beyond health such as service delivery innovations in the aged care sector.

A limitation of this study was the heterogeneity of and the lack of adequate data from the studies included in our sample that made it impossible empirically test whether the instruments used in the studies included in this review perform differently in various contexts by conducting meta-correlations or meta-regressions.

CONCLUSIONS

This review has highlighted that in addition to health status, older people define quality of life based on broader dimensions. Older people derive wider quality of life benefits from service innovations which may not necessarily have a positive impact upon health status. To reflect this multi-dimensional nature of and to assess the wider quality of life benefits for older people, the most appropriate instrument to be used in the aged care sector should ideally not only measure health status and functional ability but also the wider quality of life dimensions. Such dimensions include social connectedness/participation, psychological wellbeing and independence. Currently, there is no single instrument which is preference-based (commensurate with the QALY scale) and suitable for application in CUA that incorporates both health status and these broader elements of quality of life. This review therefore recommended use of the generic preference-based instrument, EQ-5D-5L to obtain QALYs together with the ICECAP-O or the ASCOT that facilitate the measurement of broader quality of life dimensions as defined by older people.

The next chapter presents the results of an empirical study that assessed quality of life during the very early pilot phase of CDC in Australia prior to the system wide transition of service delivery in the community aged care sector to a CDC model. This study documented an empirical comparison of the quality of life of older people who had been recently initiated on a CDC model of community aged care service delivery and those who were still receiving services according to the traditional provider directed model. Quality of life was measured using the newer five-level version of the EQ-5D, EQ-5D-5L in combination with the ICECAP-O.

CHAPTER 6

EARLY IMPACT OF CONSUMER DIRECTED CARE ON QUALITY OF LIFE

This is one of the two chapters reporting results of studies aimed at assessing the impact of CDC on quality of life. The empirical study reported in this chapter was conducted during the earliest stage of the transition to consumer directed care (CDC) in December 2013. This cross-sectional study (n=139) aimed at assessing the quality of life and capability of older people receiving community aged care services under the CDC model of service delivery compared to those receiving the traditional provider directed care (PDC) or non-CDC services. Quality of life and capability were measured using the five-level version of the EuroQoL five dimensions (EQ-5D-5L) and the older people-specific capability index (ICECAP-O). The results revealed that quality of life of individuals receiving CDC or PDC models of service delivery was broadly similar. However, those individuals receiving a CDC service generally reported themselves at higher levels of control/independence according to the ICECAP-O.

This chapter contains material from BULAMU, N., KAAMBWA, B., GILL, L., CAMERON, I., MCKECHNIE, S., FIEBIG, J., GRADY, R. & RATCLIFFE, J. 2016. Impact of consumer-directed care on quality of life in the community aged care sector. Geriatr Gerontol Int.

6.1 AIM OF THE STUDY

As highlighted in Chapter 3, consumer directed care (CDC) was introduced in the aged care sector in Australia following a review of the provision of community aged care services commissioned by the federal government in 2010 (Productivity Commission, 2011a). The pilot program was implemented as the ‘CDC initiative’ for older people still living in the community (KPMG, 2012). The first phase commenced in June 2010 where 500 community aged care places were allocated under the CDC model to existing clients or new clients who were interested in and judged by the service provider as able to direct their own care, followed by another 500 places in 2011 (KPMG, 2012). Widespread implementation of CDC across the community aged care sector was rolled out in July 2015 and its application in the residential aged care sector is still being explored (KPMG, 2014, Department of Health, 2015b, KPMG, 2012).

In line with the Donabedian analytical framework and within the theoretical framework of extra-welfarism, this is one of the studies undertaken to assess the outcomes of a CDC model of services. The aim of this study was to utilise the EQ-5D-5L and ICECAP-O instruments to compare the quality of life and capability of older adults (65 years and older) receiving community aged care services (CACS) under the newly initiated CDC model and those under the agency/provider-directed care (PDC) model of service delivery. A secondary objective was to utilise the ICECAP-O and EQ-5D-5L instruments to further examine the relationship between key socio-demographic characteristics and older people's quality of life and capability.

6.2 METHODS

Participants for this cross-sectional study were recruited from five aged care organisations providing community aged care services (CACS) in South Australia and New South Wales during the earliest stage of the transition to CDC, December 2013. The inclusion criteria were individuals aged 65 years or older, still living in their own home or in the community and current recipients of community aged care services (either CDC or PDC). Organisation staff approached clients who met the eligibility criteria to assess their interest in participating in the study. Because of the descriptive nature of the study, there was no formal sample size requirement. Individuals who expressed interest were invited to provide informed consent and to self-complete the EQ-5D-5L and ICECAP-O instruments (the informed consent form and quality of life questionnaire is provided in *Appendix 6.1 and 6.2 respectively*). Demographic information such as age, living arrangement, and education level were also collected.

6.2.1 Quality of life

Quality of life was assessed using the ICECAP-O an older people-specific preference-based measure of capability (Flynn et al., 2011, University of Birmingham, 2014) and the EQ-5D-5L a generic multi-attribute utility instrument used to measure health status and HRQoL (EuroQol Group, 2014). The newer five level version, EQ-5D-5L which comprises five levels for each of the five dimensions (no problems, slight problems, moderate problems, severe problems and unable to/extreme problems) was used in this study. Both instruments were identified in the systematic review (Chapter 5) as suitable for measuring quality of life outcomes in older people.

6.2.2 Consumer directed care and socio-demographic characteristics

Evidence from literature has demonstrated uptake and satisfaction with self-directing models of care particularly among younger age groups, a trend facilitated by the availability of information/knowledge about CDC (Benjamin et al., 2000, Carlson et al., 2007, Ottmann and Mohebbi, 2014). It was hypothesised in this study that older people who are relatively younger, with prior knowledge of CDC, living on their own and requiring less hours of support would be keen on CDC services.

6.2.3 Quality of life and consumer directed care

Consistent with findings from the evaluation of the CDC pilot here in Australia (KPMG, 2012), it was hypothesized that older people receiving CDC services would be found to have a better quality of life compared to those receiving traditional PDC services.

6.2.4 Data analysis

Data were analysed using the statistical software package STATA version 12 (StataCorp, 2015). Demographic characteristics and quality of life/capability scores were summarised using descriptive statistics. Tests of differences to account for the distributional nature of the variables (Pearson chi-square tests and Wilcoxon rank sum (Mann-Whitney U) test) were applied to test for differences between the two groups (CDC versus PDC). Multiple imputation (Schafer, 1997) was applied to account for the missing values on some variables (Table 6.1) prior to running the statistical tests. The imputation procedure implemented an iterative Markov chain Monte Carlo method based on a multivariate normal regression (StataCorp, 2015). Each missing value was replaced with a set of 50 plausible values so as to account for the uncertainty about the right value to impute (Schafer, 1997) then each of the 50 resultant multiply imputed datasets were analysed using standard complete-case procedures and the results combined by applying Rubin’s rules (Rubin, 1987).

Multivariate regression analysis was performed to determine the relationship between quality of life as measured by the ICECAP-O and EQ-5D-5L (dependent variables) and several independent variables including gender, hours of informal care support received at the time of the study and the mode of service delivery (receiving CDC or PDC services). As has been done elsewhere

(Galobardes et al., 2006, Feldman et al., 1989, Howe et al., 2011, Ma and McGhee, 2013), the level of education was included as a proxy for income due to the absence of the latter. Both main and interaction terms were considered with the decision about which terms to include in the final model based on whether or not model fit was improved through calculation of R^2 statistic (Colin Cameron and Windmeijer, 1997). Robust regression models dealing with outliers within data, were applied using the 'mmregress' command in Stata (Verardi and Croux, 2009) on both the complete cases and imputed data and the results compared. A significance level threshold of 5% (0.05) was assumed as the criterion for determining statistical significance.

6.3 RESULTS

Table 6.1 below shows the variables used in the analysis of results and their level of completeness.

Table 6.1: Variables used in analysis (with level of completeness)

Variable	Description	Missing (%) n = 139
EQ-5D-5L	Measure of health-related quality of life, continuous variable	0
ICECAP-O	Measure of capability, continuous variable	8 (5.76%)
Age	Age in years, continuous variable	7 (5.04%)
Gender	Dummy variable (0 = Female, 1 = Male)	3 (2.16%)
Birthplace	Dummy variable (1 = Australia, 0 = Others)	3 (2.16%)
Heard about CDC	Dummy variable (1 = Yes, 0 = No)	3 (2.16%)
Living arrangement	Dummy variable (1 = On your own, 0 = With others)	3 (2.16%)
Have informal carer	Dummy variable (1 = Yes, 0 = No)	6 (4.32%)
Hours of support	Hours of formal care support received, continuous variable	50 (35.97%)
Education level	Dummy variable (1 = Up to secondary school, 0 = Beyond secondary school)	7 (5.04%)

EQ-5D-5L = EuroQol 5 dimensions 5 level, ICECAP-O = ICEpop CAPability measure for Older people, CDC = Consumer Directed Care

6.3.1 Characteristics of the sample

The total sample was comprised of 139 older adults with n=81 receiving CDC services. Table 6.2 below summarises the key socio-demographic characteristics for the study sample. Most respondents were female (61%), aged above 80 years, living on their own (54%) and had an informal carer (82%). The PDC group had a greater proportion of respondents aged 80 years and over. A greater proportion of the PDC respondents had not heard about CDC and lived on their own. Differences between the groups were not statistically significant except more respondents in the CDC group had an informal carer (*p=0.041*), used more hours of support (*p=0.001*) and had a higher level of education (*p=0.002*).

Table 6.2: Key socio-demographic characteristics

Characteristic	**CDC (n=81)**	**PDC (n=58)**	**Total (n=139)**	**p-valueǂ**
Continuous variables				
Age				
Mean(sd)	81.22(6.21)	82.41 (6.28)	81.72 (6.24)	
Median(range)	82(68,95)	83 (68,98)	83 (68,98)	0.398¥
Hours of support				
Mean(sd)	6.59 (3.55)	4.92 (2.22)	5.89 (3.17)	
Median(range)	6.06(1.75,27.50)	5.00 (0,12.00)	5.50 (0,27.50)	**0.001*¥**
Categorical variables				
Age category				0.274
65-79 years	28 (35%)	15 (26%)	43 (31%)	
80+ years	53 (65%)	43 (74%)	96 (69%)	
Gender				0.869
Male	31 (38%)	23 (40%)	54 (39%)	
Female	50 (62%)	35 (60%)	85 (61%)	
Birthplace				0.427
Australia	55 (68%)	43 (74%)	98 (71%)	
Other	26 (32%)	15 (26%)	41 (30%)	
Heard about CDC				0.282
Yes	41 (51%)	24 (41%)	65 (47%)	
No	40 (49%)	34 (59%)	74 (53%)	
Living arrangement				0.201
On your own	40 (49%)	35 (60%)	75 (54%)	
With spouse or other family	41 (51%)	23 (40%)	64 (46%)	
Have informal carer				**0.041***
Yes	71 (88%)	43 (74%)	114 (82%)	
No	10 (12%)	15 (26%)	25 (18%)	
Education level				**0.002***
Up to secondary school	60 (74%)	28 (48%)	88 (63%)	
Beyond secondary school	21 (26%)	30 (52%)	51 (37%)	

*SD=standard deviation, ǂChi-square test used to generate p-values comparing CDC to PDC; ¥Two sample Wilcoxon rank sum (Mann-Whitney) test used to generate p-values differentiating between CDC and PDC; *statistically significant result at 0.05 level of significance*

6.3.2 Quality of life outcomes

Table 6.3: Summary statistics for the EQ-5D-5L and ICECAP-O instruments

Instrument		EQ-5D-5L	ICECAP-O
Total sample (n=139)	**Mean (sd)**	0.47 (0.30)	0.76 (0.17)
	95% CI	0.42, 0.53	0.73, 0.78
	Median (IQR)	0.57 (0.25, 0.68)	0.79 (0.65, 0.89)
CDC (n=81)	**Mean (sd)**	0.46 (0.33)	0.73 (0.17)
	95% CI	0.39, 0.53	0.70, 0.77
	Median (IQR)	0.57 (0.24, 0.66)	0.76 (0.63, 0.87)
PDC (n=58)	**Mean (sd)**	0.49 (0.27)	0.79 (0.17)
	95% CI	0.42, 0.57	0.74, 0.83
	Median (IQR)	0.59 (0.28, 0.69)	0.81 (0.70, 0.90)
p-value¥		0.510	0.053

EQ-5D-5L = EuroQol 5 dimensions 5 level, ICECAP-O = ICEpop CAPability measure for Older people, SD=Standard deviation, CI=Confidence interval, IQR=Inter-quartile range. ¥Two sample Wilcoxon rank sum (Mann-Whitney) test used to generate p-values differentiating between CDC and PDC

The mean score for the total sample was 0.47 (sd 0.30) according to the EQ-5D-5L and 0.76 (sd 0.17) according to the ICECAP-O. Higher mean scores were observed in the PDC group for the EQ-5D-5L and the ICECAP-O than the CDC group although this difference was not statistically significant. There was however a trend towards significance (*p=0.053*) for ICECAP-O scores in PDC group to be higher than those in the CDC group.

Table 6.4 shows the distribution of participants' responses across levels of dimensions of the EQ-5D-5L differentiated by CDC status. The only significant between-group differences were for the 'mobility' (*p=0.004*) dimension; a higher proportion of respondents in CDC group reported no problems in walking (22%) compared to PDC group (7%). While no one in the PDC group reported being unable to walk, 10% in the CDC group were unable to walk. Most responses to the usual activities dimension in the PDC group were for slight problems (33%) but moderate problems (36%) in the CDC group. There were between-group non-significant differences seen for other dimensions too. Greater proportions of respondents in the PDC group reported no problems with self-care (49%) and were not anxious or depressed (42%) but had severe problems with mobility

(33%), while a greater proportion in the CDC group reported moderate problems with usual activities (36%). Moderate pain or discomfort was equally distributed across both groups. For the anxiety/depression dimension, the most prevalent response in the PDC group was slight anxiety/depression (44%) and no anxiety/depression (38%) in the CDC group.

Table 6.4: Distribution of EQ-5D-5L responses across levels of dimensions by CDC status

Dimension	CDC	PDC	p-value[ƚ]
Mobility	**n=81**	**n=58**	
I have no problems in walking about	18 (22%)	4 (7%)	
I have slight problems in walking about	12 (15%)	18 (31%)	**0.004***
I have moderate problems walking about	21 (26%)	17 (29%)	
I have severe problems in walking about	22 (27%)	19 (33%)	
I am unable to walk about	8 (10%)	0 (0%)	
Self-care	**n=81**	**n=57**	
I have no problems washing or dressing myself	36 (44%)	28 (49%)	
I have slight problems washing or dressing myself	10 (12%)	10 (18%)	0.535
I have moderate problems washing or dressing myself	22 (27%)	13 (23%)	
I have severe problems washing or dressing myself	7 (9%)	5 (9%)	
I am unable to wash or dress myself	6 (7%)	1 (2%)	
Usual Activities (e.g. work, study, housework, family or leisure activities)	**n=81**	**n=57**	
I have no problems doing my usual activities	14 (17%)	7 (12%)	
I have slight problems doing my usual activities	14 (17%)	19 (33%)	0.054
I have moderate problems doing my usual activities	29 (36%)	12 (21%)	
I have severe problems doing my usual activities	12 (15%)	14 (25%)	
I am unable to do my usual activities	12 (15%)	5 (9%)	
Pain/Discomfort	**n=80**	**n=55**	
I have no pain or discomfort	14 (18%)	7 (13%)	
I have slight pain or discomfort	18 (23%)	14 (25%)	0.805
I have moderate pain or discomfort	26 (33%)	18 (33%)	
I have severe pain or discomfort	17 (21%)	10 (18%)	
I have extreme pain or discomfort	5 (6%)	6 (11%)	
Anxiety/Depression	**n=81**	**n=55**	
I am not anxious or depressed	31 (38%)	23 (42%)	
I am slightly anxious or depressed	23 (28%)	24 (44%)	0.111
I am moderately anxious or depressed	21 (26%)	6 (11%)	
I am severely anxious or depressed	4 (5%)	2 (4%)	
I am extremely anxious or depressed	2 (2%)	0 (0%)	

*CDC=consumer directed care; Total number of respondents varies per dimension due to missing responses; [ƚ]Pearson's chi-square test to generate p-values differentiating between CDC and PDC; *statistically significant values at 0.05 level of significance*

Table 6.5 shows the distribution of participants' responses to the ICECAP-O and the between group differences for the attributes. The only significant difference was for the 'role' attribute (*p= 0.020*). For instance, the most prevalent response to this dimension question in the CDC group was 'I am able to do a few of the things that make me feel valued' (40%) and 'I am able to do many of the things that make me feel valued' (42%) in the PDC. Other non-significant differences in dimension responses between the groups were also observed. Greater proportions of respondents in the CDC group indicated that they could have a lot of love and friendship (40%), thought about the future with some concern (36%) and were able to do a few of the things that made them feel valued compared to the PDC group. Greater proportions of respondents in the PDC group indicated that they had a lot of enjoyment and pleasure (51%) and were able to be independent in many things (59%) than in the CDC group. The most prevalent responses to the security dimension question in the CDC group was ‘I think about the future with little concern’ and ‘I think about the future with some concern’ (both 36%) while ‘I think about the future with some concern’ was the most popular response in the PDC group (33%).

Table 6.5: Distribution of ICECAP-O responses across levels of attributes by CDC status

Dimension	CDC	PDC	p-value[‡]
Attachment/Love and Friendship	**n=75**	**n=57**	
I can have all the love and friendship that I want	29(39%)	22(39%)	
I can have a lot of the love and friendship that I want	30(40%)	22(39%)	0.721
I can have a little of the love and friendship that I want	16(21%)	12(21%)	
I cannot have any of the love and friendship that I want	0(0%)	1(2%)	
Security/Thinking about the future	**n=78**	**n=58**	
I can think about the future without any concern	13(17%)	16(28%)	
I can think about the future with only a little concern	28(36%)	16(28%)	0.445
I can only think about the future with some concern	28(36%)	19(33%)	
I can only think about the future with a lot of concern	9(12%)	7(12%)	
Role/Doing things that make you feel valued	**n=77**	**n=57**	
I am able to do all of the things that make me feel valued	19(25%)	13(23%)	
I am able to do many of the things that make me feel valued	17(22%)	24(42%)	**0.020***
I am able to do a few of the things that make me feel valued	31(40%)	19(33%)	
I am unable to do any of the things that make me feel valued	10(13%)	1(2%)	
Enjoyment/Enjoyment and pleasure	**n=81**	**n=57**	
I can have all the enjoyment and pleasure that I want	17(21%)	8(14%)	
I can have a lot of the enjoyment and pleasure that I want	34(42%)	29(51%)	0.489
I can have a little of the enjoyment and pleasure that I want	28(35%)	17(30%)	
I cannot have any of the enjoyment and pleasure that I want	2(2%)	3(5%)	
Control/Independence	**n=81**	**n=56**	
I am able to be completely independent	5(6%)	6(11%)	
I am able to be independent in many things	37(46%)	33(59%)	0.068
I am able to be independent in a few things	29(36%)	16(29%)	
I am unable to be at all independent	10(12%)	1(2%)	

*Total number of respondents varies per dimension due to missing responses; CDC=consumer directed care; [‡]Pearson's chi-square test to generate p-values differentiating between CDC and PDC; *statistically significant values at 0.05 level of significance*

Table 6.6: Tests of association between EQ-5D-5L dimensions by CDC status

Dimension	**CDC**		**PDC**		**Test of difference**	
	Mean (sd)	**95% CI**	**Mean (sd)**	**95% CI**	**z-statistic**	**p-value**[¥]
Mobility	2.88 (1.31)	2.59, 3.17	2.88 (0.96)	2.63, 3.13	-0.064	0.949
Self-care	2.22 (1.30)	1.93, 2.51	1.96 (1.12)	1.67, 2.26	-1.005	0.315
Usual activities	2.93 (1.27)	2.64, 3.21	2.84 (1.19)	2.53, 3.16	-0.415	0.678
Pain/Discomfort	2.76 (1.16)	2.50, 3.02	2.89 (1.18)	2.57, 3.21	0.513	0.608
Anxiety/Depression	2.05 (1.04)	1.82, 2.28	1.76 (0.79)	1.55, 1.98	-1.458	0.145

CDC=Consumer directed care, SD=Standard deviation, CI=Confidence interval; [¥]Two sample Wilcoxon rank sum (Mann-Whitney) test used to generate p-value differentiating between CDC and PDC

Table 6.6 above shows results of the tests of association between dimension scores of the EQ-5D-5L and CDC status. The results reveal a negative association between CDC status and all dimensions except pain/discomfort. Participants receiving PDC services were more likely to have fewer problems with mobility, self-care, and usual activities and to be less anxious/depressed. Participants receiving CDC services were more likely to have less pain/discomfort. However, none of the differences were statistically significant.

Table 6.7 below shows the results of the tests of association between dimension scores of the ICECAP-O and CDC status. A negative association between CDC status and the ‘attachment’ and ‘enjoyment’ attributes is observed while a positive association is observed with ‘security’, ‘role’ and ‘control’ attributes. Participants receiving PDC services were more likely to have more love and friendship, enjoyment and pleasure, while those receiving CDC services were more likely to think about the future with less concern, do things that made them feel valuable and feel in control or independent. A significant association was only observed for the ‘control’ attribute (*p=0.017*).

Table 6.7: Tests of association between ICECAP-O attributes by CDC status

Capability attribute	CDC		PDC		Test of difference	
	Mean(sd)	95% CI	Mean (sd)	95% CI	z-statistic	p-value[¥]
Attachment	3.17 (0.76)	3.00, 3.35	3.14 (0.81)	2.93, 3.36	-0.140	0.888
Security	2.58 (0.90)	2.37, 2.78	2.71 (1.01)	2.44, 2.97	0.766	0.443
Role	2.58 (1.00)	2.36, 2.81	2.86 (0.79)	2.65, 3.07	1.705	0.088
Enjoyment	2.81 (0.79)	2.64, 2.99	2.74 (0.77)	2.53, 2.94	-0.421	0.674
Control	2.46 (0.79)	2.28, 2.63	2.79 (0.65)	2.61, 2.96	2.391	**0.017***

*CDC=Consumer directed care, SD=Standard deviation, CI=Confidence interval; [¥]Two sample Wilcoxon rank sum (Mann-Whitney) test used to generate p-values differentiating between CDC and PDC; *statistically significant values at 0.05 level of significance*

Table 6.8 below shows the mean EQ-5D-5L scores by socio-demographic characteristics differentiated by CDC status. Mean scores for the CDC and PDC groups followed a similar trend with higher scores obtained for participants aged 80+ years, males, those born in Australia, those who lived on their own and participants who had no informal carer. Between group differences were observed for 'heard about CDC' and 'education level' variables where participants in the CDC group who had not heard about CDC and those with education level 'Not beyond secondary school' had higher scores. Participants with prior knowledge of CDC and those with education level 'beyond secondary school' had a higher score in the PDC group. Overall, mean scores for the PDC group were relatively higher than the CDC group but these differences were not statistically significant.

