Residential aged care and dementia: A health economic perspective

by

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SUMMARY

Federal government expenditures on residential aged care currently exceed $10 billion per year, and health economics provides an important but underutilized framework for prioritising expenditures. The measurement of quality of life is a key requirement both for health economic analysis and for quality assessment. Importantly, more than half of Australians currently residing in residential aged care facilities have a diagnosis of dementia, and thus the inclusion of people with dementia is paramount in any robust evaluation of residential aged care services. This thesis provides a detailed assessment of the costs of care and quality of life in a residential aged care setting, and highlights the key issues and implications for economic evaluation methodology and practice in this sector.

The four studies contained in this thesis are based on a subset of data from INSPIRED, a large-scale cross-sectional, observational study to investigate services provided in the residential care environment for dementia; Studies one through three used available case analysis, while study four used multiple imputation to account for missing data. Data were collected from 17 aged care facilities for 541 residents across 4 states over the 14-month period from January 2015 to February 2016.

The first study assessed the quality of life of residents and undertook an empirical comparison of the world's most widely-used generic measure of health-related quality of life (EQ-5D-5L) with a condition-specific quality of life measure for dementia (DEMQOL-U) in the full cohort of 541 individuals, which included a high proportion (64 per cent) of people living with a diagnosis of dementia. Self and proxy (family member, friend or carer) assessments of quality of life were also compared and identified generally poor agreement in the utility scores generated by the alternative instruments.

The second study examined the daily operating costs of 17 residential aged care facilities. This study indicated labour costs to be the largest single contributor to total daily operating costs. The assessed level of care need of the residents was identified as a key cost driver.

The third study comprised a comprehensive assessment of health system costs associated with the provision of residential aged care for five South Australian residential aged care facilities (N=180 residents) and investigated the relationships between health care and residential aged care costs according to the size of the facility and geographic location. Findings suggested lower operating costs and lower Medicare costs on average for regional facilities compared with metropolitan facilities but higher pharmaceutical costs.

The final study synthesized costs and outcomes at the individual level to explore the factors which contributed to resident quality of life. Using the same sample of 180 South Australian residents from five South Australian residential aged care facilities, residential aged care and health care utilisation data were combined with individual level factors using generalized linear models (GLM). Findings demonstrated a number of factors which were associated with quality of life in residential aged care including the individual’s level of physical functioning and their access to and utilisation of medical services. A greater understanding of this vulnerable population may inform a more tailored approach to residential aged care delivery in the future.

LIST OF PUBLICATIONS AND ABSTRACTS ARISING FROM THIS THESIS

Publications

Easton, T., Milte, R., Crotty, M., & Ratcliffe, J. (2016). Advancing aged care: a systematic review of economic evaluations of workforce structures and care processes in a residential care setting. *Cost Effectiveness and Resource Allocation, 14*(12). doi: 10.1186/s12962-016-0061-4

Easton, T., Milte, R., Crotty, M., & Ratcliffe, J. (2017). Where's the evidence? A systematic review of economic analyses of residential aged care infrastructure. *BMC Health Services Research, 17*(226). doi: 10.1186/s12913-017-2165-8

Manuscripts under review

Easton, T., Milte, R., Crotty, M., & Ratcliffe, J. (2017b). An empirical comparison of the measurement properties of the EQ-5D-5L, DEMQOL-U and DEMQOL-Proxy-U for older people in residential care. *Quality of Life Research* (Accepted for publication 15 Dec 2017).

Conference Presentations

**denotes presenting author*

Easton, T., Milte, R., Crotty, M., & Ratcliffe*, J. (2016). Self-reported quality of life in residential care: An empirical comparison of the EQ-5D-5L and DEMQOL-U. 38th Annual Australian Health Economics Society Conference, 26-27 September, Fremantle, Australia.

Easton, T., Milte, R., Crotty, M., & Ratcliffe*, J. (2016). Proxy assessment of quality of life in residential care settings: An empirical comparison of the EQ-5D-5L and DEMQOL-Proxy-U. 38th Annual Australian Health Economics Society Conference, 26-27 September, Fremantle, Australia.

Conference Posters

Easton, T, Perimal-Lewis, L, Milte, R, Crotty M, Ratcliffe, J. (2015). Economic Evaluations of Nursing Homes: A Systematic Review of Alternative Models of Care. AcademyHealth 2015 Annual Research Meeting, 14 June, Minneapolis, United States.

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.

The INSPIRED study was a large-scale cross-sectional study, for which the design and data collection was informed and undertaken by a team comprising of researchers, clinicians, and industry stakeholders. When I commenced my candidature, the primary research objectives had already been established, but I was able to contribute to aspects of the study design.

I participated in preliminary discussions with stakeholders and assisted in the study design and ethics process for INSPIRED along with other members of the research team. I was fully responsible for the Facility Cost Survey presented in this thesis. This involved the survey design, as well as the data collection, extraction, cleaning and analysis of all facility-level costs.

For the resident-level component, I was involved in the recruitment of participants and data collection in conjunction with other staff working on the project. I contributed to the resident data collection process at residential aged care facilities, which involved administering PAS-Cog assessments, distributing study information, consenting participants, and completing resident and family member questionnaires via interviews with the residents and family members. I also contributed to data extraction, inputting hard-copy questionnaires into database, data cleaning and data checking. I used the quality of life data from this part of the INSPIRED study to conduct the empirical comparison of three quality of life measures contained in this thesis.

For the health system costs and the synthesis of costs and outcomes reported in this thesis, I used the INSPIRED data from five South Australian residential aged care facilities. This was agreed upon early in my candidature to ensure the data would be available on time, as South Australia was the first state to commence data collection, and there were significant lag times to obtain Medicare and hospitalisation data.

Signed..

Date..

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I would like to thank the aged care organisations, the facility managers and the staff for their time, advice and assistance in collecting the facility cost data. I would also like to sincerely thank the INSPIRED study participants and their family members for their participation and interest in the study. The assistance of facility staff, care worker researchers, facility pharmacists and data collectors in each state is gratefully acknowledged for their efforts.

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CHAPTER 1: INTRODUCTION

This thesis applies a health economic perspective to residential aged care in Australia in order to investigate and improve our understanding of the costs of providing care, the quality of life of older people living with cognitive decline and dementia, and the implications for economic evaluations conducted in a residential aged care setting.

Dementia is a syndrome, which is a collection of diseases with similar characteristics, and is associated with over 100 different underlying diseases (World Health Organization, 2012). Dementia is characterised by the progressive loss of mental and physical functioning in affected individuals, resulting from the ongoing death of brain cells (Australian Institute of Health and Welfare, 2012a). This ongoing death of brain cells is referred to as progressive neurodegeneration, and may affect cognitive, functional, psychiatric, behavioural, and physical abilities, ultimately causing death. There is no cure for dementia, and no medications have yet been found to effectively slow or stop the disease progression (Kenigsberg et al., 2016; Ousset et al., 2014).

The life span of an individual following a diagnosis of dementia is highly variable, but ranges on average from 1.1 to 8.5 years (Brodaty, Seeher, & Gibson, 2012). While a cure has not yet been found, there is a lot that can be done to improve the quality of life of people living with dementia. Current Australian guidelines pertaining to residential aged care recommend that a resident’s preferences be sought and incorporated into care decisions and that care decisions promote the quality of life and dignity of all residents (Commonwealth of Australia, 2006). A greater understanding of this vulnerable population (i.e. people living with dementia), which comprises over half of the residents of Australian residential aged care facilities, may inform a more tailored approach to residential aged care delivery in the future. The suite of studies contained in this thesis is based on a subset of data from the large-scale study named ‘INSPIRED: Investigating services provided in the residential care environment for dementia.’ The INSPIRED study was a cross-sectional, observational study to evaluate the services being provided at residential aged care facilities in Australia, with a particular focus on services for people living with dementia. Data were collected from 17 aged care facilities for 541 residents over a 14-month time period from January 2015 to February 2016.

This chapter provides an introduction and background for the research undertaken in this thesis, firstly providing an overview of Australian residential aged care, and then focusing on the ageing population, the increasing prevalence of dementia, and the importance of considering quality of life in this subgroup in order to increase our understanding and improve the way we provide care in the future. The chapter then moves to a description of the theoretical framework for this thesis and finishes with an explanation of the rationale behind the project.

Health economic evaluation is well established in the health care sector, where it is commonly applied to evaluate pharmaceuticals and medical technologies. However, its use in the aged care sector to date has been minimal. Overall, the work presented in this thesis provides a unique contribution to knowledge with regard to the application of a health economics framework to the aged care setting, understanding the costs of providing care, and the factors associated with quality of life in a residential aged care setting. This thesis also contains one of the first direct comparisons internationally of a generic preference-based measure of health-related quality of life with a dementia-specific preference-based measure in a residential aged care setting.