Table 6.8: EQ-5D-5L mean scores and tests of association by socio-demographic characteristics and CDC status

Characteristic	**CDC**		**PDC**		**Test of difference**	
	Mean (sd)	**95% CI**	**Mean (sd)**	**95% CI**	**z-statistic**	**p-value**[¥]
Age category						
65-79 years	0.39(0.36)	0.25, 0.53	0.49(0.29)	0.33, 0.65	0.994	0.320
80+ years	0.50(0.30)	0.42, 0.58	0.50(0.27)	0.41,0.58	0.066	0.947
Gender						
Male	0.54(0.37)	0.41, 0.68	0.59(0.22)	0.49, 0.68	-0.044	0.965
Female	0.41(0.29)	0.33, 0.49	0.43(0.28)	0.34, 0.53	0.656	0.512
Birth place						
Australia	0.50(0.33)	0.41, 0.59	0.50(0.26)	0.41, 0.58	-0.172	0.864
Other	0.38(0.30)	0.25, 0.50	0.49(0.30)	0.33, 0.66	1.124	0.261
Heard about CDC						
Yes	0.44(0.32)	0.34, 0.55	**0.55(0.25)**	0.45, 0.65	1.162	0.245
No	**0.48(0.34)**	0.37, 0.59	0.46(0.28)	0.36, 0.55	-0.098	0.922
Living arrangement						
On your own	0.55(0.29)	0.46, 0.65	0.50(0.27)	0.41, 0.60	-0.451	0.652
With spouse or other family	0.37(0.34)	0.26, 0.48	0.48(0.28)	0.36, 0.60	1.259	0.208
Have informal carer						
Yes	0.45(0.33)	0.37, 0.53	0.45(0.26)	0.37, 0.53	-0.035	0.972
No	0.54(0.32)	0.31, 0.77	0.62(0.28)	0.46, 0.77	0.860	0.390
Education level						
Up to Secondary school	**0.47(0.32)**	0.39, 0.55	0.45(0.30)	0.33, 0.56	-0.031	0.975
Beyond Secondary school	0.43(0.37)	0.27, 0.60	**0.54(0.24)**	0.45, 0.63	0.967	0.334
Whole sample	0.46 (0.33)	0.39, 0.53	0.49 (0.27)	0.42, 0.57	0.658	0.511

CDC=Consumer directed care, SD=Standard deviation, CI=Confidence interval; [¥]*Two sample Wilcoxon rank sum (Mann-Whitney) test used to generate p-values differentiating between CDC and PDC*

Table 6.9 below shows the differences in mean ICECAP-O scores by socio-demographic characteristics. Mean scores for the CDC and PDC groups followed a similar trend with higher scores observed for participants aged 80+ years, those born in Australia, those with prior knowledge of CDC, those with no informal carer and participants with education level beyond secondary school. Between group differences were observed for gender and living arrangement where females in the CDC group and males in the PDC group had a higher score. This was also observed with living arrangement where participants in the CDC group who lived alone had a higher score than those who lived with spouse or other family. Participants living with a spouse or family in the PDC group had significantly higher scores (*p = 0.020*) than those in the CDC group. Overall mean scores for the PDC group were relatively higher than the CDC group.

Table 6.9: ICECAP-O mean scores and tests of association by socio-demographic characteristics and CDC status

Characteristic	**CDC** **Mean (sd)**	**95% CI**	**PDC** **Mean (sd)**	**95% CI**	**Test of difference** **z-statistic**	**p-value**$^{¥}$
Age category						
65-79 years	0.73 (0.15)	0.67,0.79	0.78 (0.25)	0.64,0.92	1.670	0.095
80+ years	0.74 (0.18)	0.69,0.79	0.79 (0.14)	0.75,0.83	1.201	0.230
Gender						
Male	0.73 (0.17)	0.67,0.80	**0.81 (0.13)**	0.75,0.87	1.645	0.100
Female	**0.74 (0.17)**	0.69,0.79	0.77 (0.19)	0.70,0.84	1.188	0.235
Birth place						
Australia	0.74 (0.18)	0.69,0.79	0.79 (0.18)	0.73,0.84	1.421	0.155
Other	0.72 (0.16)	0.65,0.78	0.78 (0.13)	0.71,0.85	1.313	0.189
Heard about CDC						
Yes	0.76 (0.16)	0.70,0.81	0.82 (0.11)	0.77,0.87	1.319	0.187
No	0.71 (0.18)	0.66,0.77	0.76 (0.20)	0.69,0.83	1.454	0.146
Living arrangement						
On your own	**0.79 (0.14)**	0.75,0.84	0.78 (0.18)	0.72,0.85	0.037	0.970
With spouse or other family	0.68 (0.18)	0.62,0.73	**0.79 (0.15)**	0.72,0.85	2.323	**0.020***
Have informal carer						
Yes	0.73 (0.18)	0.69,0.77	0.77 (0.18)	0.71,0.83	1.392	0.164
No	0.78 (0.12)	0.70,0.87	0.83 (0.13)	0.76,0.90	1.305	0.192
Education level						
Up to Secondary school	0.72 (0.18)	0.68,0.77	0.77 (0.20)	0.69,0.85	1.474	0.141
Beyond Secondary school	0.76 (0.16)	0.69,0.84	0.80 (0.14)	0.75,0.85	0.785	0.432
Whole sample	0.73 (0.17)	0.70,0.77	0.79 (0.17)	0.74,0.83	1.937	0.053

*CDC=Consumer directed care, SD=Standard deviation, CI=Confidence interval; $^{¥}$Two sample Wilcoxon rank sum (Mann-Whitney) test used to generate p-values differentiating between CDC and PDC; *statistically significant result at 0.05 level of significance*

Table 6.10 shows results of the robust regression depicting the relationship between the EQ-5D-5L scores and the independent variables. A significant positive relationship was observed with age, gender, and living arrangement. A higher quality of life was statistically associated with younger participants (*p =0.008*), males (*p<0.001*) and older people living alone (*p=0.009*). For the younger participants, the positive relationship between age and quality of life was weakened as the hours of informal care support increased.

Table 6.10: Regression (mmregress), dependent variable EQ-5D-5L score

Variable	**Coefficient**	**Standard error**	**p-value**
Main effects			
Aged 65-79 years (reference = 80+ years)	0.227	0.085	**_0.008*_**
Male Gender	0.188	0.050	**_0.000*_**
Heard about CDC	0.071	0.057	0.213
Born in Australia	0.109	0.056	0.052
Hours of formal care support	-0.012	0.007	0.061
Living on your own	0.135	0.051	**_0.009*_**
Educated up to secondary school (reference = educated beyond secondary school)	0.055	0.051	0.280
Interactions			
Hours of formal care support*Aged 65-79 years	-0.040	0.015	**_0.011*_**
Constant	0.323	0.097	0.001
Scale parameter		0.224	
Intercept parameter		0.256	
R squared		0.234	

*Age category = 65-79 years, Gender = Male, Birthplace =Born in Australia, Living arrangement =Living alone, Education=Up to secondary school, Hours of formal care support - continuous variable; *Statistically significant result at 0.05 level of significance*

Table 6.11 below shows the relationship between ICECAP-O scores and independent variables. A significant positive relationship was observed for hours of support (*p=0.023*) and living alone (*p=0.018*).

Table 6.11: Regression (mmregress), dependent variable ICECAP-O score

Variable	Coefficient	Standard error	p-value
Main effects			
Aged 65-79 years (reference = 80+ years)	0.116	0.110	0.293
Male Gender	0.013	0.040	0.755
Heard about CDC	-0.045	0.035	0.203
Born in Australia	0.044	0.040	0.267
Hours of formal care support	0.009	0.004	***0.023****
Living on your own	0.106	0.043	***0.016****
Educated up to secondary school	-0.019	0.048	
(reference = educated beyond secondary school)			0.688
Interactions			
Hours of formal care support*Aged 65-79 years	-0.016	0.019	0.391
Constant	0.663	0.075	0.000
Scale parameter		0.138	
Intercept parameter		0.167	
R squared		0.311	

*Age category = 65-79 years, Gender = Male, Birthplace =Born in Australia, Living arrangement =Living alone, Education=Up to secondary school, Hours of formal care support - continuous variable; *Statistically significant result at 0.05 level of significance*

6.4 DISCUSSION

The main objective of this study was to apply the ICECAP-O and EQ-5D-5L instruments to empirically compare the quality of life and socio-demographic characteristics of older people receiving community aged care services under a newly initiated CDC service delivery model and traditional PDC services. The results indicated lower quality of life for older people in the CDC group had but this difference was not statistically significant. In bivariate analyses, a significant difference in capability was observed between the CDC and PDC groups for participants who were living with a spouse/family or others. In the multivariate regression analyses, living alone was associated with higher quality of life and capability scores on average. In addition, being younger (65-79 years of age), and male gender were associated with higher quality of life. It is notable however; that younger participants who received more hours of formal care support had a trend (*p=0.011*) towards a lower quality of life than those who received less hours of support. For the ICECAP-O, receiving more hours of support was also associated with a higher capability. These results suggest that receiving more hours of formal care support contributed to improvement in older people's capability.

Consistent with Australian statistics on older people receiving CACS, most participants in this study were over 80 years of age, females and were born in Australia (AIHW, 2018). The finding that the majority of participants had not heard about CDC is unsurprising as at the time of questionnaire administration, CDC had only been very recently initiated (Productivity Commission, 2011a, KPMG, 2012).

More participants in the CDC group had informal carers (*p=0.041*), utilised more hours of formal care support (*p=0.001*) and had secondary school education (*p=0.002*). Research has demonstrated that older people are more willing to take up CDC services if they have support in the form of family or friends who would alleviate the stress associated with directing their own care (Spillman et al., 2007, Ottmann et al., 2009b, McCaffrey et al., 2015). A recent DCE study conducted among older people and carers to identify attributes of a preferred CDC model revealed that informal carers desired to have control and participate in decision making with regard to care received, a key tenet of the CDC model of service delivery (Kaambwa et al., 2015b). However, in their evaluation of direct payments (DP) in England, Clark and Spafford. (2001) questioned the extent of recipients' choice and control in the management of their care as opposed to that of their informal carers (Clark and Spafford, 2001). It was not clear in this study whether allocation to the CDC model of service delivery had been determined by the informal carers or the consumers themselves or both.

Lower quality of life and capability was reported for the CDC group compared to the PDC group. The total sample score on the EQ-5D-5L in this study was lower than that obtained in other studies that applied the EQ-5D-3L, an earlier version of the measure, to a similar Australian populations (Couzner et al., 2013) and much lower than the EQ-5D-5L age adjusted population norms (McCaffrey et al., 2016). Receiving the CDC model was also correlated with lower scores across dimensions of the EQ-5D-5L. Coupled with the fact that participants in the CDC group utilised more hours of support and a greater proportion had informal carers, these findings suggest that the CDC group were more dependant than the PDC group. Being a new intervention in the aged care sector, it is likely that service providers initiated most new entrants into care onto CDC. Service providers involved with the IB in the UK reported that older people often sought social care services in times of crisis and as such, new enrolees were likely to have lower quality of life and capability (Moran et al., 2013).

Research including both younger and older populations has demonstrated mixed results ranging from improved health status for cash and counselling recipients in the USA to no significant improvement for recipients of individualized budgets in Germany (Carlson et al., 2007, Arntz and Thomsen, 2011). Glendinning and colleagues found that for older people, the increased levels of anxiety and psychological distress associated with adjusting to managing their own care under CDC approaches over-rides the benefits and satisfaction that can be obtained (Glendinning et al., 2008, Moran et al., 2013). The CDC pilot among older people in Australia reported improvements in quality of life and wellbeing for the older people receiving CDC services using the ICECAP-O although the differences between CDC and PDC were not statistically significant (KPMG, 2012). The findings of this study have indicated better outcomes for the PDC group, although these were also not statistically significant. This can be attributed to the short time for which respondents were in receipt of CDC services (less than 12 months) that did not permit for complete adjustment and realizing the broader benefit of the new model. It’s also notable that the CDC group in this study appeared to be more dependent and therefore had lower levels of quality of life and capability compared to the PDC group.

The distribution of participants' responses for the EQ-5D-5L was similar in both groups for the self-care, mobility and pain/discomfort dimensions, with the most prevalent levels chosen by participants being level 1 for self-care, level 4 for mobility and level 3 for pain/discomfort. Level 5 (the worst level) was the least chosen response for all dimensions. Statistically significant between group differences were observed only for the mobility dimension.

The most frequent responses to the ICECAP-O were capability level 3 for security and level 2 for enjoyment and control attributes. The lowest level of capability was the least chosen for each of the attributes. These findings are similar to previous studies conducted among older people for the enjoyment and control attributes but not for the security and role attributes, with more respondents in this study choosing the higher levels of capability on these dimensions (Coast et al., 2008a, Couzner et al., 2012, Couzner et al., 2013). Between groups, differences in the distribution across attribute levels were not statistically significant except for the role attribute where more participants in the CDC group reported level 3. This suggests that fewer participants in the CDC group had the capability to do things that made them feel valued and supports the previous suggestion that the CDC group were more dependant than the PDC group.

As previously highlighted, findings from studies assessing the impact of CDC service delivery models on quality of life have varied between no change and some change; however, none of them has considered the effect of older people's socio-demographic characteristics on health status and wellbeing and the model of service delivery (Glendinning et al., 2008, KPMG, 2012). The regression analysis revealed that living alone was associated with higher quality of life and capability. Being younger and male was associated with a higher quality of life while receiving more hours of formal care support was associated with higher levels of capability. Review of more established CDC models revealed that a CDC approach was preferred by consumers who were more dependent and needed more hours of support as it facilitated increased flexibility with care coordination and independence in how funds were used which better met their needs (Health Foundation, 2010, Health Foundation, 2011). It is possible that although older people receiving more hours of support are more dependent, the increased choice and control with a CDC model contributes to improvement in capabilities. In addition, a CDC service was associated with a greater sense of control and independence, this finding is supported by literature that argues that CDC services promote a greater sense of independence and autonomy (Litvak et al., 1987, Doty et al., 1996, Benjamin and Matthias, 2001, Gadsby, 2013).

Client contributions following means-testing or income tested fees (ITF) are now mandatory to eligibility for subsidised CACS under CDC, however, data on income could not be obtained at the time of the study. The level of education variable was included as a proxy for income but it was not found to be statistically significant (Galobardes et al., 2006, Feldman et al., 1989, Howe et al., 2011, Ma and McGhee, 2013). It could be hypothesised that older people with higher income can afford the ITF and would be willing to take on CDC, trading off entirely free services for more control of their care under CDC. However, preliminary reports on the impact of means-testing on services have indicated that older people with higher incomes are tending to utilise informal care provided by family members or other less expensive options of care and may only be seeking government subsidised care when in need of the higher levels of care as they are deemed as providing greater value for money (Aged Care Financing Authority, 2017a). More research in this area, including investigating the relationships between quality of life, income levels and assessed care needs will be necessary in the future as recent reforms implementing client assigned funding become more established in community aged care.

One main limitation of this study was the inability to randomise the participants. A purposive sample was the most feasible alternative considering that CDC had only been initiated with only a few service providers implementing it at the time this study was conducted. In addition, older people were only initiated onto CDC type of services under the discretion of the service providers and after consultation with service recipients.

CONCLUSION

The findings from this study undertaken during the early stages of the transition to CDC indicate that the quality of life of individuals receiving CDC or PDC models of service delivery as measured by the ICECAP-O and EQ-5D-5L instruments was broadly similar. The short time period respondents were in receipt of CDC may have contributed to the insignificant change in quality of life and capability. In addition, it is likely that individuals in the CDC group were more dependent as they were receiving more hours of care, which may have contributed to lower quality of life for the CDC group relative to the PDC group. Therefore, further research is required to substantiate the preliminary findings reported here. This should assess the change over time in quality of life and capability and incorporate a longer period post program implementation to provide a more comprehensive assessment of the quality of life impacts of the CDC model of service delivery.

The next chapter assesses the quality of life and capability of older people at a later point following the Australian community aged care system wide transition to a CDC model. It was aimed at understanding the variation in quality of life and capability outcomes according to the amount of time that study participants were in receipt of a CDC model of services.

CHAPTER 7

HAS CONSUMER DIRECTED CARE IMPROVED THE QUALITY OF LIFE OF OLDER AUSTRALIANS?

This chapter reports the results of the second study undertaken after the system wide transition of the community aged care sector to a consumer directed care (CDC) model of service delivery in July 2015. The aims of this study were to assess the impact of a CDC model of service delivery on quality of life and capability and to determine the extent of variation in quality of life according to the length of exposure to CDC. Quality of life was assessed using the EQ-5D-5L and the older people-specific capability index ICECAP-O. One hundred and fifty older people consented to participate in this study. Although little variation was found overall in quality of life and capability outcomes according to exposure to CDC, those with a longer period of exposure indicated a stronger capability to do things that made them feel valued (p=0.014). Multivariate analysis indicated that older age (p=0.001) and fewer hours of support (p=0.001) were associated with higher quality of life whilst living alone (p=0.013) and fewer hours of support (p=0.015) were associated with higher levels of capability.

7.1 INTRODUCTION

As explained in Chapter 3, CDC was initiated in the community aged care sector in Australia as a pilot program in 2010 and was introduced throughout the entire sector from July 2015. The Australian Federal Government has embraced CDC and highlighted its benefits for the community aged care sector in empowering consumers who receive a Home Care Package (HCP) to have more choice and control over the types of care and services they access and the delivery of those services. In an environment of constrained financial resources, CDC has also been viewed by some commentators as a means of improving efficiency in the provision of care by targeting services to better meet the needs of clients and containing the costs of providing care whilst also achieving positive outcomes of control, satisfaction and improved quality of life for consumers (Doty et al., 1996, Alakeson, 2010, Gadsby, 2013).

In practice, there is currently little evidence available concerning the impact of CDC per se, as well as that of the length of exposure to CDC, on the quality of life of consumers and the findings of previous empirical studies are mixed. A study to evaluate the effects of a CDC home care programme compared with standard provider directed care (PDC) in Germany found that CDC extended the levels of support provided to consumers by aged care providers but that there was no discernible effect upon quality of life or health outcomes (Arntz and Thomsen, 2011). In the US, the Cash and Counselling Demonstration and Evaluation program reported an increased likelihood of recipient satisfaction with care arrangements and quality of life and a decreased likelihood of unmet needs without any discernible negative impacts upon health outcomes (Carlson et al., 2007). In contrast the evaluation of the individual budgets pilot programme in the UK raised concerns about the benefits of CDC for older people and how these can be maximised (Glendinning et al., 2008, Moran et al., 2013).

In the earlier empirical study reported upon in chapter 6 of this thesis to compare the quality of life of older people receiving CDC (n=81) versus those receiving traditional PDC (n=58), no discernible differences in overall quality of life were found. However, higher levels of self-reported control and independence were found for those in receipt of CDC suggesting that the main policy objectives of transferring choice' and 'control' away from the aged care provider and to the individual were being met.

The main objective of this second cross-sectional study was to shed further light on the relationship between CDC and quality of life following the system wide transition that commenced in July 2015.

7.1.1 Study Objectives

The primary objective of this cross-sectional study was to extend the empirical work undertaken in chapter 6 to:

- Examine the relationship between CDC and quality of life and capability at a later stage of the evolution of CDC in the Australian community aged care sector; and
- The secondary objective was to determine the extent to which quality of life and capability outcomes, may or may not be impacted by the length of time individuals were exposed to a CDC model of services.

It was hypothesized that as the benefits of CDC may take some time to be realised in practice, those HCP recipients with a longer period of exposure to a CDC model of services may report higher quality of life and capability outcomes relative to those with a shorter period of exposure.

7.2 METHODS

7.2.1 Study sample

A purposive sample of older Australians receiving aged care services from five aged care service providers operating across New South Wales and South Australia was obtained for this cross-sectional study. In combination, these service providers were representative of aged care service providers in Australia in both clientele (a reasonable spread of both metro and non-metro clients) and scope of services. Consumers were invited to participate in the study if they were 65 years or older, still living in their own home or the community and in receipt of a current HCP, and (according to the judgement of the aged care provider) sufficiently cognitively intact to provide informed consent to participate. Because of the poor response rates in older people, study information packs containing the questionnaire and consent form were mailed out to all their clients who met these eligibility criteria over a six months period from September 2015 to February 2016. *A copy of the questionnaire and consent form is provided in Appendix 7.1*. Interested participants self-completed the questionnaire and signed the consent form, which were then returned to the service provider. A follow-up reminder phone call was made to non-responders.

7.2.2 Measurement and valuation of quality of life

Quality of life and capability were assessed using the EQ-5D-5L and ICECAP-O respectively. As highlighted in chapter 5, both instruments were applied in this context since no single instrument currently captures all aspects of quality of life as defined by older people. The EQ-5D-5L is focused on health status and physical functioning whilst the ICECAP-O incorporates other broader attributes of quality of life beyond health that have been found to be important to older people including psychosocial functioning and feelings of control and independence (Milte et al., 2014, Bulamu et al., 2015).

7.2.5 Data analysis

Data were analysed using STATA version 14 (StataCorp, 2015).

Participants' demographic characteristics were summarised and descriptive statistics were generated to summarize the quality of life scores of the entire sample (complete cases). Multiple imputation was used to account for missing values prior to running statistical tests (Schafer, 1997). An iterative Markov chain Monte Carlo method based on a multivariate normal regression was used in the imputation and each missing value in the dataset was replaced with a set of 50 plausible values (StataCorp, 2015). The number of imputations was chosen to maximize the relative efficiency of the point estimates based on these imputations compared with those based on an infinite number of imputations. Representing the maximum fraction of missing observations by λ, the relative efficiency of an estimate based on m imputations compared with one based on an infinite number can be approximated by $(1+\lambda/m)-1$ (Schafer, 1997).The 50 resultant multiply imputed datasets were then each analysed using standard complete-case procedures and Rubin's rules were applied to combine the results (Rubin, 1987). Bivariate analysis was conducted based on the imputed dataset to assess the relationship between quality of life and the time individuals were in receipt of a CDC model of services (less than vs greater than 12 months) and the Wilcoxon rank sum (Mann- Whitney U) test of difference was utilised to test the difference between the two groups.

With the system wide transition having commenced in July 2015, time on CDC was categorised into 0-12 months or greater than 12 months to differentiate recipients as either early (>12 months) or late CDC transitions (0-12 months). This categorisation was in line with early versus late cut-offs used in similar evaluations of CDC aged care services in Australia (Gordon et al., 2012).

The relationship between quality of life and capability (dependent variables) and length of stay on CDC as well as several independent variables was assessed using multivariate regression analysis. Data on income was not available at the time of the study, however, education has been used in the literature as a proxy for income (Galobardes et al., 2006, Howe et al., 2011, Feldman et al., 1989, Ma and McGhee, 2013). Consequently, education level was included in the regression models as a proxy for income. A generalised linear model (GLM) framework that is able to deal with the twin problems of heteroscedasticity and skewness was applied to the imputed data using the 'glm' command in Stata (Verardi and Croux, 2009, McCullagh and Nelder, 1989). The choice of

GLM family and link function was guided by Manning’s modified park test (Manning, 1998). Both main effects and interaction terms were considered and the decision about which terms were included in the final model was based on whether or not model fit was improved as assessed by the Akaike information criterion (AIC) and Bayesian information criterion (BIC) with lower values for both metrics indicating a better model fit (StataCorp., 2013) The criterion for determining statistical significance was assumed at a threshold of 5% (0.05).

7.3 RESULTS

The service providers identified 484 eligible individuals and subsequently sent study information packs (*Appendix 7.1*) of which 142 questionnaires and consent forms were returned. A single follow-up reminder phone call was made to initial non-responders and this contributed an additional eight responses. Overall, the final response rate was 31% which is broadly consistent with response rates achieved in research studies conducted with older people using a postal self-completion survey mode of administration (Auster and Janda, 2009, Palonen et al., 2016). Table 7.1 below shows the variables used in the analysis and their associated level of completeness.

Table 7.1: Variables used in the analysis with level of completeness

Variable	Description	Missing (% of total n=150)
EQ-5D-5L score	Measure of health-related quality of life, continuous variable	10 (6.7)
ICECAP-O score	Measure of capability, continuous variable	9 (6.0)
Age	Age in years, continuous variable	9 (6.0)
Gender	Dummy variable (1 = Female, 0 = Male)	5 (3.3)
Birthplace	Dummy variable (1 = Australia, 0 = Others)	5 (3.3)
Heard about CDC	Dummy variable (1 = Yes, 0 = No)	8 (5.3)
Living arrangement	Dummy variable (0 = On your own, 1 = With others)	6 (4.0)
Have informal carer	Dummy variable (1 = Yes, 0 = No)	7 (4.7)
Hours of support	Hours of formal care support, continuous variable	55 (37.0)
Education level	Dummy variable (0=Up to secondary school, 1= Beyond secondary school)	9 (6.0)
Time on CDC	Dummy variable (0= 0-12months, 1= >12 months)*	16 (10.7)
Time with care provider	Period in days, continuous variable	64 (42.7)

*EQ-5D-5L = EuroQol 5 dimensions 5 level; ICECAP-O = ICEpop CAPability measure for Older people; CDC = Consumer Directed Care. *This categorisation was in line with early versus late cut-offs used in similar evaluations of CDC aged care services in Australia*

7.3.1 Demographic characteristics

The total sample was 150 older adults [66% females] with a mean age of 82.67 years (sd=7.55). 86 (64%) of the respondents had been receiving a CDC service for up to 12 months. The average number of months on CDC across the entire sample was 10 months (sd 7.1). The average number of hours for which they received any form of support was 6.61 hours (sd 4.95). Most of the respondents (66%) indicated that they lived on their own although 85% also reported having an informal carer.

There was no statistically significant difference between individuals who had been exposed to CDC for ≤ 12 months and those that had it for >12 months in terms of all respondent characteristics except for age. Those who had spent a shorter amount of time on CDC were older. Table 7.2 below summarises the demographic characteristics of the total sample based on complete cases and differentiated according to the time the individual had been exposed to CDC.

Table 7.2: Key demographic characteristics for total sample and by time spent on CDC

Characteristic (Continuous variables)	Total: complete cases			Time spent on CDC		
				0–12 months (n=86)	>12 months (n=48)	p-value[¥]
	N	Mean (sd)	Median (range)	Mean (sd)	Mean (sd)	
Age	141	82.67 (7.55)	84.00 (60,99)	83.15 (7.45)	80.65 (7.32)	**0.024***
Hours of support	95	6.61(4.95)	5 (1, 40)	6.73 (5.60)	6.96 (3.84)	0.557
Time on CDC (days)	134	292.90 (216.42)	218.00 (0, 1085)	161.08 (71.50)	529.06 (185.86)	0.000
Time with provider (days)	86	1381.14 (1219.90)	1181.00 (0, 6766)	1389.12 (1253.34)	1387.89 (1210.32)	0.781

Characteristic (Categorical variables)	Total sample N	%	0-12 months n	%	>12 months n	%	p-value[ŧ]
Gender							
Male	50	34	29	35	17	36	0.850
Female	95	66	55	65	30	64	
Living arrangements							
On your own	95	66	58	70	26	55	0.095
With spouse or other family	49	34	25	30	21	45	
Education level							
Up to secondary school	106	75	57	70	39	83	0.112
Beyond secondary school	35	25	24	30	8	17	
Birthplace							
Australia	107	74	60	71	35	74	0.709
Other	38	26	24	29	12	26	
Have informal carer							
Yes	121	85	68	83	40	85	0.747
No	22	15	14	17	7	15	

*n for total sample and divided according to length of exposure to CDC may not total up to 150 because of missing data on some participant characteristics; SD=standard deviation, CDC=Consumer directed care; [¥]Two sample Wilcoxon rank sum (Mann-Whitney) test used to generate p-values for comparison between the '0-12 months on CDC' group versus the '>12 months on CDC' group; [ŧ]Chi-square test used to generate p-values for comparison between the '0-12 months on CDC' group versus the '>12 months on CDC' group; *Statistically significant result at 0.05 level of significance*

7.3.2 Quality of life

Quality of life scores for the total sample and differentiated by time spent on CDC (less than or greater than 12 months) are presented in Table 7.3 below. The mean quality of life score for the total sample was 0.56 (sd 0.26) and 0.76 (sd 0.17) for capability. These mean scores are lower than those found in a previous study that assessed the quality of life of older people in the general population (EQ-5D-3L: aged 65-79 years mean=0.79; aged 80+ years mean=0.76. ICECAP-O aged 65-79 years mean=0.81; aged 80+ years mean=0.76) with the magnitude of the differences being more evident for the EQ-5D-3L (Couzner et al., 2013).

Contrary to initial expectations, higher scores were observed for participants who had been receiving a CDC model of services for a short time compared with those who had received services for longer. This difference was found to be statistically significant for the ICECAP-O (*p=0.042*).

Table 7.3: Quality of life scores for total sample and differentiated by time on CDC

Instrument		**EQ-5D-5L**	**ICECAP-O**
Total sample (complete cases n=140)	**Mean (sd)**	0.56 (0.26)	0.76 (0.17)
	95% CI	0.52, 0.60	0.73, 0.79
	Median (IQR)	0.62 (0.38, 0.75)	0.79 (0.68, 0.89)
0 -12 months (n =94)	**Mean (sd)**	0.57 (0.26)	0.78 (0.16)
	95% CI	0.52, 0.62	0.75, 0.81
	Median (IQR)	0.66 (0.38, 0.75)	0.81 (0.69, 0.88)
> 12 months (n =47)[a]	**Mean (sd)**	0.54 (0.26)	0.72 (0.18)
	95% CI	0.47, 0.62	0.67, 0.77
	Median (IQR)	0.57 (0.38, 0.76)	0.77 (0.67, 0.89)
p-value[¥]		0.494	**0.042***

*EQ-5D-5L = EuroQol 5 dimensions 5 level, ICECAP-O = ICEpop CAPability measure for Older people, CDC = Consumer Directed Care, SD = Standard deviation, CI = Confidence interval; [a]N for EQ-5D-5L was 46; [¥]Two sample Wilcoxon rank sum (Mann-Whitney) test to generate p-value for comparison between the '0-12 months on CDC' group versus the '>12 months on CDC' group; *Statistically significant result at 0.05 level of significance*

Table 7.4 below shows the distribution of EQ-5D-5L responses across the levels of each dimension for the total sample and differentiated by time on CDC and Table 7.5 shows the distribution of ICECAP-O responses across attribute levels differentiated by time on CDC. Most respondents indicated limitations according to each attribute. Overall, the responses were concentrated in the middle two levels for each attribute. No statistically significant differences in EQ-5D 5L dimension response scores according to the time individuals had been exposed to CDC were revealed in Table 7.4.

Table 7.4: Distribution of EQ-5D-5L responses across levels of dimensions

Dimension	Total	Time spent on CDC		p-value[ŧ]
		0-12 months	>12 months	
Mobility	**143**	**n=96**	**n=47**	
I have no problems in walking about	14	6 (6%)	8 (17%)	0.196
I have slight problems in walking about	27	21 (22%)	6 (13%)	
I have moderate problems walking about	50	35 (36%)	15 (32%)	
I have severe problems in walking about	40	25 (26%)	15 (32%)	
I am unable to walk about	12	9 (9%)	3 (6%)	
Self-care	**143**	**n=96**	**n=47**	
I have no problems washing or dressing myself	57	39 (41%)	18 (38%)	0.108
I have slight problems washing or dressing myself	26	21 (22%)	5 (11%)	
I have moderate problems washing or dressing myself	34	17 (18%)	17 (36%)	
I have severe problems washing or dressing myself	14	11 (11%)	3 (6%)	
I am unable to wash or dress myself	12	8 (8%)	4 (9%)	
Usual Activities	**143**	**n=96**	**n=47**	
I have no problems doing my usual activities	12	7 (7%)	5 (11%)	0.170
I have slight problems doing my usual activities	28	22 (23%)	6 (13%)	
I have moderate problems doing my usual activities	51	34 (35%)	17 (36%)	
I have severe problems doing my usual activities	31	23 (24%)	8 (17%)	
I am unable to do my usual activities	21	10 (10%)	11 (23%)	
Pain/Discomfort	**144**	**n=96**	**n=48**	
I have no pain or discomfort	20	14 (15%)	6 (13%)	0.679
I have slight pain or discomfort	28	21 (22%)	7 (15%)	
I have moderate pain or discomfort	61	38 (40%)	23 (48%)	
I have severe pain or discomfort	26	16 (17%)	10 (21%)	
I have extreme pain or discomfort	9	7 (7%)	2 (4%)	
Anxiety/Depression	**145**	**n=96**	**n=49**	
I am not anxious or depressed	56	40 (42%)	16 (33%)	0.397
I am slightly anxious or depressed	52	35 (36%)	17 (35%)	
I am moderately anxious or depressed	29	18 (19%)	11 (22%)	
I am severely anxious or depressed	6	2 (2%)	4 (8%)	
I am extremely anxious or depressed	2	1 (1%)	1 (2%)	

Total number of respondents varies per dimension due to missing responses; Percentages are rounded off to the nearest whole number; [ŧ]Pearson's chi-square test to generate p-values comparing '0-12 months on CDC' group to the' >12 months on CDC' group.

Individuals who had been exposed to CDC services for a longer time were more likely to report themselves as doing things that make them feel valued (*p = 0.014*). The majority (65%) of respondents who had been exposed to CDC for over 12 months reported themselves as being able to do all or many of the things that 'make me feel valued' as opposed to 42% of respondents who had been exposed to CDC for 12 months or less.

Table 7.5: Distribution of ICECAP-O responses across levels of attributes

Dimension	**Total**	**Time spent on CDC**		**p-valueŧ**
		0-12 months	**>12 months**	
Attachment/Love and Friendship	**142**	**n=94**	**n= 48**	
I can have all of the love and friendship that I want	6	3 (3%)	3 (6%)	0.252
I can have a lot of the love and friendship that I want	23	12 (13%)	11 (23%)	
I can have a little of the love and friendship that I want	63	42 (45%)	21 (44%)	
I cannot have any of the love and friendship that I want	50	37 (39%)	13 (27%)	
Security/Thinking about the future	**143**	**n=96**	**n=47**	
I can think about the future without any concern	14	8 (8%)	6 (13%)	0.536
I can think about the future with only a little concern	41	29 (30%)	12 (26%)	
I can only think about the future with some concern	47	29(30%)	18 (38%)	
I can only think about the future with a lot of concern	41	30 (31%)	11 (23%)	
Role/Doing things that make you feel valued	**146**	**n=97**	**n=49**	
I am able to do all of the things that make me feel valued	10	3 (3%)	7 (14%)	**0.014***
I am able to do many of the things that make me feel valued	63	38 (39%)	25 (51%)	
I am able to do a few of the things that make me feel valued	50	39 (40%)	11 (22%)	
I am unable to do any of the things that make me feel valued	23	17 (18%)	6 (12%)	
Enjoyment/Enjoyment and pleasure	**144**	**n=96**	**n=48**	
I can have all of the enjoyment and pleasure that I want	5	1 (1%)	4 (8%)	0.092
I can have a lot of the enjoyment and pleasure that I want	55	35 (36%)	20 (42%)	
I can have a little of the enjoyment and pleasure that I want	62	43 (45%)	19 (40%)	
I cannot have any of the enjoyment and pleasure that I want	22	17 (18%)	5 (10%)	
Control/Independence	**147**	**n=98**	**n=49**	
I am able to be completely independent	9	5 (5%)	4 (8%)	0.524
I am able to be independent in many things	53	34 (35%)	19 (39%)	
I am able to be independent in a few things	77	52 (53%)	25 (51%)	
I am unable to be at all independent	8	7 (7%)	1 (2%)	

*Total number of respondents varies per dimension due to missing responses, Percentages are rounded off to the nearest whole number; ŧPearson's chi-square test to generate p-values comparing '0-12 months on CDC' group to the' >12 months on CDC' group; *Statistically significant result at 0.05 level of significance*

Table 7.6 and Table 7.7 below illustrate the association between dimensions of the EQ-5D-5L and the ICECAP-O respectively, and the time on CDC. For the EQ-5D-5L, a higher score for a dimension/attribute is commensurate with more impairment. Length of time on CDC was negatively associated with the Mobility dimension and positively associated with all other dimensions of the EQ-5D-5L, although none of these associations was found to be statistically significant. Similarly, for the ICECAP-O a higher score for a dimension/attribute implies more capability. None of the associations were found to be statistically significant except for the role attribute. Respondents who had been in receipt of CDC services for a shorter time (0-12 months) were more likely to score higher, indicating a higher level of capability, on the role attribute than those in receipt of CDC for a longer time (0-12 months).

Table 7.6: Tests of association between dimensions of the EQ-5D-5L by time on CDC

Dimension	**0-12 months**		**>12 months**		**Test of difference**	
	Mean (sd)	**95% CI**	**Mean (sd)**	**95% CI**	**z-statistic**	**p-value¥**
Mobility	3.10 (1.05)	2.89, 3.32	2.98 (1.19)	2.63, 3.33	-0.328	0.743
Self-care	2.25 (1.32)	1.98, 2.53	2.36 (1.29)	1.98, 2.74	0.550	0.582
Usual activities	3.07 (1.09)	2.85, 3.29	3.30 (1.27)	2.93, 3.67	1.105	0.269
Pain/Discomfort	2.80 (1.11)	2.58, 3.03	2.90 (1.02)	2.60, 3.19	0.652	0.515
Anxiety/Depression	1.84 (0.87)	1.67, 2.02	2.12 (1.03)	1.83, 2.42	1.512	0.130

¥Two sample Wilcoxon rank sum (Mann-Whitney) test used to generate p-values comparing '0-12 months' group to the' >12 months group; SD=Standard deviation, CI=Confidence interval

Table 7.7: Tests of association between ICECAP-O attributes by time on CDC

Attribute	**0-12 Months**		**>12 months**		**Test of difference**	
	Mean (sd)	**95% CI**	**Mean (sd)**	**95% CI**	**z-statistic**	**p-value¥**
Attachment	3.20 (0.78)	3.04, 3.36	2.92 (0.87)	2.66, 3.17	-1.925	0.054
Security	2.84 (0.97)	2.65, 3.04	2.72 (0.97)	2.44, 3.01	-0.646	0.518
Role	2.72 (0.79)	2.56, 2.88	2.33 (0.88)	2.08, 2.58	-2.744	**0.006***
Enjoyment	2.79 (0.74)	2.64, 2.94	2.52 (0.80)	2.29, 2.75	-1.836	0.066
Control	2.62 (0.70)	2.48, 2.76	2.47 (0.68)	2.27, 2.66	-1.158	0.247

*SD=Standard deviation, CI=Confidence interval; ¥Two sample Wilcoxon rank sum (Mann-Whitney) test used to generate p-values comparing '0-12 months on CDC' group to the' >12 months on CDC' group; *Statistically significant result at 0.05 level of significance*

7.3.3 Predictors of quality of life

The results of robust regression models assessing whether time on CDC and other demographic characteristics of the sample predicted changes in quality of life and capability are shown in Tables 7.8 and 7.9.

Table 7.8 shows the results of the regression model where the dependent variable was the EQ-5D-5L score. Being older (*p=0.001*) predicted a higher score on the EQ-5D-5L and every hour of formal care was associated with a 0.02 fall, on average, in the EQ-5D-5L score (*p=0.001*).

Table 7.8 Predictors of HRQoL - EQ-5D-5L score: GLM Regression Model Results

Variable	**Coefficient**	**Standard Error**	**p-value**
Age	0.019	0.006	**0.001***
Living with others	-0.067	0.085	0.432
Have informal carer	-0.122	0.110	0.270
Hours of formal care support	-0.025	0.008	**0.001***
Education level	0.023	0.094	0.807
>12months on CDC	-0.039	0.087	0.649
Constant	-1.833	0.492	0.000
Number of observations		150	
AIC		0.903	
BIC		-685.871	

*Description of variables: Age - continuous variable, Living arrangement = Living with others, Have an informal carer = Yes, Hours of formal care support - continuous variable, Education level = Beyond secondary school, Time on CDC = > 12 months; *Statistically significant result at 0.05 level of significance*

Results of the regression model with the ICECAP-O score as the dependent variable are presented in Table 7.9. The relationship between the ICECAP-O on one hand and living arrangement and hours of support on the other were found to be statistically significant: living with others was found to be associated with a 0.1 lower ICECAP-O score on average than living alone (*p=0.013)* and every hour of formal care was associated with a 0.01 fall in total ICECAP score on average (*p=0.015*).

Table 7.9 Predictors of capability - ICECAP-O score: GLM Regression Model Results

Variable	**Coefficient**	**Standard error**	**p-value**
Age	0.004	0.003	0.079
Female Gender	-0.045	0.041	0.267
Living with others	-0.098	0.040	**0.013**[*]
Have informal carer	0.067	0.051	0.190
Hours of formal care support	-0.010	0.004	**0.015**[*]
Education level	-0.030	0.043	0.485
>12months on CDC	0.056	0.038	0.144
Constant	-0.601	0.217	0.006
Number of observations		150	
AIC		1.554	
BIC		-703.891	

Description of variables: Age - continuous variable, Gender =Female, Living arrangement = Living with others, Have an informal carer = Yes, Hours of formal care support - continuous variable, Education level = Beyond secondary school, Time on CDC = > 12 months; [*]Statistically significant result

7.4 DISCUSSION

Overall, findings from this study indicate differences in quality of life for older Australians in receipt of CACS according to whether health status (EQ-5D-5L) or capability (ICECAP-O) is used as the defining characteristic of quality of life. The magnitude of the differences in quality of life scores is similar to what was observed in the earlier study reported in chapter 6 (Bulamu et al., 2016) and in other studies which have applied both instruments simultaneously in similar population groups (Davis et al., 2012, Couzner et al., 2013). However, as would be expected in a sample of dependent older people receiving community aged care services, the mean scores for this population are lower than those found in a previous study that sought to assess the quality of life of older people in the general population, the majority of whom were living independently in the community (Couzner et al., 2013). This difference between instrument scores is not surprising and further highlights the different dimensions of quality of life assessed by the EQ-5D-5L and the ICECAP-O. The overall findings are consistent with research in other countries where CDC type models of service delivery have been associated with high self-reported levels of HRQoL (Benjamin et al., 2000, Brown et al., 2007, Forder et al., 2012).

In contrast to initial expectations, the study findings also reveal that older people who received a CDC type of service for a shorter time reported higher quality of life on both the EQ-5D-5L and ICECAP-O than those who were in receipt of CDC for longer. These differences were not found to be statistically significant, although they were approaching statistical significance for the ICECAP-O ($p=0.052$). Several researchers have argued that optimism is positively correlated with, and contributes to, a better quality of life amongst older people experiencing chronic conditions (Bowling et al., 2002, Kepka et al., 2013, Vilhena et al., 2014). Although generally apprehensive, older people in the early stages of receiving CDC have expressed optimism about the increased level of control, sense of independence and flexibility over their care accorded to them by a CDC model of service delivery, and this may have contributed to the higher self-reported quality of life and capability in the relatively newly transitioned group (0-12 months) (Barnes, 1997, Clark et al., 2004). After experiencing CDC for a while, it is possible that some consumers realised that it did not meet their initial expectations. This trend was observed in the UK where older people receiving individualised budgets reported dissatisfaction in relation to the much anticipated elements of control and flexibility due to tight budgets that did not leave much room for flexibility to purchase services beyond those previously received under provider-directed care model (Glendinning et al., 2008, Moran et al., 2013). Similar concerns were expressed by consumers in a previous qualitative study (N=45) conducted during the initial stages of the transition to a CDC model of service delivery (Gill et al., 2016).

This difference could also be explained by the evolution of CDC, in that aged care service providers have become more competent in the design and provision of CDC type services over time. Therefore, respondents who are more recently initiated on a CDC model are receiving a better and more streamlined system unlike the >12 months cohort who experienced the ‘teething problems’ associated with the initial transition to CDC. However, it could also be a sign of unfulfilled expectations by those who have been receiving the service/s from an existing provider for a longer time; in that providers may have aggressively marketed their services to attract consumers and increase market share. However, once signed up the high consumer expectations may not be met but the actual and/or perceived transaction costs associated with changing providers is too high a barrier for consumers to switch to a different provider organisation.

A greater proportion of older people in receipt of CDC for >12 months reported themselves as being able to do the things that made them feel valued (table 7.5). Although capability on the role dimension was higher for respondents in receipt of CDC for shorter period (table 7.7), the relationship between the capability score and time on CDC was not statistically significant (table 7.9) and so cannot be relied on. CDC has been widely argued to promote consumer control; it is possible that this might build some capacity in individuals to self-manage and undertake tasks which make them feel more valued and this increases the longer they are on the package (Doty et al., 1996, Alakeson, 2010, Moran et al., 2013).

Regression analysis revealed that being older and receiving fewer hours of formal care support were associated with higher quality of life according to the EQ-5D-5L whilst for the ICECAP-O, living alone and receiving fewer hours of formal care support were associated with a higher capability. Empirical studies measuring quality of life/wellbeing over the course of the life-span or in different age groups have tended to report that quality of life is ‘U-shaped’ with age; being high at the onset, dipping to a minimum between the ages of 35 to 50 years then rising again into old age (Blanchflower and Oswald, 2004, Blanchflower and Oswald, 2008, Stone et al., 2010, McCaffrey et al., 2016). It is also argued that individuals adapt to circumstances and change their aspirations over the life-course which in turn influences their perceptions of what defines quality of life/wellbeing (Ryff, 1989, Blanchflower and Oswald, 2008). As discussed in chapter 5, quality of life for older people encompasses domains beyond health status to include psychological wellbeing (Bowling et al., 2002), social participation (Nilsson et al., 1998, Gabriel and Bowling, 2004, Levasseur et al., 2009), home and community environment (Gabriel and Bowling, 2004, Borglin et al., 2005, Levasseur et al., 2008, Levasseur et al., 2009, Milte et al., 2014), and independence or control over their life (Gabriel and Bowling, 2004, Levasseur et al., 2009, Milte et al., 2014, Ratcliffe et al., 2017). Similarly, a participatory research study undertaken in the UK to understand wellbeing among older people identified people/relationships; health, care and support; psychological and financial resources; secure places and environment as the key factors that defined wellbeing in this population (Ward et al., 2012). Although it is often the case that health and functional status deteriorate with age, it has also been found that social and psychological factors may remain constant or even improve with age contributing to a higher quality of life and wellbeing. (Netuveli and Blane, 2008). These findings may offer a potential explanation for the positive relationship found here between the EQ-5D-5L and age.

If hours of formal care received act as an indicator of dependency with fewer hours of support associated with lower levels of dependency, it is not surprising that a fewer hours of support was associated with better self-reported quality of life.

Assessment of quality of life in this population using the ICECAP-O measure of capability has demonstrated higher levels of control and better functioning in roles that make older people feel valuable among those in receipt of a CDC service for a longer time. The regression analysis revealed that older people who lived alone were more likely to have both higher levels of capability scores. It can be argued that the attribute gains in control and the role attributes of capability for older people in receipt of a CDC type of service for a longer time demonstrate increased levels of control among older people receiving a CDC type of service.

In interpreting the results, it is important to consider the main limitations to this study: firstly, the relatively small sample size; secondly, the limited number of covariates examined in the regression models; and thirdly, the cross-sectional nature of the study and the inability to randomise participants that precludes the ability to attribute causality in the analysis. Lastly, a purposive sample was used as eligibility for CDC initially (prior to July 2015) was based on providers' assessment of older people's ability to manage their own care. This sample mainly comprises respondents who were on CDC for less than 12 months and may therefore not be very representative of the older people receiving CACS in the general population.

CONCLUSION

In summary, the findings of this study indicated no discernible differences in overall quality of life and capability according to the time for which older people were exposed to a CDC model of community aged care service delivery. Extended longitudinal follow up would be helpful in substantiating these initial findings and facilitate a more detailed examination of the relationship between the evolution of CDC and its longer-term influences on quality of life.

Following this assessment of quality of life and capability outcomes associated with a CDC model of service delivery, the focus of the next chapter is to identify the main cost drivers associated with the provision of home care packages for older people according to a CDC model. Chapter eight also investigates the extent of variation in costs according to the type of home care package and the length of time respondents were exposed to CDC.

CHAPTER 8

COST ANALYSIS OF CDC HOME CARE PACKAGES

In this chapter, a retrospective study was conducted to identify the costs associated with and the cost drivers in the delivery of a consumer directed care (CDC) model of delivering community aged care services (CACS) and assess whether these costs vary according to the time consumers are in receipt of a CDC model of service. Akin to the method of costing adopted for Medical Benefits Scheme (MBS) and Pharmaceutical Benefits Scheme (PBS) items, the cost of CDC at the level of the client was estimated according to the fees charged by aged care service providers for home care package services provided during a specific financial year. A micro-costing approach was applied using pre-existing client level data. Multivariate regression analysis was applied to examine the relationship between cost of services per day and key independent variables including HCP level, the hours of formal care support received, clients' living arrangements and time spent in receipt of CDC. The main cost drivers associated with the provision of CDC were care services, administration and care coordination/case-management. The key predictors of cost were the home care package and the hours of formal care support received. There is need for more research to understand the cost associated with a CDC service especially following the introduction of client assigned funding in February 2017.

8.1 BACKGROUND

The Donabedian analytical framework presented in chapter 1 considers the structure, processes and outcomes associated with the delivery of aged care services. In this context, the structure of aged care has been defined as the policy and regulation frameworks governing the provision of aged care services, discussed in chapter 2. The process of care reflects the delivery of services under a consumer directed care model, this includes client assessment and allocation of home care packages (HCPs) under the aged care assessment team (ACAT) and direct service provision by aged care service providers (chapter 2 and 3). Lastly the outcomes of care encompass the direct benefits or detriments to consumers including quality of life, independence and control as well as the cost associated with receiving a CDC model of service at the different levels of care or HCP. Outcomes in terms of quality of life and capability have been assessed in chapter 6 and 7. This chapter assesses outcomes in terms of the cost of services to the consumer.