1.1 Background

1.1.1 Residential aged care in Australia

Residential aged care in Australia is regulated and subsidised by the federal government and is available to people with substantial care needs. Permanent places in care homes are offered to people who are no longer able to be supported in the community, while short-term respite places are available on a temporary basis for older people who need short-term care but are planning to return to their own home. Residents of aged care facilities are predominantly above the age of 80 and this population is typically characterised by high rates of physical and mental illness, dementia, and physical disabilities causing reduced or impaired mobility (Australian Institute of Health and Welfare, 2012b).

Australian federal government expenditure on aged care services was approximately $15.8 billion in 2014-15 with over two-thirds of this ($10.8 billion) being spent on residential care (Steering Committee for the Review of Government Service Provision (SCRGSP), 2016). This federal government expenditure, which provides approximately two thirds of aged care provider’s operating revenues, accounted for 0.9 per cent of gross domestic product (GDP) in 2014-15 and is predicted to increase to 1.7 per cent by 2054-55 (Commonwealth of Australia, 2015).

The government provides daily subsidies directly to care homes based on the level of care required for each resident in three categories: activities of daily living (ADL), behaviour (BEH), and complex health care (CHC). Additional government funding in the form of supplements are also provided for residents with specific care requirements such as oxygen and enteral feeding and for accommodation-related items such as significant refurbishments and newly built facilities. Some rural and remote facilities also receive viability supplements to assist with the additional costs arising from the provision of care in isolated locations with financially disadvantaged populations (Commonwealth of Australia, 2015b). While little is known about differing outcomes between localities in Australian residential aged care facilities, a number of recent studies pertaining to geographical inequalities in health care more broadly have reported a higher burden of ill health outside of major cities (Alston, Allender, Peterson, Jacobs, & Nichols, 2017; Bagheri, Furuya-Kanamori, Doi, Clements, & Sedrakyan, 2017; Youl et al., 2016),

In order to limit its fiscal exposure, the government controls the number of aged care places available. A comprehensive assessment and approval by Aged Care Assessment Services (ACAT) is mandatory for admission to a government-subsidised residential care home. The government also regulates the fees that residential care providers are able to charge their residents. All residents pay a basic daily fee equal to 85 per cent of the single person rate of the basic Age Pension. The Age Pension is a government allowance paid to older Australians, with eligibility subject to income and asset testing as well as a minimum age. Additional co-payments from residents towards accommodation costs and costs of care are subject to income and assets testing.

Since 2009, the number of residential aged care places in Australia has increased by approximately 10 per cent to 195,825 total places as at 30 June 2016 (Aged Care Service lists, 2016). Over the same period, the number of residential aged care facilities has been steadily declining each year. Data collated from the Department of Health indicate the number of residential aged care facilities declined from 2,783 at 30 June 2009 to 2,669 at 30 June 2016 – a drop of 4 per cent. In terms of geographical distribution, approximately 60 per cent of residential aged care facilities are located in major cities, while roughly 40 per cent are located in regional, rural and remote areas of Australia (Alston et al., 2017; Bagheri et al., 2017; Youl et al., 2016).

To understand the overall contribution of this thesis in providing a health economics perspective to the Australian residential aged care sector, it is pertinent to provide a summary of the previous work that has been conducted over the past 20 years and how aged care policy has developed during this period.

1.1.2 Overview of Australian research and reforms in residential aged care

Prior to 1997, residential aged care in Australia was provided in hostels (low care) and nursing homes (high care), and each structure had its own distinct policy parameters and monetary contribution structures. In 1997 the government passed the Aged Care Act 1997 into law, effectively eliminating the distinction between nursing homes and hostels in favour of a single resident classification scale for determining financial subsidy amounts (McIntosh, 1998). This reform also introduced an accreditation system for care homes, requiring care homes to meet a certain standard of care in order to obtain certification to operate (McIntosh, 1998). The Aged Care Act 1997 continues to provide the legislative framework for the regulatory, funding, and quality aspects of Australia's aged care system (Commonwealth of Australia, 2015b). Since 1997, the government has commissioned a number of aged care reviews and aged care policy has continued to progress towards a more harmonised system with a growing emphasis on sustainability from the perspective of the government.