As previously highlighted, commencing July 2015, all community aged care places are provided under a consumer directed care model (CDC). More reforms aimed at increasing consumer empowerment and creating a market-based system were implemented in February 2017. In these most recent reforms home care package (HCP) funds are allocated to the consumer as opposed to the previous system where funds were allocated to the aged care service provider (Department of Health, 2015b). In this way CDC adopts a cash-for–care approach where the consumer can purchase services from one or a mix of service providers with the flexibility of changing service providers in pursuit of better services.

In their review of the implications of cash-for-care schemes internationally, Arksey and Kemp (2008) argue that CDC models of service delivery may result in improved efficiency and costs savings for the aged care system because of several key factors. Firstly, it is argued that by more closely aligning community aged care services to the needs of clients, older people will be supported to remain living at home for a longer period of time which is a less expensive option relative to institutionalised care (Timonen et al., 2006, Brown et al., 2007, Kröger and Leinonen, 2012). Secondly, Arksey and Kemp (2008) indicate that CDC models of care tend to be associated with less bureaucracy in outsourcing care, which reduces the transaction costs associated with delivering care from multiple sources including providing the ability to expand the aged care workforce by employing family members. According to current legislation governing the community aged care system in Australia and reflecting the delivery of services under a CDC model, the service provider is still responsible for sourcing care and consumers are not allowed to employ family members (Department of Health, 2015b). As such, potential cost savings in the Australian aged care system pertaining to CDC are more likely to be obtained from delayed admission to institutionalised care coupled with increased competition among providers following the allocation of budgets to clients that commenced in February 2017.

The following parts of this section describe the principles underlying costing study methodology. Section 8.2 describes the methods applied in this study while section 8.3 presents the results. Section 8.4 is a discussion of the findings of the study.

Prior to undertaking a costing analysis, it is important to define the perspective or viewpoint to be considered. The perspective is determined by ‘who’ is asking the question about cost and ‘why’ (Drummond et al., 2005a, Morris et al., 2007b). The commissioner of the study or the final audience of the study results, more generally referred to as the decision-maker, typically defines the perspective. The perspective then determines the range of costs to be included in the analysis. Common perspectives include the community or societal perspective; this is the broadest perspective, advocated for use when evaluating publicly funded programs, where all costs to society irrespective of who incurs them are considered (Morris et al., 2007b, Drummond et al., 2005a, Byford and Raftery, 1998). Other viewpoints include the provider perspective, the perspective of a specific institution or government body (such as the health care sector or aged care sector, the hospital or aged care institution) or even the individual patients or clients receiving care (Drummond et al., 2005b, Drummond et al., 2006).

8.1.1 Identifying costs

According to economic theory, costs generally refer to the foregone benefit of resources invested, also referred to as the 'opportunity cost' (Drummond et al., 2005b). Costs are broadly classified as direct or indirect costs. Direct costs are those that are directly attributed to a program or service and indirect costs are costs incurred in seeking or receiving a program or service but which cannot be directly linked (Drummond et al., 2005b). For example, when considering the delivery of services under a CDC model in the community aged care sector direct costs may include:

- Administration and overhead costs incurred by the service provider;
- cost of personal care services provided to the client;
- health care costs in the provision of health and occupational/allied health services in the community;

Indirect costs on the other hand may include:

- family costs in the provision of informal care, and
- costs incurred by other sectors such as transport (seniors' concessions) and environment (modifications to community spaces for older people with mobility difficulties and/or other physical disabilities).
- Productivity costs in case the older person is still employed

Where the perspective for the costing study is that of the health care or aged care system, then only direct costs associated with the provision of the program or service being evaluated need to be taken into consideration. If a full societal perspective is adopted for the costing exercise, productivity losses due to illness or disability and any private spending need to be captured. Although the inclusion of informal care is mandatory when taking a full societal perspective for economic evaluation, informal care can also be included in the health and aged care perspectives. If substitution of informal carers with formal care providers is possible then informal care is included, otherwise it is not included.

8.1.2 Measuring costs/resource use

Measurement of resource use involves determining the quantity of resources used over the specified study period (Drummond et al., 2005b). Resources refer to the cost items identified in 8.1.1 above. The study period, also referred to as the time horizon, should be long enough to facilitate the calculation of costs that are relevant to an assessment of the efficiency of the program or service. Costs can be measured using the bottom-up approach, also known as micro-costing, or the top-down approach which is also referred to as macro-costing (Morris et al., 2007b).

Micro-costing

The bottom-up approach involves collecting cost data on the individual items and then aggregating these to obtain the overall cost. Micro-costing has been argued to facilitate a more detailed understanding of the program through component cost analysis. It provides accurate estimates of costs and enables easy adjustment of results in case of changes in component prices (Morris et al., 2007b, Raftery, 2000, Ruof et al., 2003). However, the bottom-up approach is time consuming as it relies on primary data collection and the high level of specialised costing generated may hinder the transferability of cost data and the wider generalizability of the costing estimates generated (Raftery, 2000).

Macro-costing

The top-down costing approach (also referred to as gross costing) is where total or average costs are extracted and apportioned to the different cost items (Raftery, 2000, Morris et al., 2007b). This approach is relatively less time consuming because it relies on secondary data relating to the overall costs associated with the program or service which are often more readily available. However, this approach has been argued to be less precise and may therefore potentially lead to biased cost estimates and is less sensitive to the interventions under study (Drummond et al., 2005b, Raftery, 2000).

The choice between micro- and macro-costing depends upon the level of detail required for the decision maker. In practice, both approaches are routinely used. For health economic evaluation, micro-costing is most often preferred with macro-costing being used in cases where resource/time constraints are an issue and/or micro-level data are not available (Drummond et al., 2005b, Raftery, 2000).

8.1.3 Valuation of resources used

This defines the value placed on goods and services. It involves attaching unit prices to each of the cost items. Unit prices are routinely based on the market value/price where this is available. In the health and aged care sectors, the market price is often interpreted as the fees paid by government and/or consumers for a service. An example is the medical benefits scheme (MBS) fees allocated to different diagnostic and medical procedures and pharmaceutical benefits scheme (PBS) fees allocated to pharmaceuticals in Australia.

Inflation and discounting

In cases where unit prices applied are from a previous period, such prices need to be adjusted to reflect current values based on the rate of inflation. For studies that require extrapolation of results beyond one year, costs should also be discounted to reflect their current value based on a standard discount rate (Drummond et al., 2005b).

8.1.4 Study Objectives

The main objectives of this costing study were to:

- identify the relevant cost categories and their relative proportions in determining the total costs associated with the provision of HCP’s according to a CDC models at various levels of client dependency (high vs low dependency);
- explore the relationship between daily costs and potential predictors including HCP level and length of time for which respondents were in receipt of CDC.

8.2 METHODS

8.2.1 Study sample

The study sample comprised of older Australians receiving community aged care services from five aged care service providers operating across New South Wales (2) and South Australia (3). In combination, these service providers were representative of aged care service providers in Australia in both clientele (a reasonable spread of both metro and non-metro clients) and scope of services. Older people were invited to participate if they were 65 years or older, still living in their own home or the community and in receipt of a current HCP, and (according to the judgement of the aged care provider) sufficiently cognitively intact to provide informed consent to participate. The aged care providers mailed out a study information pack to their clients who met these eligibility criteria over a six months period from September 2015 to February 2016. The information pack contained a quality of life survey (reported upon in chapter 7) and consent form to participate in the costing study. Consent was sought to obtain retrospective cost data for the previous 12 months– form provided in *Appendix 7.1*. Signed consent forms were then returned to the service provider. A follow-up reminder phone call was made to non-responders.

8.2.2 Identification of resources

In this study resources were defined at the level of the individualised budget in terms of how much the government and clients contributed to the budget and how much clients were charged for services. As such, it was undertaken from the government and the clients' perspective as the payers. The Australian government contributes at least 90% of the budget while the client is responsible for between 7% to 100% depending on their level of income and HCP level (Aged Care Financing Authority, 2016). A bottom-up costing approach using pre-existing client level data was applied. The time horizon for the cost analysis was 12 months and therefore discounting was not necessary (Drummond et al., 2005b). There was no adjustment for inflation because costs were incurred within the same financial year.

Cost of services

Akin to the method of costing adopted for Medical Benefits Scheme (MBS) and Pharmaceutical Benefits Scheme (PBS) items, the cost of CDC at the level of the client was estimated according to the fees charged by aged care service providers (or third party providers) for services provided during a specific financial year and this was used as a proxy for cost. These costs varied based on the combination of services offered. The main categories of services provided were administration, case management or coordination, care services and third-party provider services. Administration services included the service provider's program overheads and staff costs. Case management or coordination was provided to facilitate the provision of care. To offer a HCP under a CDC model, aged care service providers assign case officers to coordinate clients' care including explaining to them how the CDC model works, designing a care-plan and individualised budget and organising the care services according to the client's needs and desired schedule (You et al., 2016, You et al., 2017). This aggregate cost including staff costs, agency costs and transport expenses associated with the provision of case management or coordination services. Care services included the provision of personal care for activities of daily living (bathing, dressing, feeding) and instrumental activities of daily living (such as shopping, accompanying the older person to appointment or social events), nursing care (for services such as medication monitoring or wound cleaning), restorative care services and respite care. The other component of care was on services related to, but beyond, direct care provision and often provided by a third party. Such services included equipment purchases or hire, clinical care, occupational therapy, physiotherapy, podiatry, nutritionist services, gardening and lawn mowing, house modifications, cleaning services and entertainment. Aged care providers facilitated the payments to third parties for these services.

The four main categories defining per capita cost were therefore:

1. Administration
2. Case management/care coordination
3. Care services
4. Other services (third party provided services)

8.2.3 Measurement and valuation of cost

Akin to the MBS and PBS fees, measurement and valuation of costs was based on fees charged on clients' accounts for services received. The market value of the services was reflected in the fees charged as reported in clients' annual and monthly service/activity statements obtained from the service providers. An example of the service statements is provided in *Appendix 8.1*. The statements indicated the quantity received and the value or unit cost for each cost item/service.

8.2.4 Data analysis

Data were analysed using statistical software STATA version 14 (StataCorp, 2015). Descriptive statistics were generated to summarize costs, quality of life and demographic characteristics. For pragmatic purposes, the HCP levels of care were categorised into two groups: the lower levels of care – HCP level 1 or 2 (HCP level 1/2) and the higher levels of care – HCP level 3 or 4 (HCP level 3/4). Similar to evaluations of CDC aged care services in Australia, time on CDC was categorised into 0-12 months or greater than 12 months to differentiate recipients as either early (>12 months) or late CDC transitions (0-12 months) (Gordon et al., 2012).

To account for the variation in the time associated with the cost data, cost was standardised by creating a **daily cost** variable for each cost category. This provides a uniform parameter for comparison across the entire study sample. The daily cost per cost category for each participant was calculated based on the period associated with each cost data estimate i.e.

$$Daily\ cost = Total\ cost\ \div No\ of\ days\ associated\ with\ cost\ data$$

The Wilcoxon rank sum (Mann-Whitney U) test of difference was applied to test the variation of costs between sub-samples by HCP level and by time on CDC. The relationship between daily costs (expenses) and several independent variables was assessed using multivariate regression analysis. A generalized linear model (GLM) with a gamma distribution and log link was used to explore this relationship (Willan and Briggs, 2006). This model controls for skewness and heteroscedasticity and approximates the distribution of the data based on the modified Park test (Manning and Mullahy, 2001). The choice of GLM family and link function was guided by Manning's modified park test (Manning, 1998). Both main effects and interaction terms were considered and the decision about which terms were included in the final model was based on whether model fit was improved as assessed by the Akaike information criterion (AIC) and Bayesian information criterion (BIC) with lower values for both metrics indicating a better model fit (StataCorp., 2013).

The criterion for determining statistical significance was assumed to be the traditional threshold of 5% (0.05).

8.3 RESULTS

A total of 484 eligible older people were identified and subsequently study information packs were mailed out to them, 93 consented to participate in the costing study.

8.3.1 Demographic characteristics

As shown in Table 8.1, most respondents were born in Australia (75%), had an informal carer (86%). It’s important to note that although some respondents lived alone, they still had an informal carer who did not live with them. As such, 69% respondents lived on their own but 79% reported themselves as having an informal carer. Majority of respondents (62%) were receiving a lower level of support (HCP level 1 or 2. During the data collection period, fourteen respondents (15%) transitioned between HCP levels; four transitioned within their level while 10 transitioned across the category. Overall, the mean quality of life scores for the costing study sample were like the scores for the entire quality of life study reported in Chapter 7.

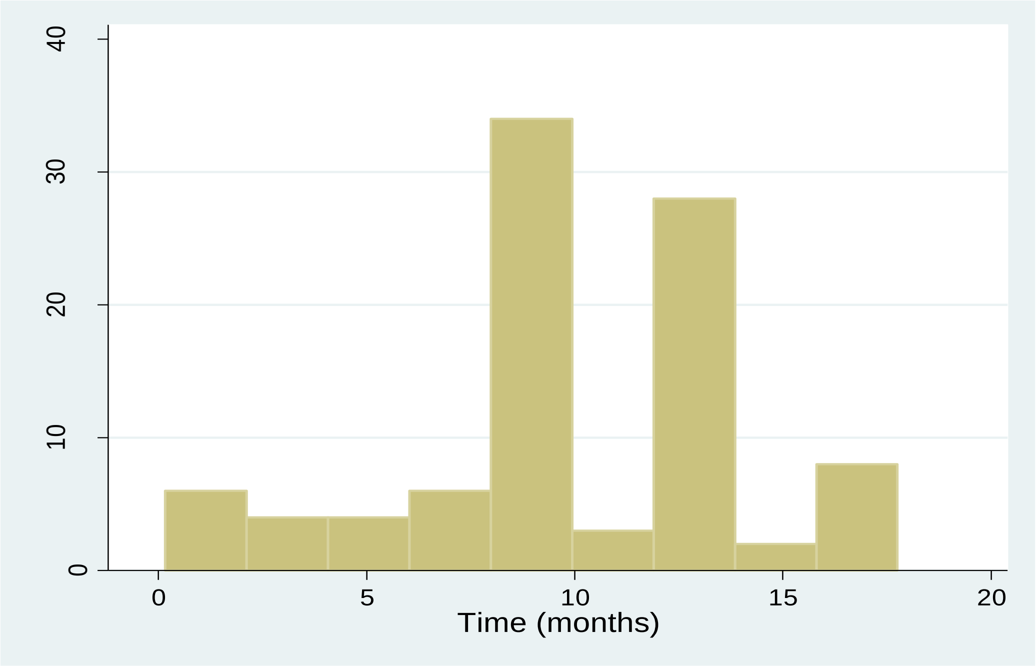
Table 8.1: Demographic characteristics of the study sample

Characteristic	Estimate		
Continuous variables	**n**	**Mean (sd)**	**Median (IQR)**
Age	93	82.3 (6.9)	84 (78, 87)
Hours of formal care support	63	6.3 (3.6)	5 (4, 9)
Time on CDC (months)	90	9 (5)	7 (5, 14)
Cost data collection period (months)	93	10 (4)	9 (8, 12)
Time with provider (months)	75	47 (45)	39 (17, 52)
EQ-5D-5L	93	0.56 (0.26)	0.62 (0.38, 0.73)
ICECAP-O	93	0.76 (0.15)	0.80 (0.70, 0.87)
Categorical variables	**n**	**%**	
Gender	**92**		
Male	30	33	
Female	62	67	
Living arrangement	**90**		
On your own	61	68	
With spouse or other family	29	32	
Education level	**90**		
Up to secondary school	67	74	
Beyond secondary school	23	26	
Birthplace	**90**		
Australia	69	75	
Other	23	25	
Have informal carer	**92**		
Yes	79	86	
No	13	14	
Home Care Package (HCP) level	**93**		
HCP level 1/2	58	62	
HCP level 3/4	35	38	
HCP level transition	**14**	**15**	
Within category transition	*4*	*1 to 2=1, 4 to 3=2, 3 to 4=1*	
Transition across categories	*10*	*2 to 4=8, 2 to 3=2*	

SD=Standard deviation, IQR=Inter-quartile range, CDC=Consumer directed care, EQ-5D-5L = EuroQol 5 dimensions 5 level, ICECAP-O = ICEpop CAPability measure for Older people, HCP=Home Care Package

Because some respondents had not been with the organisation for at least 12 months, on average, clients received a CDC type of service for nine months while the average costing period was 10 months. Figure 8.1 below shows the variation in costing period for the study sample.

Figure 8.1: Variations in costing period for the study sample



8.3.2 Summary of cost items and unit prices

Table 8.2 below summarises the most common cost items and the average unit prices charged across service providers. A costing template to aid uniform categorising of cost data from different service provider organisations operating with different accounting mechanisms has been proposed and is provided in appendix 8.2.

Table 8.2: Average unit prices (Australian dollars) for common cost items

Item	Unit	Mean (sd)	Median (IQR)
Administration			
HCP 1	Day	1.40 (0)	1.40 (1.40, 1.40)
HCP 2	Day	10.05 (4.98)	10.19 (6.20,13.78)
HCP 3	Day	12.57 (3.98)	10.29 (9.85, 16.85)
HCP 4	Day	23.35 (7.93)	24.51(15.47,30.50)
Care coordination			
HCP 1	Day	1.31 (0)	1.31 (1.31, 1.31)
HCP 2	Day	6.32 (3.05)	6.37 (4.69, 7.18)
HCP 3	Day	15.43 (10.02)	21.30 (3.30, 21.95)
HCP 4	Day	19.69 (10.10)	18.56 (17.19,31.22)
Care Services			
HCP 1	Hour	51.70 (0)	51.70 (51.70,51.70)
HCP 2	Hour	43.45 (14.96)	48.50 (38.87,53.09)
HCP 3	Hour	43.22 (19.4)	52.34 (36.64,54.36)
HCP 4	Hour	49.26 (17.92)	54.64 (45.20,58.71)

HCP=Home Care Package

8.3.3 Total Cost by Home Care Package level and by time on CDC

Figures 8.2 - 8.4 below show the distribution of the mean cost per category over time. Regardless of HCP level, the cost of CDC was observed to increase with the time respondents were in receipt of CDC services. When cost was disaggregated by HCP level, as expected services are costlier for the higher-level packages (HCP 3 and 4) compared to the lower level packages (HCP 1 and 2).

Figure 8.2: Distribution of Cost of services for the total sample

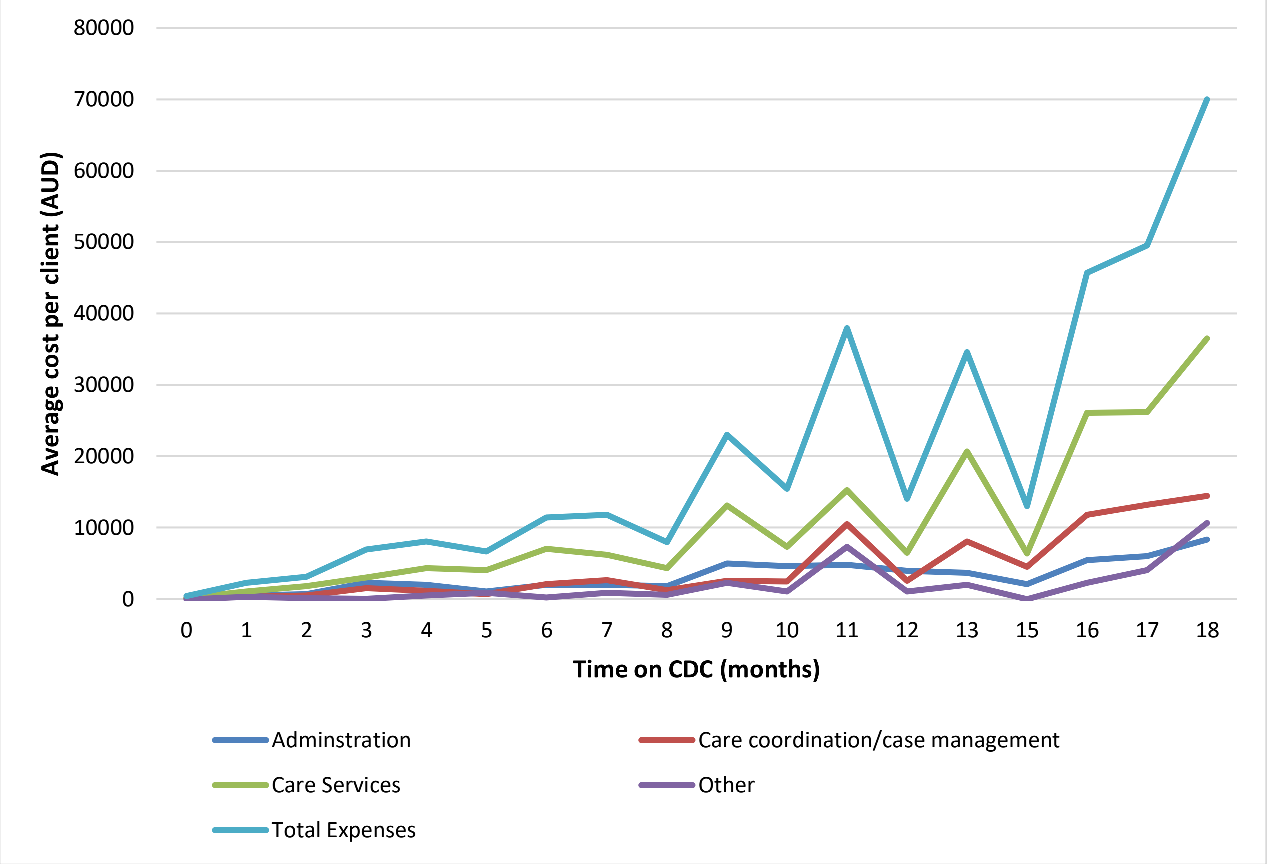


Figure 8.3: Distribution of Cost of services for HCP level 1/2

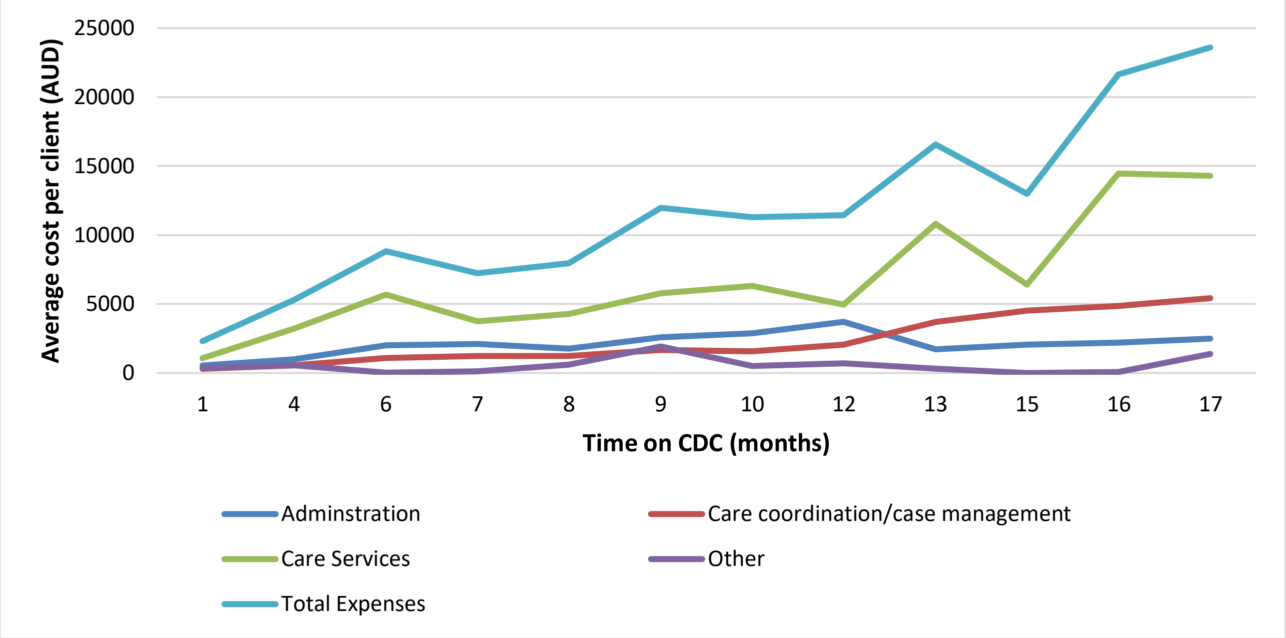
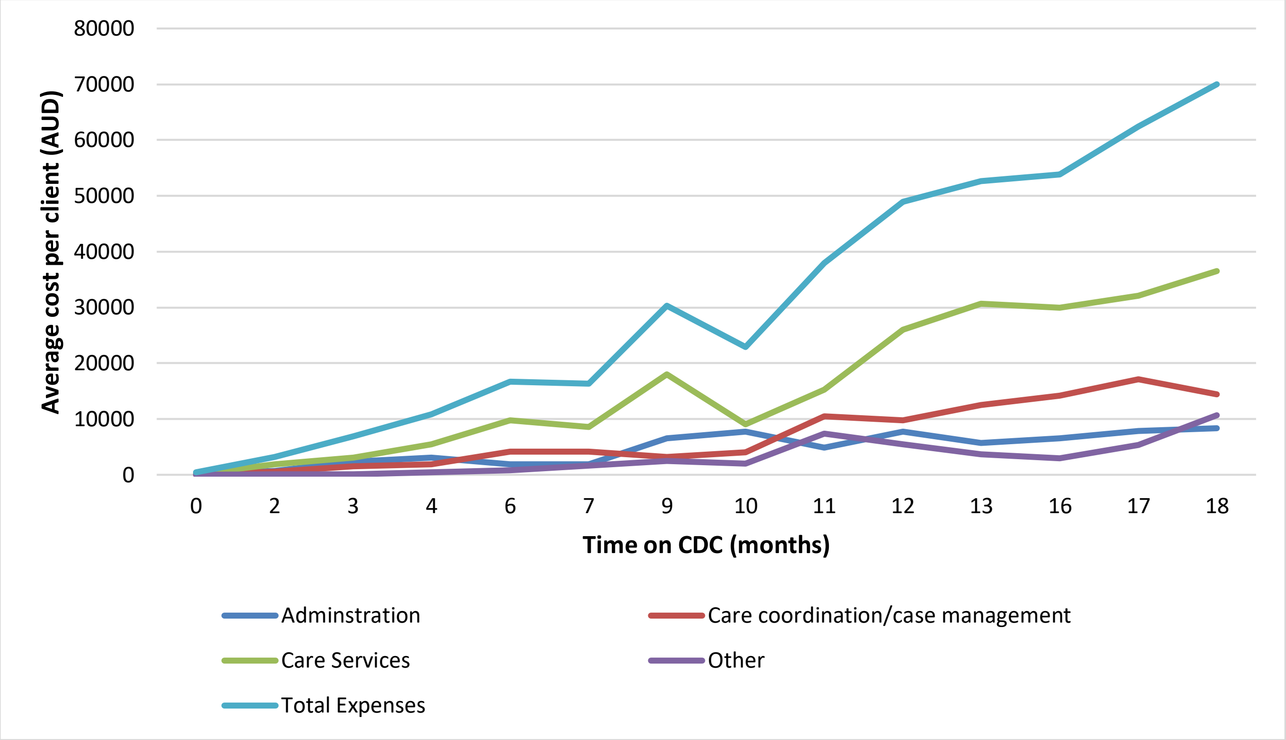


Figure 8.4: Distribution of Cost of services for HCP level 3/4



8.3.4 Daily cost of services

The tables (8.3 and 8.4) and figures (8.5 and 8.6) that follow summarise the daily costs under each cost category for the total sample and differentiated by HCP level and time on CDC.

Table 8.3: Daily cost of services

Cost category	**Total sample (n=95)**		**HCP level 1/2 (n=59)**		**HCP level 3/4 (n=36)**		**0-12 months (n=57)**		**>12 months (n=38)**	
	Mean (sd)	**Median (IQR)**	**Mean (sd)**	**Median (IQR)**	**Mean (sd)**	**Median (IQR)**	**Mean (sd)**	**Median (IQR)**	**Mean (sd)**	**Median (IQR)**
Administration	14 (9)	13 (9,17)	10 (5)	10 (5,13)	22 (8)	20 (15,30)	14 (10)	11 (7,19)	15 (6)	14(11, 16)
Care coordination or case management	11 (9)	7 (5,18)	6 (3)	6(4,7)	19 (10)	19 (16,24)	9 (8)	6 (4,16)	14 (11)	8 (7, 21)
Care Services	34 (26)	27 (16,49)	20 (11)	19 (12,27)	57 (27)	56 (37,72)	33 (28)	26(12,46)	36 (23)	28 (17,55)
Other	5 (8)	2 (0,6)	3 (7)	1 (0,3)	9 (9)	5 (2,12)	4 (8)	1 (0,6)	7 (8)	4 (1, 9)
Total cost per day	**64 (41)**	**46 (37,94)**	**39 (18)**	**39 (30,45)**	**106 (36)**	**110 (85,129)**	**60 (44)**	**45 (30,89)**	**71 (37)**	**57 (39,110)**

All amounts rounded off to the nearest Australian Dollar (AUD); SD=Standard deviation, IQR=Inter-quartile range, HCP=Home Care Package

Table 8.3 above summarizes the daily costs for the total sample and for the sub-samples based on HCP level and on the time respondents were in receipt of a CDC model of service delivery. Similar to the total costs in the figures above, higher mean daily costs were observed for respondents who had received a CDC model of service for >12 months compared with their counterparts who had received it for 0-12 months. However, savings over time would have been expected owing to economies of scale i.e. costs to reduce as more people access the programs and over a longer time period as these programs become more well established. It is possible that these savings were masked by the disproportionate distribution of the low- and high-level HCPs in both groups, 68% of respondents in the 0-12 months group received the lower level HCPs which are less costly compared to a nearly equal distribution between low (53%) and high (47%) care HCPs in the >12months group.

Figure 8.5 and 8.6 below show the distribution of costs for the total sample and by HCP level. Over 50% of costs was on care services, 22% for administration and 17% for case management or care coordination. Other costs accounted for about 8% of costs. A similar trend was observed when the distribution of costs was analysed by HCP levels.

Figure 8.5: Distribution of daily costs for the total sample

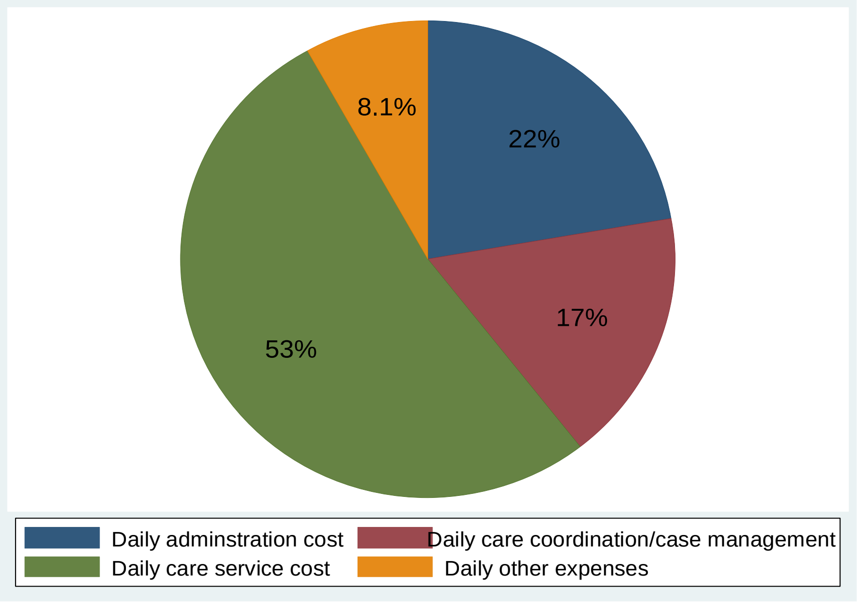


Figure 8.6: Distribution of costs by HCP level

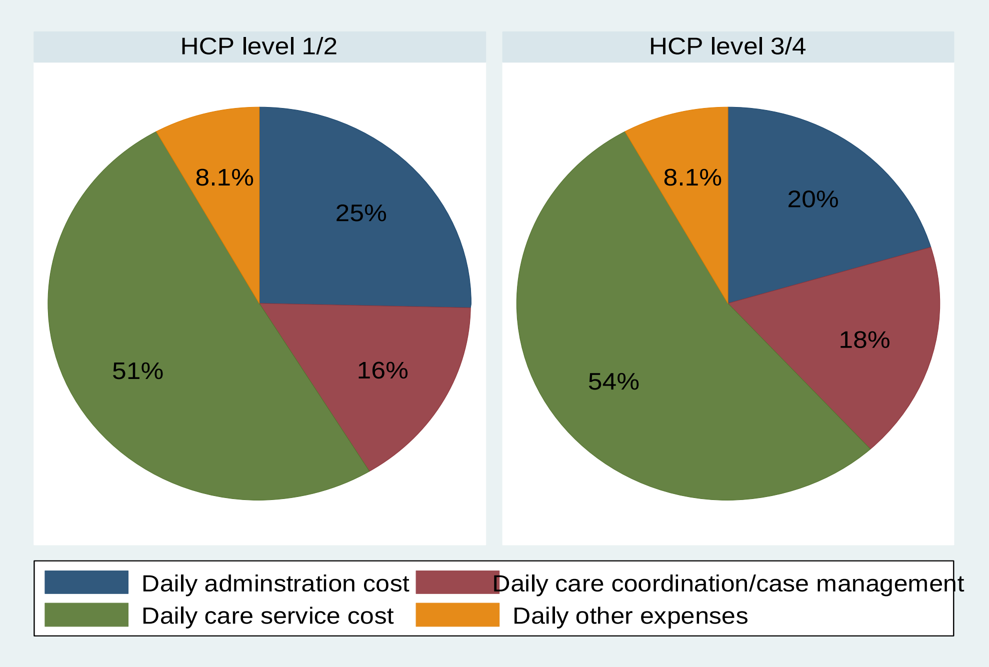


Table 8.4: Variation in daily cost by Home Care Package (HCP) level and by Time on CDC

Cost category	**HCP level 1/2 (n=59)**					**HCP level 3/4 (n=36)**				
	0-12 months (n=39)		**>12 months (n=20)**		**p-value¥**	**0-12 months (n=18)**		**>12 months (n=18)**		**p-value¥**
	Mean (sd)	**Median (IQR)**	**Mean (sd)**	**Median (IQR)**		**Mean (sd)**	**Median (IQR)**	**Mean (sd)**	**Median (IQR)**	
Administration	9 (5)	9 (5,11)	12 (4)	14 (10,14)	**0.000***	26 (7)	29 (19,31)	17 (7)	16 (11,21)	**0.003***
Care coordination/case management	6 (3)	6 (3,6)	7 (2)	7 (7,8)	**0.001***	17 (8)	18 (16,19)	21 (11)	21 (18,31)	0.067
Care Services	19(12)	17(10,27)	21 (9)	18(15,26)	0.481	62 (30)	56 (36,78)	52 (23)	56 (39,62)	0.467
Other costs	3 (8)	0 (0,2)	3 (2)	2 (1,4)	**0.042***	6 (6)	4 (1,9)	11 (10)	9 (4, 19)	0.097
Total cost per day	**37(21)**	**37(27,46)**	**43(10)**	**41(38,44)**	**0.132**	**111(37)**	**111(89,133)**	**101(32)**	**110(81,127)**	**0.527**

*SD=Standard deviation, IQR=Inter-quartile range, HCP=Home Care Package; ¥Two sample Wilcoxon rank sum (Mann-Whitney) test used to generate p-values for comparison between the '0-12 months on CDC' group versus the '>12 months on CDC' group *Statistically significant result at 0.05 level of significance*

Table 8.4 above illustrates the variation in daily costs by HCP levels and further by the time on CDC. For participants receiving HCP 1/2 higher costs were observed for administration, care coordination and other expenses in the >12months group. On the other hand, for those receiving HCP 3/4, higher costs on administration were observed for participants who were newly initiated on CDC (0-12 months).

Other expenses (third party provided services)

Table 8.5 below shows the difference in expenses on other items by HCP level and by time on CDC. Major cost items in this category were transport (to and from appointments or events), foot-care/podiatry, supplies (nursing and continence supplies), home maintenance (gardening, cleaning, lawn maintenance, contractors), equipment purchases or hire, other care (clinical care, occupational therapy, physiotherapy, social worker, nutritionist), other assistance in the home (meal preparation and other forms of domestic assistance), and social activities (entertainment, group activities or other programs).

The biggest cost drivers for the total sample were equipment, transport, home maintenance and supplies, in that order. However, this differed by HCP level, with HCP level 1/2 spending more on home maintenance and transport while HCP level 3/4 spent the most on equipment and supplies. When older people who had spent the same time on CDC were differentiated by their levels of care, as expected HCP level 3/4 spent significantly more on supplies for both the newly initiated and those who had been on CDC for longer. Also, for those who had been on CDC for longer, HCP level 3/4 spent more on other forms of care such as occupational therapy and physiotherapy than the lower levels of care.

Table 8.5: Other costs (as total costs) for the different HCP levels with same Time on CDC

Cost category	Total sample (n=95)		0-12 months (n=57)					>12 months (n=38)				
			HCP level 1/2 (n=39)		HCP level 3/4 (n=18)		p-value¥	HCP level 1/2 (n=20)		HCP level 3/4 (n=18)		p-valu
	Mean (sd)	Median (IQR)	Mean (sd)	Median (IQR)	Mean (sd)	Median (IQR)		Mean (sd)	Median (IQR)	Mean (sd)	Median (IQR)	
Transport	208 (330)	5 (0,332)	78 (146)	0 (0,77)	135(255)	0 (0,187)	0.754	398(462)	267(9,644)	350 (376)	310(0,695)	0.575
Foot-care	47 (118)	0 (0,0)	10 (56)	0 (0,0)	39 (106)	0 (0,0)	0.147	49 (127)	0 (0,61)	133 (170)	18(0,260)	0.112
Supplies	179 (518)	0 (0,120)	28 (81)	0 (0,0)	316(383)	99(0,538)	**0.0001***	3 (11)	0 (0,0)	568(1026)	164(0,435)	**0.0002***
Home maintenance	194 (461)	0 (0,143)	130(452)	0 (0,0)	90 (173)	0 (0,68)	0.599	358(479)	66 (0,760)	257 (611)	0 (0,40)	0.196
Equipment	313(1584)	0 (0,0)	6 (29)	0 (0,0)	67 (162)	0 (0,0)	0.173	62 (136)	0 (0,47)	1506(3458)	0 (0,540)	0.501
Other care	105 (380)	0 (0,0)	10 (57)	0 (0,0)	52 (133)	0 (0,0)	0.137	34 (92)	0 (0,0)	442 (783)	20 (0,488)	**0.027***
Other assistance	21 (122)	0 (0,0)	37 (187)	0 (0,0)	9 (40)	0 (0,0)	0.982	9 (27)	0 (0,0)	12 (38)	0 (0,0)	0.869
Social	60 (292)	0 (0,0)	84 (383)	0 (0,0)	124(361)	0 (0,0)	0.662	1 (4)	0 (0,0)	10 (22)	0 (0,0)	0.111
Unspecified	1 (6)	0 (0,0)	0 (0)	0 (0,0)	0 (0)	0 (0,0)	-	3 (11)	0 (0,0)	0 (0)	0 (0,0)	0.403

*SD=Standard deviation, IQR=Inter-quartile range, HCP=Home Care Package; * Statistically significant result at 0.05 level of significance, ¥Two sample Wilcoxon rank sum (Mann-Whitney) test used to generate p-values for comparison between HCP level 1/2 and HCP level 3/4 at the same time on CDC.*

8.3.5 Predictors of daily total costs

Table 8.6 below presents the results of a GLM regression analysis estimated to explore the relationship between daily costs and potential predictors. A statistically significant relationship was observed between daily expenditures and two variables: ‘hours of formal care support’ received and the ‘HCP level’. This result suggested that when all other independent variables are controlled for, these two variables have a statistically significant positive relationship with the cost of services per day; with more hours of support and a higher HCP level being associated with higher daily costs. As the interaction term between ‘hours of formal care support’ and ‘HCP level’ was insignificant, the relationship between costs and ‘hours of formal care support’ did not differ according to an HCP level. Similarly, the relationship between cost of services per day and HCP level did not differ according to the hours of support received. Further, the insignificant interaction term between ‘HCP level’ and ‘Time on CDC’ suggested that the relationship between cost of services per day and HCP level did not differ according to the time clients were in receipt of CDC services.

Table 8.6: Relationship between expenses per day and key demographic characteristics:

Variable	**Coefficient**	**Standard error**	**p-value**
Age	-0.002	0.007	0.720
Hours of formal care support	0.069	0.026	**0.007***
Time on CDC	0.142	0.116	0.220
Gender	-0.152	0.095	0.111
Living arrangement	-0.064	0.096	0.503
HCP level	1.162	0.257	**0.000***
HCP level*Time on CDC	-0.217	0.180	0.228
HCP level*Hours of formal care support	-0.037	0.033	0.270
Constant	3.566	0.579	**0.000**
Number of observations		93	
AIC		10.258	
BIC		-362.584	

*Description of variables: Age - continuous variable; Hours of formal care support - continuous variable, Time on CDC – dummy variable (0= 0-12 months, 1= > 12 months), Gender - Dummy variable (1=Female, 0=Male), Living arrangement - Dummy variable (0=on your own, 1= with others), HCP level – categorical variable (0=HCP level 1/2, 1=HCP level 3/4); *Statistically significant result at 0.05 level of significance*

8.4 DISCUSSION

The study provides unique insights into the types of services being accessed and their relative proportions in contributing to overall costs of care at an individual level. The results showed that over 50% of costs were due to care services and it was evident that regardless of the HCP level, administration and case coordination/care management fees accounted for a significant proportion of total costs: nearly 40% for the total sample, 41% for HCP level 1/2 and 38% for level 3/4.

As highlighted in chapter 1, the government is the principal funder of the aged care sector, spending AUD$16.2 billion in 2015-16 and funding is expected to increase to $20.8 billion by 2019-20 (Aged Care Financing Authority, 2017a). From 2016-17 to 2019-20, a total of $78.6 billion was allocated towards aged care
with government expenditure on community aged care services estimated to increase by 16.7% (compared to 5.9% on residential care) annually in line with increasing demand as evidenced by current trends (Deloitte Access Economics, 2016). The introduction of income-tested client contributions with CDC in the community aged care sector was one of the government's initiatives to balance public and private contributions and slowly shift costs to the clients, making aged care services more financially sustainable. Aged care funding reports for the past three years indicate some evidence of cost-shifting to the client with the client contribution rising from 7% in 2013/14 (Aged Care Financing Authority, 2015) to 10% in 2014/15 (Aged Care Financing Authority, 2016) and consumer expenditure of up to AUD4.6 billion in 2015/16 (Aged Care Financing Authority, 2015, Aged Care Financing Authority, 2016, Aged Care Financing Authority, 2017a). However, it is still too early to observe substantial levels of cost-shifting.

The proportion of costs attributed to administration and care coordination in this study is higher than that obtained in the CDC pilot evaluation where most providers charged between 20-30% of total expenses for administration and case management (KPMG, 2015). Evaluation of individualised budgets pilot implemented in the social care sector (including but not limited to older people) in the UK revealed a care coordination/case management (referred to as support planning) cost of £2218 per annum (2016 equivalent of £2773) (Glendinning et al., 2008). The costs in this study (particularly for HCP level1/2) are comparable to the UK; the annual cost for care coordination/case management is $4015 (£2502) for the total sample with $2190 (£1365) for

HCP level 1/2 and $6935 (£4322) for HCP level 3/4.

When the sample was differentiated by HCP level and by time spent on CDC, it was observed that older people receiving lower level of care and in receipt of CDC services for 12 months or more spent more on administration and care coordination than their counterparts in receipt of CDC services for less than 12 months. This was a cost differential of $5 per day for daily administration and $1 per day for care co-ordination equating to an annual cost saving of $2190 in administration and care-coordination costs for those who are relatively new to CDC. The reasons for this cost differential are not entirely clear, as it is not directly reflected in other costs such as for care services. However, CDC has been associated with improved levels of control and older people who have been newly initiated onto CDC have demonstrated improvement in their capability to perform activities that make them feel valued (Bulamu et al., 2016). Hence, it may be that as service providers have become more familiar and comfortable with CDC and as it has become more embedded as an established service model, they have built consumers' capacity and encouraged them to participate more in the direction and delivery of their own care. This has resulted in a commensurate reduction in the volume and frequency of administration and care coordination expenses for those who have recently initiated (0-12 months). This is consistent with consumers' hopes expressed in the CDC pilot evaluation that with increased client participation there would be a reduction in administration and care coordination fees (KPMG, 2015). It is important to note, however, that for HCP level 3/4, this pattern was not repeated; older people who were in receipt of CDC services for less than 12 months spent more on daily administration and care-coordination relative to those who were in receipt of CDC services for more than 12 months. This finding may be indicative of the increased dependency and the complexity of care needs for older people receiving higher-level packages utilising higher volume of administrative services particularly during the initial stages of receiving care. However, considering that fees charged by the service provider were used as a proxy for cost in this study, the high administration costs can also be attributed to supplier driven charges since the fees charged may also include a cost buffer/level of profit margin for the service provider.

In February 2017, new policies were introduced where by aged care funds are allocated to individuals and not aged care providers as was the case previously. This reform provides the opportunity for older people to transfer their packages from one provider to another and also provides them with the opportunity to choose services from multiple providers if they choose to do so (Department of Health). It is envisaged that over time this reform will lead to increased competitiveness in the market and subsequently lower the cost of administration and care coordination and freeing up more resources to be spent on direct care provision (StewartBrown, 2017).

In considering services purchased from third party providers, it was found that older people who had been on CDC for longer spent more for both HCP levels. Again, this may be associated with their increased levels of control and participation in their care and subsequent purchase of more services besides care. The variation in categories by HCP level, transport, home maintenance and equipment for HCP level 1/2 and other forms of care such as occupational therapy and physiotherapy for HCP level 3/4 reflect the greater care needs in the higher levels of care and the different patterns of care provided in the lower and higher levels of care packages.

The main cost drivers in this study, similar to findings from recipients of individualised budgets in the UK, were receiving more hours of formal care support and a higher HCP level, both of which were associated with higher daily costs (Glendinning et al., 2008). This finding is to be expected to the extent that receiving more hours of support and a higher HCP level are indicators of higher dependency. A higher volume of services is consumed by more dependant older people, which translates into increased cost.

A major strength of this study was that it was the first one of its kind in Australia and internationally to provide a detailed investigation of the main cost drivers for HCPs provided according to a CDC model of services in the community aged care sector. However, there are a few limitations to this study which are important to acknowledge. These include the relatively small sample size and the heterogeneity in the financial statements received from the different aged care service providers, which made it difficult to categorise some cost items. Another limitation was the inability to obtain data on actual costs for cost items. Fees charged by the service provider were used as a proxy for cost and these fees may also include the service provider's profit mark-up. However, this effect is expected to be minimal in this study because all service providers included were not-for-profit.

CONCLUSION

In summary this costing study has highlighted that over 50% of total HCP costs in a consumer directed model of service delivery in the community aged care sector are associated with the provision and receipt of care services. However, administration and care coordination account for nearly 40% of the total costs. Older people receiving HCP 1/2 (compared to those receiving HCP 3/4) and those in receipt of a CDC service for more than 12 months (compared to those in receipt of CDC for a shorter period) spent relatively more on administration and case management/care coordination. The hours of formal care support received and the home care package level were identified as key predictors of daily costs.

This cost analysis was conducted shortly after the system wide initiation of CDC and during a period when aged care places were still being assigned to aged care service providers. With changes in the allocation of HCP funds to clients that commenced in February 2017, it is anticipated that the market will become more competitive over time as consumers can move their HCPs to providers who offer them the greatest value for money in the provision of high-quality services and care. It is therefore possible that service provider fees (administration and care coordination) as a proportion of overall HCP expenditures may reduce over time as service providers compete in the market to provide more direct care services within HCPs at a lower cost to the consumer.

The next chapter presents a summary and discussion of the key messages and findings from this thesis. The strengths, limitations and recommendations for future research are also outlined.