In 1998, following the legislation of the Aged Care Act 1997, the government appointed Professor Len Gray to conduct a two year review of the reforms to assess the access, affordability, quality, efficiency, industry viability, impact on state and territory programs, choice and appropriateness, and other considerations such as dementia-specific care (Gray, 2001). The two year review, published in 2001, concluded that the reforms had "delivered substantial improvements to the aged care system" (Gray, 2001, p.xxxi). Many of the recommendations provided by Gray focused on improving cooperation between different care providers and care settings to ensure the best use of resources. There was also a recommendation calling for further investigation into the needs and care options for people with dementia with a specific focus on infrastructure requirements. All seven recommendations were accepted by the federal government (Commonwealth of Australia, 2001).

In 2004, Professor Warren Hogan completed a government-commissioned review of pricing arrangements in residential aged care (Hogan, 2004). The Hogan Review examined current and alternative funding arrangements for the industry; operating and capital cost pressures; efficiency and productivity; long-term sustainability; long-term financing options and produced a number of recommendations for reform. The government response placed emphasis on initiatives to build better aged care homes by targeting assistance more directly to the needs of the residents and to improve quality of care through supplements and performance benchmarks. The response also included an increased viability supplement for rural and remote facilities as well as a commitment to introduce new financial supplements in 2006 to better target assistance to residents with dementia and provide support for research into neuro-degenerative diseases.

Following on from the Hogan Review, the accounting and consulting firm Grant Thornton undertook a nation-wide aged care survey with the support of Professor Warren Hogan. This survey collected data from 686 facilities (approximately 25 per cent of the residential aged care industry) on financial performance, major influences on provider operations, and development options for the future. The results highlighted a disincentive in the sector to build new aged care facilities, as the modern facilities catering to consumer preferences for privacy and comprehensive care, for instance by providing single rooms rather than shared, were earning only half as much as the older institutional-style facilities (Grant Thornton Australia, 2008). Further research into financial viability was undertaken by Deloitte Access Economics in 2009 and 2011, reaffirming the disincentive to invest in residential aged care infrastructure (Access Economics, 2009; Deloitte Access Economics, 2011).

In 2011, the Productivity Commission published a report which reviewed the Australian aged care sector and developed regulatory and funding options for improved residential and community aged care (Productivity Commission, 2011). This report was the catalyst for a number of reforms and legislative changes including the introduction of a national contact centre, a complete overhaul of the funding system, and plans to implement national voluntary quality indicators for aged care providers. These most recent reforms placed an emphasis on consumer choice, sustainability and affordability, and aimed to stimulate investment and growth in the aged care industry.

In a bid to improve the sustainability of the aged care sector, much of the research noted above has focused on the financial viability, or profitability, of aged care organisations. The issue of quality has also been a recurring topic, with the 2011 Productivity Commission report *Caring for Older Australians* stating “the ultimate objective of aged care is the ‘wellbeing’ or quality of life of the care recipient” (p.212) (Productivity Commission, 2011). The issue, however, is a lack of research in this area from which to inform service delivery (Hogan, 2004). Presently, the main process in place to ensure quality of care is the Accreditation program implemented by the Aged Care Standards and Accreditation Agency (Productivity Commission, 2011). In order to be eligible for government subsidies, aged care facilities must be accredited. Within a quality assurance framework, accreditation assesses an organisation’s processes in a number of areas such as privacy and dignity, security, fire safety, management systems, and staff development. The accreditation requirements are largely seen as successful in that they set a minimum standard for care quality and remove underperforming homes (Gray, 2001; Hogan, 2004; Productivity Commission, 2011). Aged care facilities must meet all requirements (there are 44 in total), which include items such as the need to have ‘systems in place to identify and ensure’ regulatory compliance (Sch 2 pt 2 Item 2.2), as well as ensuring that all management and staff have ‘appropriate knowledge and skills to perform their roles effectively’ (Sch 2 pt 2 Item 2.3) (Commonwealth of Australia, 2014). However, a long standing critique of this system is its omission of quality of care indicators (beyond a minimum standard) or health and quality of life outcomes (Gray, 2001; Hogan, 2004. Accreditation focuses primarily on the processes a facility has in place and not the outcomes or quality of life of the residents themselves.

More recently, the policy focus in the Australian aged care sector has largely shifted towards greater consumer choice and flexibility in the care provided. In the home care setting, a model of service delivery called ‘Consumer Directed Care’ was introduced to all home care packages from 1 July 2015, allowing consumers to have more choice and control about the type of care and services they access (Commonwealth of Australia, 2015b). While there is currently no similar program in the residential care setting, there is potential for this program to transition to the residential care setting in the future. The implications of this could be significant for resident quality of life, as consumers would presumably have a greater ability to choose between service providers and residential care facilities to best meet their needs.