CHAPTER 9

TOWARDS A SUSTAINABLE CDC MODEL OF COMMUNITY AGED CARE SERVICES

This research has examined aspects of the introduction and implementation of a consumer directed care (CDC) model of service delivery in the Australian aged care sector. It has identified instruments that are suitable for measuring quality of life outcomes among older people receiving community aged care services; investigated the changes in quality of life and capability associated with receipt of a CDC model of community aged care services and identified the costs associated with and the cost drivers in the delivery of this model of service. This chapter summarises these key findings and their implications for policy in aged care and provides recommendations for future research documenting the evolution of CDC in the Australian aged care sector.

9.1 SUMMARY OF MAIN FINDINGS

9.1.1 Instruments for measuring quality of life among older people

A systematic review of economic evaluation methodologies applied to assess service delivery interventions in the community aged care sector revealed firstly, the paucity of studies with an economic evaluation focus and secondly, that most studies that had been conducted in this context lacked methodological rigour (Chapter 4). The exclusion of carer impacts was also highlighted as an important omission. Nevertheless, evidence from the review suggested that the most suitable type of economic evaluation to be applied in this sector is a CUA. CUA was recommended as the preferred type of economic evaluation in the community aged care sector with the appropriate choice of instrument for the measurement and valuation of quality of life addressing domains that are important to older people. A second systematic review was conducted to identify the most suitable instrument/instruments to be applied in this sector (Chapter 5). This review revealed that as there was no ideal instrument suitable for application in this context, two or more instruments should be used to capture the broader benefits and aspects of quality of life as defined by older people. The EQ-5D, which is a generic preference-based measure of health status validated for application among older people including those with cognitive impairment, was identified as one such suitable instrument. This is to be applied in combination with a measure with a broader quality of life focus on domains that are important to older people such as the older people-specific ICECAP-O, designed as a measure of capability or the ASCOT designed to measure quality of life outcomes in a social care context such as aged care.

9.1.2. Impact of CDC on quality of life and capability

In line with the extra-welfarist theoretical framework, the outcomes of a CDC model of service delivery were assessed as quality of life and capability in two empirical studies using the five-level version of the EQ-5D (EQ-5D-5L) and the ICECAP-O respectively. The first study was conducted between November and December 2013, during the initiation phase of CDC (Chapter 6) when both the traditional service provider-directed care and CDC were being implemented concurrently. This study compared the quality of life outcomes for older people receiving the two models of care. Although there were no discernible differences in quality of life between both models, older people receiving CDC services reported themselves as having more control than those under traditional care. The second study was conducted between December 2015 and February 2016 following the system-wide transition of all community aged care services to a CDC model of service delivery in July 2015 (Chapter 7). Outcomes in this study were compared based on how long respondents had been in receipt of a CDC service. It was observed that respondents who had been in receipt of CDC services for a shorter time (0-12 months) had better capability. However, respondents in receipt of services for more than 12 months demonstrated increased control and capability in undertaking roles that made them feel valued. Overall at this stage, these two studies have revealed no significant discernible gains in quality of life capability because of the transition to, and length of time spent receiving CDC. Although it is still early days for tangible outcomes to be observed, overall the findings demonstrate the potential for CDC to achieve the key policy goals of greater consumer choice and control through increased participation of older people in the management of their own care.

9.1.3 Costs associated with and cost drivers of a CDC model of service delivery

This research also included a costing study of CDC undertaken from the perspectives of the government and clients (Chapter 8). Over 50% of expenditure was attributed to care services while nearly 40% was allocated to administration and care coordination. Lower fees were observed for consumers who had recently enrolled onto CDC and who were in receipt of lower levels of care (HCP levels 1 and 2). In general, these consumers spent less on administration and care coordination relative to those in receipt of higher levels of care (HCP levels 3 and 4) and in receipt

of CDC for a longer period. This may have been an indication that service provision for CDC services had become more efficient and streamlined with the service providers getting better at providing the new service over time. However, it could also be argued that low administration and coordination fees for the lower levels of care were a loss leader (whereby services are temporarily offered below cost to reduce fees and thereby attract consumers to sign up to a specific service provider and after a specified period fee levels are increased to generate profits). This was unlikely in this case because all service providers involved in the study were not-for -profit.
Another possible explanation for the lower fees was the increased availability of information that explains the CDC model of service delivery for both consumers and service providers through My Aged Care portal (Australian Government). Access to this information may have built capacity for consumers to take on more administration and coordination aspects of their own care.

Further reforms of service provision under CDC commenced in February 2017 where funds are allocated to individuals as opposed to the service providers as aged care places. With portable funding allocation consumers have the liberty to move from one service provider to another in search of better services and lower costs. This is likely to usher in more competition with reduction in the administration and coordination fees and subsequently an increased emphasis of HCP funds on direct care provision. Competition is also expected in the form of product/service differentiation as providers aim to address consumer preferences and increase their market share. Further research on the impact of these reforms on consumer quality of life, choice and control as well as product/service differentiation will be necessary as the reforms get more established in the sector.

9.2 CONTRIBUTION TO LITERATURE AND POLICY

9.2.1 Contribution to literature

This thesis offers the first comprehensive assessment of the impact of CDC services in the community aged care sector in Australia from a health economics perspective. It was novel in adapting and applying the analytical framework, first developed by Donabedian in the context of the health system to illustrate the inter-linking nature of structure, process and outcomes for the delivery of CDC in the aged care sector. Structure and process of service delivery was analysed in the context of the economic concepts of market failure and product differentiation whilst outcomes were analysed within the context of extra-welfarism theory through the measurement of quality of life and capability.

The systematic reviews undertaken in this research modified and updated previous reviews. The first review reported in Chapter 4 was unique in that it was the first of its kind to focus on service delivery interventions in community aged care, which had not been considered by previous reviews. With increased population ageing, service delivery interventions to support older people to age in place and continue living in their own homes are increasingly important. As such, like innovations in health care, economic evaluations to assess the cost effectiveness of new service interventions in this sector are necessary. The review of instruments reported in Chapter 6 specifically identified preference-based instruments suitable for application among older people in a CUA framework for economic evaluation. The quality of life domains identified as important to older people were cross-matched to existing preference-based instruments to establish instruments most suitable for application in this population. This specific focus had not been applied in previous reviews. This research contributes to the body of literature by recommending the application of CUA methodology when assessing service delivery interventions among older people, the application of quality of life instruments with a broader focus that is relevant for older people and the inclusion of informal carer costs and effects.

A comprehensive assessment of the outcomes of care within the extra-welfarist theoretical framework was undertaken applying the new five level version of the EQ-5D (EQ-5D-5L) measure of health-related quality of life in combination with the ICECAP-O measure of capability in older people. This detailed assessment of the outcomes (quality of life and capabilities) associated with transition to and receipt of a CDC model of service had not been undertaken previously.

This research is also the first of its kind to investigate cost and the main costs drivers within home care packages associated with the provision of a consumer directed care model of service delivery in the community aged care sector in Australia. Previous research undertaken in other countries e.g. England and the USA has considered aggregate costs associated with the CDC models of care implemented. This costing study applied a micro-costing approach at the individual level to generate daily and monthly costs of services. Considering the increased financial involvement and portability of HCP by the consumer that commenced in February 2017, these results provide detailed information which is easier to understand and interpret at the level of the individual consumer.

9.2.2 Contribution to health services research and policy

Conducted during the initiation and transition phase of the new policy, the results of this empirical research based on original quantitative data demonstrates early indications for improvements in quality of life and consumer choice and control associated with a CDC model of service delivery for older people. These results suggest that the key aim of CDC to improve quality of life and promote consumer choice and control can be achieved for older people receiving community aged care services in Australia. It therefore provides a framework from which a longitudinal assessment of the impact of CDC in terms of changes in quality of life and wellbeing for consumers experiencing community aged care services could be developed.

The costing study undertaken in this research applied a micro-costing approach based on individual service statements. This type of analysis was not previously possible under provider directed care as costs were typically not individualised at the level of the consumer but were aggregated at the service provider level.

Insight into the cost drivers within the HCP is important to guide policy makers to lobby service providers to design service packages that maximise the individualised funds. Service providers can now focus on developing systems and care programs to minimise the cost of administration and case management and subsequently increase emphasis of HCP funds on direct care provision. Policy makers and government on the other hand should continue to invest in platforms that build older people’s capacity to take on more administration and coordination tasks and therefore reserve increasing amounts of HCP funds for direct care services.

Further reforms of service provision under CDC commenced in February 2017 where funds are allocated to individuals as opposed to the service providers as aged care places. With portable funding allocation, consumers have the liberty to move from one service provider to another in search of better services and lower costs. Over time, price competition among providers can be expected in the form of product/service differentiation as providers aim to address consumer preferences and increase their market share.

Despite the variability in the service statements obtained from the different service providers, this research developed a costing framework for categorising and synthesising cost data assimilated from different service provider organisations operating with different accounting mechanisms (details provided in *Appendix 8.2*). This costing framework offers a useful starting point for the future development of a uniform standardised, systematic and transparent costing framework, which would be beneficial for consumers and for the community aged care sector in general, especially after further reforms implemented in February 2017.

9.3 STRENGTHS OF THIS RESEARCH

Study respondents were older people from five aged care service providers across two states in Australia, South Australia and New South Wales. This provided a relatively wide coverage and mix of older people in both metro and non-metropolitan areas. It therefore provides a reasonable snapshot of older people receiving aged care services in Australia.

The measurement of outcomes was comprehensive assessing both quality of life and capability. In addition, the instruments applied have been widely validated in the literature and are deemed suitable for application among older people.

Another significant strength of this research was the application of robust regression models and generalised linear models to identify variables that are significantly associated with quality of life and capability of older people and the cost/expenditure within the home care packages respectively. These methods consider the distribution of each of these dependent variables and demonstrate existing relationships with several predictor variables. Such methodological rigour provides reliable estimates of the different parameters being assessed.

9.4 LIMITATIONS OF THE RESEARCH

This research was conducted during a period of unprecedented change and evolution of the policy frameworks governing the aged care sector in Australia. Both the traditional provider directed care and the CDC model of services were in existence in 2013 when the baseline quality of life study was conducted, however, only the CDC model was being offered by the time of the follow up study in December 2015. Consequently, although baseline cost and quality of life data could be obtained for both CDC and PDC services, follow-up cost and quality of life data were only available for the former group. As such, a traditional economic evaluation involving a comprehensive longitudinal comparison of consumer directed care and traditional provider directed care in terms of both costs and outcomes was not possible.

As discussed in the empirical chapters of this thesis, another limitation of this work was the cross-sectional nature of these studies. Although regression analysis was applied to demonstrate the relationship between the independent variables (e.g. time on CDC) and dependent variables (quality of life and capability in Chapter 6 and 7 and costs in Chapter 8), it was not possible to establish a causal relationship between these variables due to the very nature of such econometric analysis (Gujarati, 1995). Future research should therefore seek to determine the direction of influence between the independent and dependent variables explored within this thesis.

Despite demonstrating broad coverage of aged care recipients across two Australian states, the small study samples may not be entirely representative of the population of older people receiving aged care services in Australia. Specifically, older people with cognitive impairment, those from indigenous communities and older people from culturally and linguistically diverse (CALD) backgrounds were under-represented.

9.5 RECOMMENDATIONS FOR FUTURE RESEARCH

As was observed in the evaluation of individualised budgets in the UK (Glendinning et al., 2008) and ‘cash and counselling’ in the USA (Brown et al., 2007), the process of enrolment into care, developing care-plans and actual receipt of services takes time as the delivery of CDC models require coordination and integration of consumers and service providers. This research was undertaken during the initiation and transition phases of the community aged care sector from provider directed care to a CDC model. It is therefore recommended that future research is undertaken after CDC has been assimilated into the system and both service providers and older people have adjusted to the new model of service delivery both in perception and practice. Specific recommendations relating to appropriate study samples and design, determining the type of quality of life and cost data to be collected as well as the cost perspective to be taken are presented below.

9.5.1 Study sample

Future research in this area should be conducted in a larger study sample including older Australians with cognitive impairment, indigenous Australians and older people from CALD backgrounds. Epidemiological studies indicate that 1 in 4 older people exhibit symptoms of mild cognitive impairment (Purser et al., 2005). Older people with cognitive impairment constitute a significant proportion (10%) of all people aged over 65 years in Australia, with the prevalence increasing to 30% among those aged 85 years or over and nearly half of older people in residential aged care facilities (AIHW, 2012b). With the loss of communication and memory, the main challenge for this population is their ability to self-represent; most studies rely on proxy respondents to provide feedback on care services and quality of life. However, several studies have demonstrated variations between the proxy and self-rated assessments in this population (Kunz, 2010, Yamanaka et al., 2013, Orgeta et al., 2015). To promote inclusivity, it is necessary that self-assessment is encouraged for example using interviewer-administered questionnaires and the use of audio-pictographic tools that have relatively less respondent burden compared with traditional questionnaires.

Older people from CALD backgrounds account for 22% of Australians aged 65 years and over (AIHW, 2016). Support for older people from CALD backgrounds receiving aged care services is provided through the Partners in Culturally Appropriate Care program which is regulated under the National Ageing and Aged Care Strategy for people from CALD Backgrounds (CALD Strategy) (Department of Social Services, 2015). Through this program, aged care workers receive culturally appropriate training to equip them in caring for older people from CALD backgrounds and older people from CALD backgrounds are supported to access culturally appropriate services. Although 26% of participants in this research were born outside Australia, they did not identify as being from CALD backgrounds. Future research should address the language and cultural barriers faced by older people from CALD backgrounds to participate in research studies and to contribute towards the design of new service innovations using translation/interpreter services in the administration of assessment tools and in the design and delivery of culturally appropriate aged care services.

Although this research did not include indigenous Australians, Aboriginal and /or Torres Strait Islander people constituted 1% of the population of older people in receipt of residential aged care services and 4.3% receiving low level HCP (level 1 and 2) and 1.9% receiving high level HCP (level 3 and 4) in the community in 2014/2015 (Aged Care Financing Authority, 2015). In addition to the mainstream services, there are programs specifically designed for the remote and regional Aboriginal communities under the National Aboriginal and Torres Strait Islander Flexible Aged Care Program (Department of Health, 2015a). These programs are currently not being offered under a CDC model of service. Future research should explore how to promote consumer preferences, choice and control and how to incorporate the unique care and cultural needs of this population into the service delivery programs. When evaluating the impact of interventions in these communities, it is important that tools/instruments applied capture the unique dimensions of quality of life that are relevant to the culture and practices in this population.

9.5.2 Study design

A follow up of this analysis based on a larger study sample of older people in receipt of CDC-based aged care services over a sufficiently long period with repeated measurement of quality of life, capability and costs is recommended to demonstrate the impact of the continued evolution of CDC on quality of life, capability and costs. This will facilitate a more comprehensive understanding of the longer-term impact of a CDC model of community aged care service delivery on older people’s quality of life, choice and control, and expenditure. It is also important that these findings be linked with health service data to explore other factors such as hospitalisation and increased frailty that contribute to deterioration in health status and quality of life.

9.5.3 Quality of life assessment

As highlighted in Chapter 5, there is no ideal preference-based instrument measuring health status and broader aspects of quality of life as defined by older people. The recommendation is to apply two instruments, a preference-based measure of health status and another instrument that measures the broader aspects of quality of life (Makai et al., 2014b, Bulamu et al., 2015). Moreover, research has showed that short questionnaires, such as the EQ-5D-5L and ICECAP-O have a higher response rate compared with long ones especially among older people and those with cognitive impairment (Rolstad et al., 2011). A lengthy questionnaire presents a challenge of respondent burden especially for older people. As such, future research should explore development and validation of a short instrument that incorporates both health status and the broader aspects of quality of life as defined by older people and one that is also suitable for generating QALYs in an economic evaluation framework. This instrument should be comprehensive in its coverage of all aspects of quality of life deemed important to older people whilst being practically easy to administer including among older people with cognitive impairment and the ability to customise it to older people of CALD backgrounds.

9.5.4 Costing

In collecting costing data, the main challenge faced in this research was the variability in the financial statements obtained from the different service providers. There was no uniform financial reporting framework in terms of definition and categorisation of the different items and services purchased. This made it difficult to interpret the statements and extract the data without individual consultation with the service providers. Following policy changes in February 2017 where consumers have more financial control and the option of moving from one service provider to another, it is necessary for policy makers to develop a standard articulate format to generate uniform financial statements across the entire sector and one that is easy for older people to interpret.

9.5.5 Informal carers

Future research should investigate the costs and quality of life impacts associated with CDC from the perspective of carers and wider family networks. Over 80% of the respondents in the studies reported upon in this research indicated that they had an informal carer. Several other studies have also indicated the presence of an informal carer as a determinant in older people's ability to manage their own care and willingness to take up CDC type models of care (Spillman et al., 2007, Glendinning et al., 2008, Ottmann et al., 2009b, Health Foundation, 2011, McCaffrey et al., 2015). In 2015 the economic value of informal care (if all informal care provided in 2015 was replaced by paid formal care) in Australia was estimated at $60.3 billion equivalent to approximately 60% of the health and social work industry (Deloitte Access Economics, 2015). Future research should recognise this contribution and provide a detailed consideration of the costs and outcomes associated with CDC for informal carers.

Estimating the cost of informal care involves identifying the care tasks, measuring the amount of time spent undertaking these tasks and valuation of the time. The identification of care tasks has been indicated as a potentially relatively simple exercise provided that informal care is provided over short periods (van den Berg et al., 2004). However, if care is provided over longer time periods such as is typically the case for spouse/family caregivers and in the care of older people, care tasks may overlap with routine household tasks or carer's leisure time, for example preparing meals while watching the television, a concept referred to as 'joint production' (van den Berg et al., 2004). It is therefore important for a study to provide specific guidelines to facilitate the appropriate identification of informal care tasks (Goodrich et al., 2012). Time may be valued according to several approaches. The most common approach is to value time spent by carers according to their lost productivity based on the friction cost method and the human capital approach (Koopmanschap et al., 2008, van den Hout, 2010). Unlike productivity loss associated with illness or disease or in cases where someone is leaving work to informally care for a family member, productivity loss as a result of providing informal care does not involve tasks with a direct monetary value and therefore the human capital approach and friction cost method may not be accurate in its valuation (Andersson et al., 2002, Posnett and Jan, 1996). Other methods have been proposed in the literature generally classified as revealed preference methods (opportunity cost, proxy goods and wellbeing valuation), stated preference methods (contingent valuation and conjoint analysis) and others (quality of life, well-being) (van den Berg et al., 2004, Koopmanschap et al., 2008, Weatherly et al., 2014, Posnett and Jan, 1996). Carer's utility is incorporated in some valuation methods such as contingent valuation, conjoint analysis and wellbeing valuation but not in the opportunity cost and proxy goods method.

A relatively new instrument the Carer Experience Scale (CES) which has been specifically designed for carers to measure and value the impact upon quality of life may be particularly helpful (Goranitis et al., 2014, Al-Janabi et al., 2011). However, incorporating carers' quality of life into an economic evaluation framework is an issue of contention and varies between studies. Some studies have summed carer effects together with the care recipient's effects and considered them together in the base case analysis or incorporated in the sensitivity analysis (Newall et al., Bilcke et al., Getsios et al.) while other studies report carer's effects in disaggregated format (Wu et al., 2003, Gitlin et al., 2010). Another challenge for quality of life assessment is how to separate carers' quality of life from the effect of the caring role on quality of life and the lack of consensus on how carer's quality of life is aggregated and reported when considered together with care recipient's quality of life in a cost effectiveness ratio (Hoefman et al., 2013, Weatherly et al., 2014). A systematic review on the inclusion of informal care in economic evaluation established no consensus on the preferred valuation method or the inclusion of both costs and outcomes of informal care (Goodrich et al., 2012). However, most studies identified applied the opportunity cost and proxy goods methods for valuation and over half of the studies considered the carer's outcomes (Goodrich et al., 2012). As a counterpoint Koopmanschap et al. (2008) argue that incorporating both carer costs and outcomes in the cost effectiveness ratio (CER) may result in double counting as carers may have considered their quality of life when valuing their time (Koopmanschap et al., 2008).

More recently it has been recognised that informal care may be included on either side of the ICER depending on the valuation method used and the type of economic evaluation being applied. For instance, carer effects may be accounted for on the cost side of the equation if monetary methods of valuing benefits are used and on the effects side when non-monetary methods of valuing benefits are applied (Hoefman et al., 2013, Weatherly et al., 2014).

CONCLUSION

Overall, the findings from this thesis demonstrate early indications for improvements in quality of life and consumer choice and control associated with a CDC model of community aged care service delivery for older people. As the CDC model of service delivery becomes more widely established and embedded into community aged care service provision in Australia, the methodologies applied within, and the main findings from, this thesis provide a useful basis for future longitudinal studies. Such studies should be undertaken with larger and more representative samples to provide a detailed assessment of the evolution of CDC and its longer-term impacts for older people and their informal carer-givers.

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APPENDICES

Appendix 2.1: Proposed reforms to the community aged care system

Problem/challenge	**Proposed/implemented reform**
Delivery of care	
Entry into the system and access to information	The 'My Aged Care' website and call centre were established as a starting point for the provision of government funded aged care services. Through this service older people access information about services and service providers, the steps involved in accessing these services as well as assessment of care needs and financial co-contributions for older people in need of basic care under the Commonwealth Home Support Programme (CHSP).
Continuity of care and promoting consumer choice	➢ Entry level basic community services for older people are accessed through 'My Aged Care' under the CHSP ➢ Support for carers is also provided under the CHSP ➢ Discrete care packages were replaced with a single system of integrated and flexible care provision through the home care packages (HCP). This includes support in activities of daily living (ADL) and instrumental activities of daily living (IADL) as well as specialised care such as for dementia, which are now accessed within each HCP level. ➢ The Older Persons Advocacy Network (OPAN) was established to support older people and their families in accessing and managing their care. Support for care coordination and case management is also provided by designated staff from the aged care service provider
Stopping and reversing functional decline	Time limited (up to 8 weeks) re-ablement services offering rehabilitation and restorative care to enhance functional independence are provided through the Short-term restorative care program. Assessment for these services is undertaken by the Aged Care Assessment Team (ACAT) and services are accessed through 'My Aged Care.'
Delivery of appropriate respite care	Community based and residential respite care is accessed through 'My Aged Care.' Emergency respite care is provided by the Commonwealth Respite and Carelink Centre.
Integration of aged care services with general health care to improve access and ensure responsiveness of services to aged care needs	There are several in-reach programmes are established by hospitals and residential aged care facilities with multidisciplinary aged care health teams. This is aimed at reducing the cost burdens on the health system and residents' movement between residential and hospital facilities.

Continuity of care for people with disabilities as they age and streamlining of funding mechanisms for aged care and the disability systems	People under the national disability insurance scheme (NDIS) who turn 65 can elect to continue receiving services under NDIS or access services under the Continuity of Support (CoS) programme, which is specifically designed for older people with a disability. Those who are not eligible for these programmes obtain services under the CHSP or through an HCP. Services can also be obtained through the Independent Living Centres. These services are accessed through 'My Aged Care'
Carers	
Because of their caring role, many carers have poor health, financial difficulties and are socially disadvantaged	Carer support is provided through the 'Carer gateway'. This is a national website and call centre that provides support, resources and advice to carers, including access to carer payments and assessment of carers' health wellbeing. Support for carers is also provided through the CHSP.
There are several programs offering carer support but this is administered in an ad hoc way	Streamlined support mechanisms are accessed through the 'Carer gateway'
Cultural and linguistic diversity (CALD)	
Addressing communication barriers and respecting cultural preferences and needs for older people from culturally and linguistically diverse backgrounds	Older people from CALD backgrounds obtain services through 'My Aged Care' including interpreter services through Translating and Interpreting Service (TIS National) and aged care information (brochures, posters and audio) in other languages. Support for families and service providers in negotiating/providing culturally appropriate services is accessed under the Partners in Culturally Appropriate Care (PICAC) program
Services for remote Indigenous communities	Rural, remote and Indigenous aged care services are provided through the Flexible care packages as Multi-purpose services (MPS) and the Innovative Care Program or National Aboriginal and Torres Strait Islander Flexible Aged Care Program
Housing support in the community	
No policy framework for home maintenance and modification (HMM) services, and lack of information systems for planning and development of HMM services at the national or state level	Funding for home maintenance and modification services can be accessed under the designated HCP or CHSP. Information about these services is available through both the 'My Aged Care' and the 'Carer gateway' including eligibility criteria, expected co-contributions, scope of services provided and service providers.

No access standards in building regulations specifically for older people's residential dwellings	The different state governments have developed building design standards for residential housing that meet the needs of older people e.g. the Age-friendly Living: Guidelines for Residential Development in South Australia and State Environmental Planning Policy (Housing for Seniors or People with a Disability) 2004 in New South Wales
Shortage of appropriate and affordable rental housing	It was proposed that the Council of Australian Governments (COAG) would develop a strategic policy framework for providing affordable cost-effective housing for older people
Complex and confusing financial arrangements and contracts in retirement-specific living options	The different states and territories have developed regulation guidelines for retirement villages and other retirement-specific living options
Retirement village legislation differs from one state to another. This imposes costs that deter investment	The development of a nationally consistent retirement village legislation was proposed. This would facilitate transparency in financial arrangements and residents' contractual rights and responsibilities and reduce a significant impediment to new investment in the industry
Funding	
Government subsidy and user contributions in the current system are ad hoc and inconsistent.	Policy framework was setup for income and assets assessment to determine the level of co-contribution required for individuals accessing aged care services, both the CHSP and HCP. This financial assessment is undertaken by the ACAT.
Inadequate supply based on demand and the geographic incidence of that demand	The allocation of aged care places for both community and residential care is now determined based on the nationwide population of older people in need of aged care services.
Consumer contributions vary and they are not linked to the cost of supply or consumers' capacity to pay.	Means-tested co-contributions were introduced for older people receiving CHSP and HCP as income tested fees (ITF). The rate and amount of co-contributions is determined by the Department of Human Services. There are annual and lifetime caps to the co-contributions
Prices set by the government do not entirely reflect the cost of delivering services	The aged care pricing commissioner was appointed to regulate the pricing of aged care services.
Work force	
Aged care service providers are unable to pay fair and competitive wages because existing funding and indexation mechanisms are inadequate	To enhance the attractiveness of the aged care sector to employees, competitive remuneration for the aged care workforce was recommended.

There are no vocational training packages and this leads to poor quality of training in the aged care sector	It was proposed that more accredited courses aimed at developing skills in the provision of aged care services should be developed.
Specialist 'teaching aged care facilities' are limited	The expansion of 'teaching aged care services' was also proposed. Increasing the number of teaching services to provide appropriate training for personal carers and medical, nursing and allied health students and professionals would contribute to upskilling of the workforce and the quality of services delivered.
There is variation in the quality of aged care trainings offered by the different training organisations	To ensure that appropriate minimum standards are applied in the delivery of accredited aged care courses, an independently review of the delivery of these courses was proposed. This would ensure students had the appropriate level of competence and contribute to improving the quality of services
Regulation	
Governance arrangements do not clearly separate policy, regulation and appeals. This creates conflicts of interest, duplication and confusion coupled with increased costs to the industry. The management and accountability structure within the Complaints Investigation Scheme and the Office of Aged Care Quality and Compliance is complex	Two independent agencies were established to monitor quality and complaints. The Australian Aged Care Quality Agency was established to monitor the quality of services provided while the Aged Care Complaints Commissioner was appointed to address consumer complaints and reviews. These will be replaced by the Aged Care Safety and Quality Commission in January 2019
Reporting requirements and regulations are burdensome, duplicative and inconsistent. This imposes unnecessary costs and impedes achievement of the objectives of those regulations.	Reporting frameworks across both community and residential aged care are provided by the Department of Health, Ageing and aged care.

Adapted from the productivity commission report (Productivity Commission, 2011a)

Appendix 4.2: Search strategy used in Medline

# ▲	Searches
1	(community care or home care or community aged care).tw.
2	((geriatric or elder or 'older people') adj2 (home* or apartment* or residence*)).tw.
3	(((home or community) adj5 (dwelling or based or setting*)) or (living adj5 (home or community or independent*))).tw.
4	((community or home* or respite or social or aged) adj5 (care* or welfare* or support*)).tw.
5	Homes for the Aged/ or Health Services for the Aged/ or Social Welfare/ or Community Health Services/ or Independent Living/
6	or/1-5
7	economics/ or Quality-adjusted life years/
8	exp "costs and cost analysis"/ or cost-benefit analysis/ or "cost of illness"/ or exp health care costs/
9	"Value of Life"/ec [Economics]
10	((economic* adj1 (analys* or evaluat* or model*)) or (cost adj2 (effective* or utilit* or benefit or analysis or minimisation)) or ("quality adjusted life year*" or qaly)).tw.
11	or/7-10
12	Aged/
13	"aged, 80 and over"/ or frail elderly/
14	(elder* or geriatric* or old age* or ((old* or aged) adj (person or people* or adult*))).tw.
15	(aged adj ("65" or "70" or "75" or "80" or "85")).tw.
16	or/12-15
17	6 and 11 and 16
18	**limit 17 to (english language and yr="2000 - Current")**

CRITICAL APPRAISAL CHECKLIST
FOR ECONOMIC EVALUATIONS.

Study Design: Any research design incorporating an economic evaluation

Adapted from:

Critical Appraisal Skills Programme (CASP), Public Health Resource Unit, Institute of Health Science, Oxford.

Drummond et al. Methods for the economic evaluation of health care programmes. 2nd Edition. Oxford: Oxford Medical Publications, 1997.

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IS THE ECONOMIC EVALUATION LIKELY TO BE USABLE?

1. Was a well-defined question posed in an answerable form? Consider: • Is it clear what the authors were trying to do?	**Yes**	**Can’t tell**	**No**
2. Was a comprehensive description of the competing alternatives given (i.e. can you tell who did what to whom, where and how often)?			
3. Was there evidence that the programme’s effectiveness had been established? Consider: • Was the study attached to the economic evaluation an RCT? • How valid was the study design used? (N.B. You may want to appraise it using an appropriate checklist).			

HOW WERE OUTCOMES AND COSTS ASSESSED AND COMPARED?

4. Were all the important and relevant outcomes and costs for each alternative identified? Consider: • What perspective(s) was/were taken, e.g. health service, patient, society.	**Yes**	**Can’t tell**	**No**
5. Were outcomes and costs measured accurately in appropriate units (e.g. hours of nursing time, number of physician visits, years-of-life gained) prior to evaluation?			
6. Were the outcomes and costs valued credibly? Consider: • Were opportunity costs considered?			

7. Were outcomes and costs adjusted for different times at which they occurred (discounting)?	**Yes**	**Can't tell**	**No**
8. Was an incremental analysis of the outcomes and costs of alternatives performed?			
9. Was a sensitivity analysis performed? Consider: • Were all the main areas of uncertainty considered?			

WILL THE RESULTS HELP IN PURCHASING FOR LOCAL PEOPLE?

10. Did the presentation and discussion of the results include all, or enough, of the issues that are of concern to purchasers?	**Yes**	**Can't tell**	**No**
11. Were the conclusions of the evaluation justified by the evidence presented?			
12. Can the results be applied to the local population? Consider: • Are the patients similar enough to your population? • Is your local setting similar to that in the study?			

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Economic evaluation	Involves the explicit measurement and valuation of resource consumption or cost and health outcomes (often referred to as consequences or benefits), so that they can be related to the costs of alternative treatment strategies. **N.B.** The economic evaluation needs to be set in the context of the overall quality and relevance of the study. This may mean appraising the study as well. e.g. If the RCT is of poor quality, there's no point pursuing an appraisal of the economic evaluation.
Cost-minimisation analysis (CMA)	Used when the effect of both interventions is identical (or assumed to be identical). Thus, there is no outcome measure - only costs are accounted for.
Cost-effectiveness analysis (CEA)	Used when the effect of the interventions can be expressed in terms of one main outcome measurable in natural units, e.g. improvement in cholesterol level.
Cost-utility analysis (CUA)	Used when the effect of the interventions on health status has two or more important dimensions, e.g. benefit and side effects of treatment. The outcome is a utility unit, e.g. QALY, which combines a quantitative and qualitative measure.
Cost-benefit analyses (CBA)	Used to compare interventions for two different conditions, e.g. hip replacement and CABG. Both costs and outcomes have to be measured in monetary terms.
Perspective	The viewpoint of the economic evaluation. This may be the health service, the patient, society. Generally, broader viewpoints are more relevant to questions about the allocation of resources, but also need careful thought to identify all the relevant outcomes and costs.
Opportunity cost	Addresses the idea that if resources are used in one way, they cannot be used for something else. Resources may be monitory, but may reflect other areas e.g. staff time, operating theatre use.
Marginal costs	The change in total costs resulting from a one-unit increase or decrease in the service, e.g. the cost of one additional patient.
Incremental analysis	The additional costs that one service or intervention imposes over another compared with the additional benefits it delivers.
Sensitivity analysis	The standard method of allowing for uncertainty in economic evaluations. Involves varying the values of key parameters, one at a time, to see if the results of the evaluation are sensitive to the assumptions made.
Discounting	Discounting makes current costs and benefits worth more than those occurring in the future because there is an opportunity cost to spending money now and a desire to enjoy benefits now rather than in the future. e.g. If the money was invested (wisely) now it would be worth more in one year's time.
Quality-adjusted life-year (QALY)	A measure which tries to combine a quantitative measure (months gained, years gained etc) with a qualitative measure of the quality of that time.

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Appendix 5.1: Search strategy used in Medline

Database(s): Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present

# ▲	Searches
1	"Quality of Life"/
2	(QOL or OQOL or HRQOL or HRQL or "quality of life").tw.
3	or/1-2
4	Questionnaires/ or Self report/
5	Health status indicators/
6	(questionnaire? or instrument? or measures or self report? or indices or index or inventory or inventories or tool? or score? or indicator? or scale or scales or rating* or assessment or survey*).tw.
7	ICECAP-O.tw.
8	(SF12 or SF36 or SF6D or ((SF or short form) adj2 ("12" or "36" or 6D))).tw.
9	(EQ5D or EuroQoL or EQ-5D).tw.
10	(ASCOT or WHOQoL OLD or WHO-QoL OLD or "Ferrans and Powers QLI").tw.
11	or/4-10
12	"reproducibility of results"/
13	(reliab* or valid* or reproducib*).tw.
14	Psychometrics/
15	Psychometric*.tw.
16	or/12-15
17	aged/ or "aged, 80 and over"/ or frail elderly/
18	(elder* or geriatric* or old age* or ((old* or aged) adj (person or people* or adult* or resident* or population* or men* or women* or male* or female*))).tw.
19	(aged adj ("65" or "70" or "75" or "80" or "85")).tw.
20	or/17-19
21	(Nursing home* or Long term care or Longterm care or Residential aged care or LTCF or Aged care facilit* or care home* or care facilit* or residential care or "institutionalised elders" or "Institutionalised elderly" or institutionalized elder* or skilled nursing facilit*).tw.

22	((extended care adj2 facilit*) or (geriatric adj2 (home* or facilit* or institution*)) or (long-term care adj2 (facilit* or institution* or setting* or resident* or provider*)) or (LTC adj2 (facilit* or institution* or setting* or resident* or provider*)) or (longterm care adj2 (facilit* or institution* or setting* or resident* or provider*)) or (residential adj2 (home* or care or facilit*)) or (long-stay adj2 (facilit* or institution* or resident*))).tw.
23	Homes for the Aged/ or Health Services for the Aged/ or Nursing Homes/ or intermediate care facilities/ or skilled nursing facilities/ or Long-Term Care/
24	home nursing/ or respite care/ or Home Care Services/ or Social Welfare/ or Community Health Services/ or "Activities of Daily Living"/ or Independent Living/ or Self Care/
25	((community or home* or respite or social or aged or self) adj5 (care* or welfare* or support*)).tw.
26	(((home or community or urban or rural or town or village) adj5 (dwelling or based)) or (living adj5 (home or community or independent*)) or ((retire* or senior*) adj5 (home* or communit* or facilit* or institution* or setting* or context))).tw.
27	or/21-26
28	3 and 11 and 16 and 20 and 27
29	**limit 28 to (english language and humans and yr="2000 - current" and "all aged (65 and over)")**

Appendix 5.2: Details of all the studies included in the review - Classification by instrument and context

Title	**Population**	**Instruments used**	**Main findings**
EQ-5D			
Community-based dependent older people			
a. Cognitive impairment			
Ability to perform activities of daily living is the main factor affecting quality of life in patients with dementia (Andersen et al., 2004)	Denmark N=244	EQ-5D-3L	Being dependent on others to perform activities of daily living was the main detriment to quality of life in this population
Health utility scores in Alzheimer's disease: differences based on calculation with American and Canadian preference weights (Oremus et al., 2014)	Canada N=216	EQ-5D-5L	To avoid biased results, preference weights from the research sample's country of origin should always be applied where possible
Psychometric properties of the EQ-5D in a study of people with mild to moderate dementia (Kunz, 2010)	Germany N=390	EQ-5D-3L	Proxy ratings were significantly lower compared to self-ratings at both the dimension and total score level, although higher levels of agreement were observed for older people with better functioning in activities of daily living.
The use of the EQ-5D as a measure of health-related quality of life in people with dementia and their carers (Orgeta et al., 2015)	UK N=488	EQ-5D-3L	A brief instrument like the EQ-5D-3L could be applied among people with mild to moderate dementia in an interviewer-administered format. Self- and proxy ratings were different (self-ratings being higher) and the caregiving relationship influenced the proxy-ratings; spouse caregivers rated the care-recipients higher compared to adult children acting as caregivers
b. No cognitive impairment			
Predictors of quality of life in older people living at home and in institutions (Borowiak and Kostka, 2004)	Poland N=312	EQ-5D-3L	Depression, health promoting behaviour and both social and physical participation were found to predict older people's HRQoL
Telephone reliability of the French Activity Index and EQ-5D amongst older adults (McPhail et al., 2009)	Australia N=53	EQ-5D-3L	Their findings indicated high levels of agreement between scores obtained when the instrument is administered over the phone or during face-to face interviews

Title	Population	Instruments used	Main findings
Factors Related to Performance-Based Mobility and Self-reported Physical Activity in Individuals 1-3 Years after Stroke: A Cross-sectional Cohort Study (Vahlberg et al., 2013)	Sweden N=195	EQ-5D-3L	The level of self-reported mobility and performance-based mobility were independently related to HRQoL
Residential aged care			
a. No cognitive impairment			
Determinants of health-related quality of life in institutionalized older persons in northern Sydney (Sitoh et al., 2005)	Australia N=612	EQ-5D-3L	Their findings suggested a strong and independent association between health conditions that cause loss of independence, dignity and those that cause pain such as urinary incontinence, Parkinson's disease and increased frailty, and lower HRQoL
Strategies to Implement Community Guidelines on Nutrition and their Long-term Clinical Effects in Nursing Home Residents (Torma et al., 2015)	Sweden N=101	EQ-5D-5L	There were no statistically significant differences in HRQoL for the two groups
b. Cognitive impairment			
Effects of cognitive stimulation therapy Japanese version (CST-J) for people with dementia: A single-blind, controlled clinical trial (Yamanaka et al., 2013)	Japan N=56	EQ-5D-3L	The findings in this study revealed improvements in proxy-rated quality of life but not for self-rated EQ-5D-3L scores
The agreement between proxy and self-completed EQ-5D for care home residents was better for index scores than individual domains (Devine et al., 2014)	UK N=565	EQ-5D-3L	Increased levels of agreement were observed between proxies and self-report data in individuals with depression and lower cognitive impairment. Overall, they argued that proxy data was acceptable for QALYs and index scores but less reliable for domain-specific scores
ASCOT			
Community-based dependent older people			
No cognitive impairment			
What can local authorities do to improve the social care-related quality of life of older adults living at home? Evidence from the Adult Social Care Survey (van Leeuwen et al., 2014)	UK N=29935	ASCOT	Quality of life was negatively associated with difficulty in finding information and advice about services and providers, inappropriate home design for those with functional disabilities and difficulty in getting around the local area or the external environment.

Title	**Population**	**Instruments used**	**Main findings**
Dutch translation and cross-cultural validation of the Adult Social Care Outcomes Toolkit (ASCOT) (van Leeuwen et al., 2015d)	Netherlands N=190	ASCOT	The instrument was valid, reliable and comparable to the English version; however, revisions were suggested for items under the dignity dimension, as respondents did not properly understand them.
An assessment of the construct validity of the ASCOT measure of social care-related quality of life with older people (Malley et al., 2012)	UK N=301	ASCOT and EQ-5D-3L	The ASCOT was found to exhibit good construct validity in this population.
Measuring the outcomes of long-term care (Forder and Caiels, 2011)	UK N=208	EQ-5D-3L ASCOT	The ASCOT had greater construct validity and was more suited than the EQ-5D-3L for assessing quality of life in a population of dependent older people living in the community.
Do direct payments improve outcomes for older people who receive social care? Differences in outcome between people aged 75+ who have a managed personal budget or a direct payment (Woolham et al., 2016)	UK N=339	EQ-5D-3L ASCOT	Unlike the EQ-5D-3L, the ASCOT was able to identify older people with greater social care need; a statistically significant negative relationship between the ASCOT score and the size of the budget was observed.
Residential care			
No cognitive impairment			
Quality of life outcomes for residents and quality ratings of care homes: is there a relationship? (Netten et al., 2012c)	UK N=366	ASCOT	Positive association was observed for quality ratings and residents' SCRQoL outcomes in residential aged care homes but not for residents in nursing homes.
HUI2/3			
Community-based dependent older people			
a. No cognitive impairment			
Measuring health status and decline in at-risk seniors residing in the community using the Health Utilities Index Mark 2 (Zhang et al., 2006)	Canada N=192	HUI2	HUI2 was responsive to changes in health status in this population
Sex differences in the relative contribution of social and clinical factors to the Health Utilities Index Mark 2 measure of health-related quality of life in older home care clients (Maxwell et al., 2009)	Canada and USA N=514	HUI2	Worsening depressive symptoms, multi-morbidity and increasing age were associated with declines in HRQoL. There were no gender differences in HRQoL.

Title	**Population**	**Instruments used**	**Main findings**
b. Cognitive impairment			
Health-related quality of life in Parkinson disease: correlation between Health Utilities Index III and Unified Parkinson's Disease Rating Scale (UPDRS) in U.S. male veterans (Kleiner-Fisman et al., 2010)	Canada N=68	HUI3	Poor self-care and performance in activities of daily living was associated with low levels of HRQoL.
Responsiveness and construct validity of the health utilities index in patients with dementia (Kavirajan et al., 2009)	USA N=408	HUI3 *(proxy completed)*	Proxy ratings were responsive to behaviour disturbances and clinical decline in quality of life but poorly responsive to improvements in behaviour. HUI2 was preferred to the HUI3 in this population
Predictors of Patient Self-Ratings of Quality of Life in Alzheimer Disease: Cross-Sectional Results from the Canadian Alzheimer's Disease Quality of Life Study (Naglie et al., 2011b)	Canada N=370	EQ-5D-3L QWB HUI2/3	Reported symptoms of depression were an independent predictor of quality of life
Predictors of Family Caregiver Ratings of Patient Quality of Life in Alzheimer Disease: Cross-Sectional Results from the Canadian Alzheimer's Disease Quality of Life Study (Naglie et al., 2011a)	Canada N=412	EQ-5D-3L QWB HUI2/3	Depression and functional status and were predictors of proxy-rated quality of life on all the instruments
ICECAP-O			
Community-based dependent older people			
No cognitive impairment			
Comparing measurement properties of the EQ-5D-3L, ICECAP-O and ASCOT in frail older people (van Leeuwen et al., 2015a)	Netherlands N=190	EQ-5D-3L ICECAP-O ASCOT	Compared to the EQ-5D which measures HRQoL, domains within the ASCOT and ICECAP-O measure broader aspects of quality of life. Also, the ASCOT was more responsive to change in quality of life than the ICECAP-O
Exploration of the content validity and feasibility of the EQ-5D-3L, ICECAP-O and ASCOT in older adults (van Leeuwen et al., 2015c)	Netherlands N=10	EQ-5D ICECAP-O ASCOT	The EQ-5D-3L was understood as intended but the role attribute of the ICECAP-O was poorly understood. Preference for one instrument over another was determined by the extent to which it reflected the domains that were relevant to the respondents' present quality of life.

Title	Population	Instruments used	Main findings
Quality of life of older frail persons receiving a post-discharge program (Comans et al., 2013)	Australia N=351	EQ-5D-3L ICECAP-O	Greater quality of life improvement was observed with the ICECAP-O, an older people specific instrument, compared to the EQ-5D-3L.
A validation of the ICECAP-O in a population of post-hospitalized older people in the Netherlands (Makai et al., 2013)	Netherlands N=296	ICECAP-O EQ-5D-3L	The ICECAP-O demonstrated good convergent validity with the wellbeing measures and health status measures (SF-20 and EQ-5D-3L).
Agreement between Patient and Proxy Assessments of Quality of Life among Older Adults with Vascular Cognitive Impairment Using the EQ-5D-3L and ICECAP-O (Davis et al., 2016)	Canada N=71	EQ-5D-3L ICECAP-O	A high level of agreement was observed with the EQ-5D-3L (with perfect agreement on the self-care dimension) but not with the ICECAP-O
Residential aged care			
Cognitive impairment			
Capabilities and quality of life in Dutch psycho-geriatric nursing homes: an exploratory study using a proxy version of the ICECAP-O (Makai et al., 2012)	Netherlands N=122	ICECAP-O EQ-5D-3L	Results of this study demonstrated the convergent and discriminant validity of the ICECAP-O, with significant correlation between capabilities and HRQoL measured by the EQ-5D-3L.
OPQOL			
Community-based dependent older people			
No cognitive impairment			
Dimensions and correlates of quality of life according to frailty status: a cross-sectional study on community-dwelling older adults referred to an outpatient geriatric service in Italy (Bilotta et al., 2010)	Italy N=239	OPQOL	Psychological wellbeing, leisure activities, home and neighbourhood, religion and functional independence were negatively associated with frailty. Better emotional status and higher body mass index were correlated with quality of life in older people of advanced age and the robust older subjects respectively
Older People's Quality of Life (OPQOL) scores and adverse health outcomes at a one-year follow-up. A prospective cohort study on older outpatients living in the community in Italy (Bilotta et al., 2011)	Italy N=239	OPQOL	The OPQOL total score can predict adverse health outcomes such as falls and emergency department admission while the health sub-score predicted admission to nursing homes or death
Frailty predicts trajectories of quality of life over time among British community-dwelling older people (Kojima et al., 2016)	UK N=363	OPQOL	There were variations in quality of life based on frailty; quality of life declines with increased frailty but the least frail older adults show improvement in quality of life over time.

Title	Population	Instruments used	Main findings
An empirical comparison of the OPQoL-Brief, EQ-5D-3L and ASCOT in a community dwelling population of older people (Kaambwa et al., 2015a)	Australia N=87	OPQoL-Brief EQ-5D-3L ASCOT	Relative levels of agreement were observed between the three instruments, with more agreement between the ASCOT and OPQOL-brief compared to the EQ-5D-3L
CASP-12/19			
Community-based dependent older people			
No cognitive impairment			
Loneliness and Quality of Life in Chronically Ill Rural Older Adults (Theeke and Mallow, 2013)	USA N=60	CASP-12	Loneliness is correlated with poor health and lower quality of life in this population
WHOQoL-OLD			
Community-based dependent older people			
No cognitive impairment			
Quality of life and attitudes to ageing in Turkish older adults at old people's homes (Top and Dikmetas, 2015)	Turkey N=120	WHOQoL-OLD	A positive attitude towards ageing was associated with higher levels of quality of life.

Appendix 6.1: Quality of Life Survey Consent Form

School of Medicine
Flinders Clinical Effectiveness
Flinders University
Rm 55, A Block
Repatriation General Hospital, Daws Road
Daw Park Adelaide SA 5041
Tel: 08 8275 2857
Fax: 08 8275 2854

billy.kaambwa@flinders.edu.au

http://www.flinders.edu.au/people/billy.kaambwa

CRICOS Provider No. 00114A

CONSENT FORM

Study name: A survey of your health, quality of life and well-being

Investigators: Dr Billy Kaambwa, Professor Julie Ratcliffe, Professor Maria Crotty, Dr Nikki McCaffrey, Dr Liz Gill, Mrs Julie Stone and Professor Ian Cameron

I …..

being over the age of 18 years hereby consent to participate as requested in the interview for the research project on views and preferences for consumer directed care.

- The nature and purpose of the research project has been explained to me. I have been given time to consider whether or not I wish to take part and have had the chance to discuss taking part in this study with a family member or friend. I understand it, and agree to take part.
- I know that I will be asked to take part in an interview discussing my health, quality of life and wellbeing.
- I understand that I may not benefit from taking part in the study and any risks have been explained to my satisfaction.
- I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
- I know that I can withdraw from the study at any stage and that this will not affect my care, now or in the future.