In summary, there are two key areas of focus in the current aged care policy setting. Firstly, there is the issue of financial viability more broadly, but also in the context of regional and remote facilities. Secondly, quality of life in the context of increasing prevalence of dementia in Australia’s aging population, and also in the push towards more consumer choice and flexibility.

1.1.3 Aged care and dementia

As highlighted in the summary of research and reforms in aged care policy above, a continuing challenge in the aged care sector is the provision of care for people with dementia. As of 2011, more than half (52 per cent) of the permanent residents in Australian aged care facilities had a recorded diagnosis of dementia (Australian Institute of Health and Welfare, 2012b). The burden of dementia in the Australian community has been acknowledged by the Australian government who, in 2012, recognised dementia as a National Health Priority Area (Australian Institute of Health and Welfare, 2012a).

Alzheimer’s disease is the most common type of dementia, followed by vascular dementia, frontotemporal dementia, and dementia with Lewy bodies (Australian Institute of Health and Welfare, 2012a). Symptoms and progression vary between individuals as well as between types of dementia. Dementia affects five domains: cognitive, functional, psychiatric, behavioural, and physical (See Table 1-1).

Table 1-1 Domains affected by dementia

Domain	Description
Cognitive	*Memory (creating new memories), judgment, insight, reasoning, planning, empathy*
Functional	*Instrumental activities of daily living (IADLs): complex skills needed to successfully live independently, such as preparing meals, managing finances, shopping, using the telephone, housework, and managing medications* *Activities of daily living (ADLs): basic self-care tasks such as feeding, toileting, dressing, bathing, and grooming*
Psychiatric	*Common symptoms include apathy, depression, and anxiety*
Behavioural	*Common symptoms include aggression, agitation, wandering, social and sexual dis-inhibition, and verbal outbursts*
Physical	*Incontinence, impaired swallowing, not eating, mobility (dyspraxia)*

Source: Annear et al. (2015)

Dementia has a powerful impact on a person's life and on the lives of their friends and family members. The progressive decline in cognitive and functional abilities often leads people living with dementia and their family members to seek care services, whether through community or residential care avenues (Australian Institute of Health and Welfare, 2012a). Tony Schumacher Jones, a clinician with the Dementia Behaviour Management Advisory Service and 2013 Churchill Fellow, described the experience of dementia as "intensely human":

> *For the person with dementia it affects their very being; their sense of self, their identity, the meaning of their lives, the relationships they have with others, how they see themselves and how others see them. (Jones, 2014, p. 16)*

Dementia prevalence increases dramatically with age from roughly 3 per cent in those aged 70 to 74 to over 20 per cent for those aged 85 and over (Ferri et al., 2005). Expert consensus estimates the number of people living with dementia will almost double every 20 years, reaching over 81 million people worldwide by 2040 (Ferri et al., 2005). This drastic projected increase in the prevalence of dementia will inevitably increase demand for dementia care services.

Australia, as with the majority of developed nations, is undergoing significant shifts in its population structure. Over the next 40 years, Australia's traditional working age group, comprising those aged 15 to 64, is projected to be a significantly smaller proportion of the population (declining from 66 to 60 per cent) while those aged over 65 will be a much greater proportion (increasing from 13 to 18 per cent) (Commonwealth of Australia, 2015).

Figure 1-1 highlights Australia’s ageing population structure by illustrating the proportion of the total Australian population falling into four age categories: 0 to 14; 15 to 64; 65 to 84; 85 and over, at three time points: the present; 40 years in the past; and 40 years into the future.