- I am aware that I should keep a copy of the Information Sheet and Consent Form so I can look at them in the future should I wish to.

Participant's name:

____

Signed:

____

Dated:

____

I certify that I have explained the study to the volunteer and consider that she/ he understands what is involved and freely consent to participation.

Researcher's name: ____

Signed: ____

Dated:

____

Please keep a copy of this form for you records

Appendix 6.2: Quality of life survey questionnaire

A survey of your health, quality of life and well-being

We would like to invite you to participate in a research project that seeks to assess your health, quality of life and well-being in general.

The results of this survey will be used to write a report for policy makers and aged care service providers as well as papers for academic publication.

Our work will assist policy makers and aged care service providers to make decisions about how community aged care services can be improved in the future.

Your participation in this survey is entirely voluntary. All of the information you provide will be confidential. It will be used for research purposes only and will not be used in any way in which you can be identified.

Thank you for your co-operation.

Dr Billy Kaambwa [1]
Professor Julie Ratcliffe[1]
Dr Nikki McCaffrey[1]
Ms Julie Stone[1]
Professor Mary Luszcz[2]
Professor Maria Crotty[3]
Dr Liz Gill[4]
Professor Ian Cameron[4]

[1] Flinders Health Economics Group, Flinders University
[2] Flinders Centre for Ageing Studies, Flinders University
[3] Department of Rehabilitation and Aged Care, Flinders University
[4] Centre for Rehabilitation Research Studies, University of Sydney

Section A: Demographic Characteristics

Thank you for offering to participate in our research project discussing Community aged-care services. May I ask you a few quick questions today to start the project off? Any information you provide will be treated in complete confidence and used for research purposes only.

A1.	What is your age?	
A2.	What is your gender?	☐ Male ☐ Female
A2.	Do you live	☐ on your own ☐ with your spouse ☐ with other family ☐ with others – not family
A3.	What is the highest educational qualification you have?	☐ primary school ☐ some secondary school ☐ completed secondary school ☐ trade school or similar ☐ undergrad degree ☐ postgraduate degree
A4.	Were you born in Australia?	☐ Yes ☐No, where …………………………..
A5.	What is your postcode?	………………………..
A6.	Do you have someone who helps you and acts as your informal carer?	☐ Yes ☐No
A7.	Have you heard about Consumer Directed Care?	☐ Yes ☐No
A8.	Approximately how many hours of support per week are you entitled to?	……………………………. hours per week ☐ Don’t know/ Not sure

Section B: Health, quality of life and well-being

Here are some simple questions about your health, quality of life and wellbeing in general. These questions are from six different health, quality of life and well-being questionnaires. Some of these questions may seem repetitive but please answer all of them so that we can have the best description of your health, quality of life and wellbeing.

EQ5D 5L

By ticking one answer in each group below, please indicate which statements best describes your health and quality of life today.

Please tick one

B1. Mobility

I have no problems in walking about ☐

I have slight problems in walking about ☐

I have moderate problems walking about ☐

I have severe problems in walking about ☐

I am unable to walk about ☐

B2. Self-care

I have no problems washing or dressing myself ☐

I have slight problems washing or dressing myself ☐

I have moderate problems washing or dressing myself ☐

I have severe problems washing or dressing myself ☐

I am unable to wash or dress myself ☐

B3. Usual Activities *(e.g. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ☐

I have slight problems doing my usual activities ☐

I have moderate problems doing my usual activities ☐

I have severe problems doing my usual activities ☐

I am unable to do my usual activities ☐

B4. Pain/Discomfort

I have no pain or discomfort ☐
I have slight pain or discomfort ☐
I have moderate pain or discomfort ☐
I have severe pain or discomfort ☐
I have extreme pain or discomfort ☐

B5. Anxiety/Depression

I am not anxious or depressed ☐
I am slightly anxious or depressed ☐
I am moderately anxious or depressed ☐
I am severely anxious or depressed ☐
I am extremely anxious or depressed ☐

ICECAP O Index of Capability

By placing a tick (√) in ONE box in EACH group below, please indicate which statement best describes your quality of life at the moment.

B18. Love and Friendship

I can have all of the love and friendship that I want ☐ 4

I can have a lot of the love and friendship that I want ☐ 3

I can have a little of the love and friendship that I want ☐ 2

I cannot have any of the love and friendship that I want ☐ 1

B19. Thinking about the future

I can think about the future without any concern ☐ 4

I can think about the future with only a little concern ☐ 3

I can only think about the future with some concern ☐ 2

I can only think about the future with a lot of concern ☐ 1

B20. Doing things that make you feel valued

I am able to do all of the things that make me feel valued ☐ 4

I am able to do many of the things that make me feel valued ☐ 3

I am able to do a few of the things that make me feel valued ☐ 2

I am unable to do any of the things that make me feel valued ☐ 1

B21. Enjoyment and pleasure

I can have all of the enjoyment and pleasure that I want ☐ 4

I can have a lot of the enjoyment and pleasure that I want ☐ 3

I can have a little of the enjoyment and pleasure that I want ☐ 2

I cannot have any of the enjoyment and pleasure that I want ☐ 1

B22. Independence

I am able to be completely independent ☐ 4

I am able to be independent in many things ☐ 3

I am able to be independent in a few things ☐ 2

I am unable to be at all independent ☐ 1

Do you have any comments that you would like to make about this questionnaire
(please write these in the space provided below)

Thank you for taking the time to complete this questionnaire.

Appendix 7.1: Quality of Life and Wellbeing survey questionnaire and Cost consent form

A survey of your health, quality of life and well-being

We would like to invite you to participate in a research project that seeks to assess your health, quality of life and well-being in general.

The results of this survey will be used to write a report for policy makers and aged care service providers as well as papers for academic publication.

Our work will assist policy makers and aged care service providers to make decisions about how community aged care services can be improved in the future.

Your participation in this survey is entirely voluntary. You do not have to complete all of the questions in the survey if you do not wish to and may withdraw from the study at any time without any affects to your care. All of the information you provide will be confidential. It will be used for research purposes only and will not be used in any way in which you can be identified.

Thank you for your co-operation.

Dr Billy Kaambwa [1]
Professor Julie Ratcliffe[1]
Dr Nikki McCaffrey[1]
Ms Julie Stone[1]
Professor Mary Luszcz[2]
Professor Maria Crotty[3]
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[1] Flinders Health Economics Group, Flinders University
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[4] Centre for Rehabilitation Research Studies, University of Sydney

Section A: Demographic Characteristics

Thank you for offering to participate in our research project discussing Community aged-care services. May I ask you a few quick questions today to start the project off? Any information you provide will be treated in complete confidence and used for research purposes only.

A1.	What is your age?	
A2.	What is your gender?	☐ Male ☐ Female
A2.	Do you live	☐ on your own ☐ with your spouse ☐ with other family ☐ with others – not family
A3.	What is the highest educational qualification you have?	☐ primary school ☐ some secondary school ☐ completed secondary school ☐ trade school or similar ☐ undergrad degree ☐ postgraduate degree
A4.	Were you born in Australia?	☐ Yes ☐No, where …………………………..
A5.	What is your postcode?	………………………..
A6.	Do you have someone who helps you and acts as your informal carer?	☐ Yes ☐No
A7.	Have you heard about Consumer Directed Care?	☐ Yes ☐No
A8.	Approximately how many hours of support per week are you entitled to?	……………………………… hours per week ☐ Don’t know/ Not sure

Section B: Health, quality of life and well-being

Here are some simple questions about your health, quality of life and wellbeing in general. These questions are from six different health, quality of life and well-being questionnaires. Some of these questions may seem repetitive but please answer all of them so that we can have the best description of your health, quality of life and wellbeing.

EQ-5D-5L

By ticking one answer in each group below, please indicate which statements best describes your health and quality of life today.

Please tick one

B1. Mobility

I have no problems in walking about ☐
I have slight problems in walking about ☐
I have moderate problems walking about ☐
I have severe problems in walking about ☐
I am unable to walk about ☐

B2. Self-care

I have no problems washing or dressing myself ☐
I have slight problems washing or dressing myself ☐
I have moderate problems washing or dressing myself ☐
I have severe problems washing or dressing myself ☐
I am unable to wash or dress myself ☐

B3. Usual Activities *(e.g. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ☐
I have slight problems doing my usual activities ☐
I have moderate problems doing my usual activities ☐
I have severe problems doing my usual activities ☐
I am unable to do my usual activities ☐

B4. Pain/Discomfort

I have no pain or discomfort ☐
I have slight pain or discomfort ☐
I have moderate pain or discomfort ☐
I have severe pain or discomfort ☐
I have extreme pain or discomfort ☐

B5. Anxiety/Depression

I am not anxious or depressed ☐
I am slightly anxious or depressed ☐
I am moderately anxious or depressed ☐
I am severely anxious or depressed ☐
I am extremely anxious or depressed ☐

ICECAP-O Index of Capability

By placing a tick (√) in ONE box in EACH group below, please indicate which statement best describes your quality of life at the moment

B18. Love and Friendship

I can have all of the love and friendship that I want ☐ 4

I can have a lot of the love and friendship that I want ☐ 3

I can have a little of the love and friendship that I want ☐ 2

I cannot have any of the love and friendship that I want ☐ 1

B19. Thinking about the future

I can think about the future without any concern ☐ 4

I can think about the future with only a little concern ☐ 3

I can only think about the future with some concern ☐ 2

I can only think about the future with a lot of concern ☐ 1

B20. Doing things that make you feel valued

I am able to do all of the things that make me feel valued ☐ 4

I am able to do many of the things that make me feel valued ☐ 3

I am able to do a few of the things that make me feel valued ☐ 2

I am unable to do any of the things that make me feel valued ☐ 1

B21. Enjoyment and pleasure

I can have all of the enjoyment and pleasure that I want ☐ 4

I can have a lot of the enjoyment and pleasure that I want ☐ 3

I can have a little of the enjoyment and pleasure that I want ☐ 2

I cannot have any of the enjoyment and pleasure that I want ☐ 1

B22. Independence

I am able to be completely independent ☐ 4

I am able to be independent in many things ☐ 3

I am able to be independent in a few things ☐ 2

I am unable to be at all independent ☐ 1

Pearlin Mastery Scale (note Oral interview version used)

How strongly do you agree or disagree with the following statements.

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
B23. You have little control over the things that happen to you.					
B24. There is really no way you can solve some of the problems you have.					
B25. There is little you can do to change many of the important things in your life.					
B26. You often feel helpless in dealing with the problems of life.					
B27. Sometimes you feel that you are being pushed around in life.					
B28. What happens to you in the future mostly depends on you.					
B29. You can do just about anything you really set your mind to do.					

Rosenberg Self-esteem scale

Please read each sentence and then circle the number that shows how often the sentence is true for you.

	Almost always true	Often true	Sometimes true	Not often true	Never true
B30. I feel that I'm a person of worth, at least on an equal plane with others.	1	2	3	4	5
B31. I feel that I have a number of good qualities.	1	2	3	4	5
B32. I am able to do things as well as most other people.	1	2	3	4	5
B33. I feel I do not have much to be proud of.	1	2	3	4	5
B34. I take a positive attitude towards myself.	1	2	3	4	5
B35. I think I am no good at all.	1	2	3	4	5
B36. I am a useful person to have around.	1	2	3	4	5

B37. I feel I can't do anything right.	1	2	3	4	5
B38. When I do a job, I do it well.	1	2	3	4	5
B39. I feel that my life is not very useful.	1	2	3	4	5

Section C: Consent to researchers obtaining data on the cost of the services provided to you by your community aged care provider over the last 12 months.

To determine whether the services provided to you by your community aged care provider over the last 12 months were cost effective for your particular situation, we would like to access information on how much the services that you used cost. Your service provider holds this information and they are ready to release it to us with your consent.

- Do you consent to have this cost information released to us by your community aged care provider?
(please tick the appropriate box below)

Yes ☐ No ☐

- Do you acknowledge that the nature and purpose of this cost information, especially as far as it affects you, has been fully explained to your satisfaction by the research team?
(please tick the appropriate box below)

Yes ☐ No ☐

Name:……………………………………………………….Signature: ……………………………………..

Outcomes for individuals receiving community aged care

Date: …………………………………………….

Do you have any comments that you would like to make about this questionnaire
(please write these in the space provided below)

Thank you for taking the time to complete this questionnaire.

Statement of Services

Client Code	

Statement Period	
from	to
01 Oct 2014	31 Oct 2014

Service Days	**19**
Opening Balance	**$ 642.18**

Add Income

Description	**Amount**
Client Contribution - Fees	$ 67.90
Government Funding (including supplements) : L3 - HUN - 17539	$ 1,628.87
Total Income	**$ 1,696.77**

Less Expenses

Description	**Hours**	**Amount**
Administrative Costs - 11% of income		$ 186.64
Core Advisory & Case Management Services - 24% of income	19 days	$ 407.22
Services		
L3 Consumer Directed Care - Care Services	1.50	$ 75.00
L3 Consumer Directed Care - Domestic Assistance	3.33	$ 166.50
L3 Consumer Directed Care - Personal Care	5.12	$ 294.50
L3 Consumer Directed Care - Transport	1.72	$ 86.00
L3 Consumer Directed Care - Care Services (KM)	6 km	$ 5.53
L3 Consumer Directed Care - Domestic Assistance (KM)	4 km	$ 3.91
L3 Consumer Directed Care - Personal Care (KM)	2 km	$ 1.70
L3 Consumer Directed Care - Transport (KM)	5 km	$ 4.93
Purchases		
	Total Expenses	**$ 1,231.93**

Total this statement	**$ 464.84**
Closing Balance	**$ 1,107.02**

CONSUMER DIRECTED CARE SERVICE STATEMENT

Client Name	
Client Number	
Subsidy Type	HCP Level 2
Service Area	SE Metro
Package Period	10/12/2014 to 09/12/2015
Statement Period	01/01/2015 to 31/01/2015

Package Income Summary

Government Subsidy HCP	$14,313.97
Projected Client Contribution	$890.40
Client Contribution Adjustment	-$81.60
Funds Carried Over from previous Package	$5,658.81
Total Package	**$20,781.58**

Previous Activity

Subsidy received	$857.78
Contribution invoiced	$53.46
Rollover carried	$5,658.81
Less services provided to date	-$772.55
Opening Balance as at 1/01/2015	**$5,797.50**

Current Period Activity

Item	Provider	Units	Average Rate	Debit	Credit
Subsidy received		31 days	$38.99		$1,208.69
Contribution invoiced		31 days	$2.43		$75.33
Administration Fee		$1,284.02	17.5%	$224.75	
Client Care Coordination		0.16 hours	$51.00	$8.16	
Domestic Assistance		9 hours	$40.00	$360.00	
Domestic Assistance		1 hours	$51.50	$51.50	
Garden Maintenance		4 hours	$42.00	$168.00	
Total Package Activity for current period					**$471.61**
Closing Balance including Contingency Available as at 31/01/2015					**$6,269.11**

Future Activity

Item	Provider	Units	Average Rate	Debit	Credit
Subsidy received		150 days	$38.99		$5,848.50
Subsidy received		162 days	$39.50		$6,399.00
Contribution invoiced		1 occurrences	($81.60)		-$81.60
Contribution invoiced		85 days	$2.43		$206.55
Contribution invoiced		168 days	$2.45		$409.92
Contribution invoiced		59 days	$2.46		$145.14
Administration Fee		$12,927.51	17.5%	$2,262.30	
External Processing Fee		$151.00	15%	$22.65	
Client Care Coordination		9 hours	$51.00	$459.00	
Client Care Coordination		6 hours	$55.00	$330.00	
Domestic Assistance		53.5 hours	$40.00	$2,140.00	
Domestic Assistance		39.5 hours	$44.50	$1,757.75	
Garden Maintenance		12 hours	$42.00	$504.00	
Garden Maintenance		11.5 hours	$47.50	$546.25	
Meal Preparation		1 hours	$64.50	$64.50	
Mileage within visits		448.5 KMs	$0.85	$381.23	
Nursing Care RN		15.5 hours	$90.00	$1,395.00	
Nursing Care RN		1 hours	$151.00	$151.00	
Personal Care		3.75 hours	$40.00	$150.00	
Personal Care		14 hours	$44.50	$623.04	
Personal Care		1.5 hours	$51.50	$77.24	
Personal Care		1.75 hours	$54.50	$95.38	
Personal Care		1.5 hours	$62.50	$93.76	
Personal Care		0.75 hours	$64.50	$48.38	
Shopping Assistance - Accompanied		1 hours	$44.50	$44.50	
Social Support		4 hours	$40.00	$160.00	
Social Support		0.75 hours	$43.00	$32.25	
Social Support		0.75 hours	$44.50	$33.38	
Social Support		0.75 hours	$47.00	$35.25	
Social Support		1.5 hours	$51.50	$77.24	

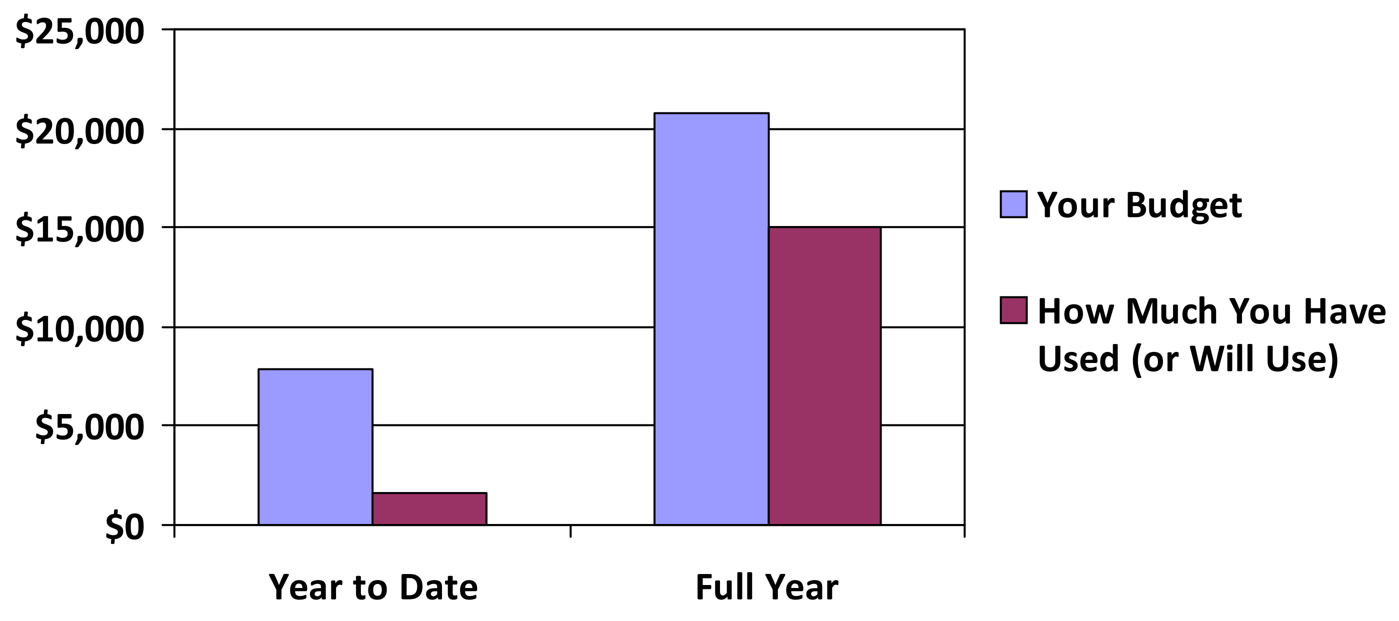
Item	Provider	Units	Average Rate	Debit	Credit
Social Support		1.5 hours	$62.50	$93.76	
Transport		2.5 hours	$40.00	$100.00	
Transport		39.5 hours	$44.50	$1,757.93	
				Projected Activity from 1/02/2015	**-$508.28**

Contingency Allowance Summary

Contingency Allocation to date	$1,431.40
Reduction in Available Contingency due to Leave	$0.00
Contingency Used to date	$0.00
Contingency Used during current period	$0.00
Available Contingency as at 31/01/2015	**$1,431.40**

Please note that unspent client contributions will not be refunded on discharge, except if they relate to an overpayment or a payment in advance of the date from which the services cease.

Expenditure Against Budget



URN:

Statement Number:
Statement Date: 28/02/2016

Statement To: **Services Provided To:**

Funder:
Active Package Days: 28

Statement Period: 01 February 2016 to 28 February 2016

Package Summary	
Opening Balance	$621.16
Funding Allocation	$1106.00
Basic Client Fee (Client Contribution)	$275.80
Contingency Set Aside this Period	($13.72)
Administration	($303.52)
Core Advisory	($110.32)
Case Management	($68.32)
Total Available Budget	**$1507.08**
Total Expenses	($742.50)
Total Expense Adjustments	$0.00
Funding Allocation Adjustments	$0.00
Basic Client Fee (Client Contribution) Adjustments	$0.00
Closing Balance (including Contingency Set Aside this Period)	**$778.30**
Total Contingency Set Aside	$142.36

Package Statement

URN:

Transactions

Date	Description	Units	Rate	Amount	Total
01/02/2016	CW-M-Fri 8am-6pm(1hr min)	1.50	$45.00	$67.50	
01/02/2016	CW-M-Fri 8am-6pm(1hr min)	0.25	$45.00	$11.25	
03/02/2016	CW-M-Fri 8am-6pm(1hr min)	0.50	$45.00	$22.50	
04/02/2016	CW-M-Fri 8am-6pm(1hr min)	1.50	$45.00	$67.50	
08/02/2016	CW-M-Fri 8am-6pm(1hr min)	1.50	$45.00	$67.50	
08/02/2016	CW-M-Fri 8am-6pm(1hr min)	0.25	$45.00	$11.25	
11/02/2016	Cancellation Fee:CW-M-Fri 8am-6pm(1hr min)	1.50	$45.00	$67.50	
15/02/2016	CW-M-Fri 8am-6pm(1hr min)	1.50	$45.00	$67.50	
15/02/2016	CW-M-Fri 8am-6pm(1hr min)	0.25	$45.00	$11.25	
17/02/2016	CW-M-Fri 8am-6pm(1hr min)	1.50	$45.00	$67.50	
18/02/2016	CW-M-Fri 8am-6pm(1hr min)	1.50	$45.00	$67.50	
22/02/2016	CW-M-Fri 8am-6pm(1hr min)	1.50	$45.00	$67.50	
22/02/2016	CW-M-Fri 8am-6pm(1hr min)	0.25	$45.00	$11.25	
24/02/2016	CW-M-Fri 8am-6pm(1hr min)	1.50	$45.00	$67.50	
25/02/2016	CW-M-Fri 8am-6pm(1hr min)	1.50	$45.00	$67.50	
				Total Expenditure:	**$742.50**

Funding Allocation	
Package Subsidy Level (HCP Level 2)	$1106.00
Funding Allocation	**$1106.00**

Appendix 8.2: Costing framework

This document provides the cost categories and sub categories with cost items under each of them. The two cost categories are the Income and Expenditure. Proposed cost items under each sub-category are summarised below

MONTHLY SERVICE STATEMENT FOR AGED CARE SERVICES

Client name:

Client number:

HCP level:

Service provider:

Statement period:

Cost category	Amount
A. INCOME	
1. Opening balance	
Funds carried over from previous package	
Unspent funds from previous funding period	
2. Government subsidy	
3. Client contribution	
B. EXPENDITURE	
1. Administration costs	
Administration fee	
External processing fee	
2. Care coordination/case management	
Client care coordination	
Core advisory services	
Case management services	
3. Care services	
Domestic assistance	
Nursing care	
Personal care	
Home support worker- day/night/weekend/public holiday	
Other care services	
Nursing or personal care supplies or consumables	
4. Other care	
Podiatry	
Physiotherapy	
Nutritionist	
Occupational therapy	

Clinical care	
Social worker/home visits	
Other allied health professional services	
5. Other assistance in the home	
Garden/lawn maintenance	
Meal preparation	
Cleaning service	
Contractor/house modification or renovation	
6. Equipment and furniture (hire or purchase)	
Personal equipment such as wheel chair	
Furniture to assist in the home such as shower stool, mattress	
7. Assistance outside the home	
Respite care	
Social support going to activities and phone calls	
Shopping assistance	
Travel/transport/mileage within visits	
8. Contingency set aside	