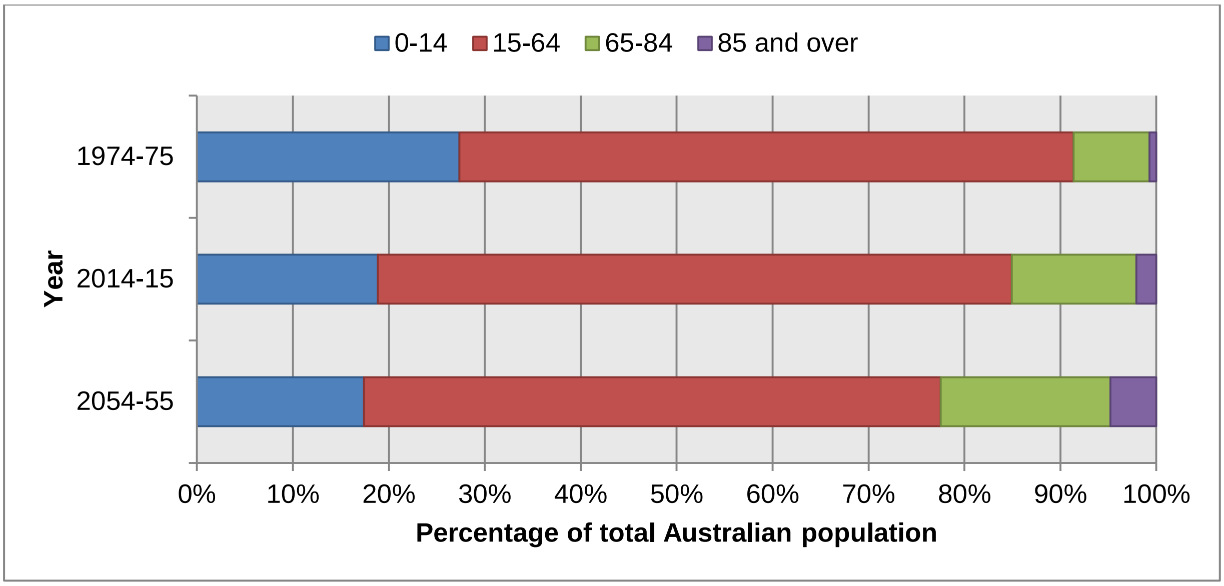


Figure 1-1 Australia's shifting population structure 1974 to 2055. Data source: 2015 Intergenerational Report (Commonwealth of Australia, 2015)

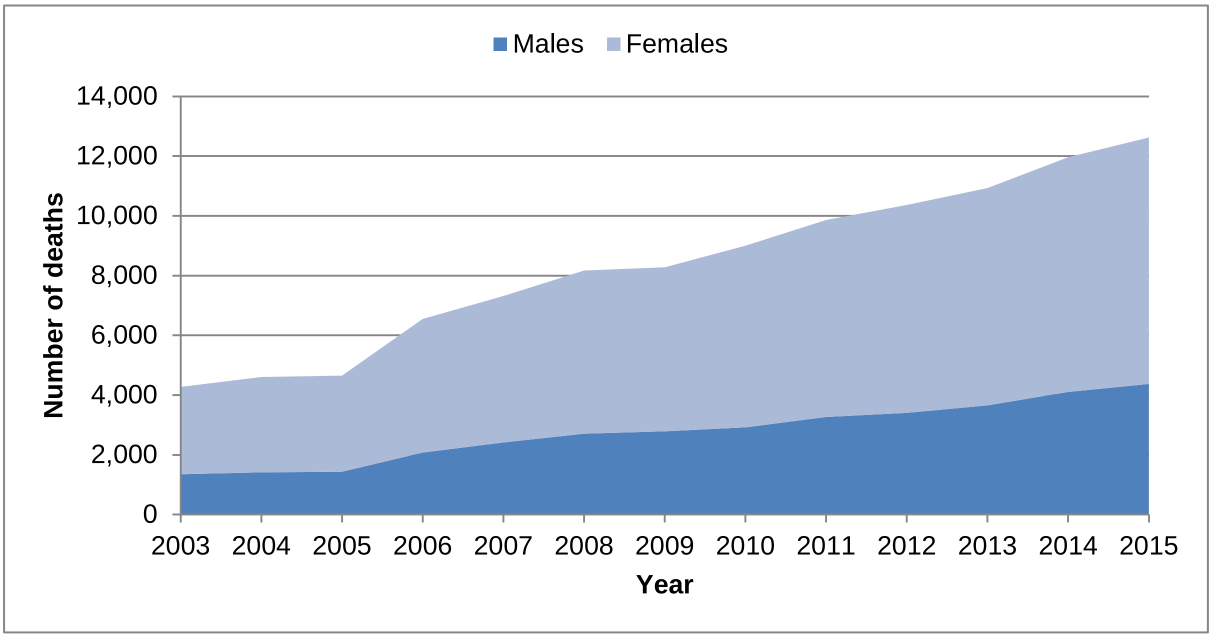


Figure 1-2 Deaths from dementia in Australia from 2003-2015 (Australian Bureau of Statistics, 2014, 2016)

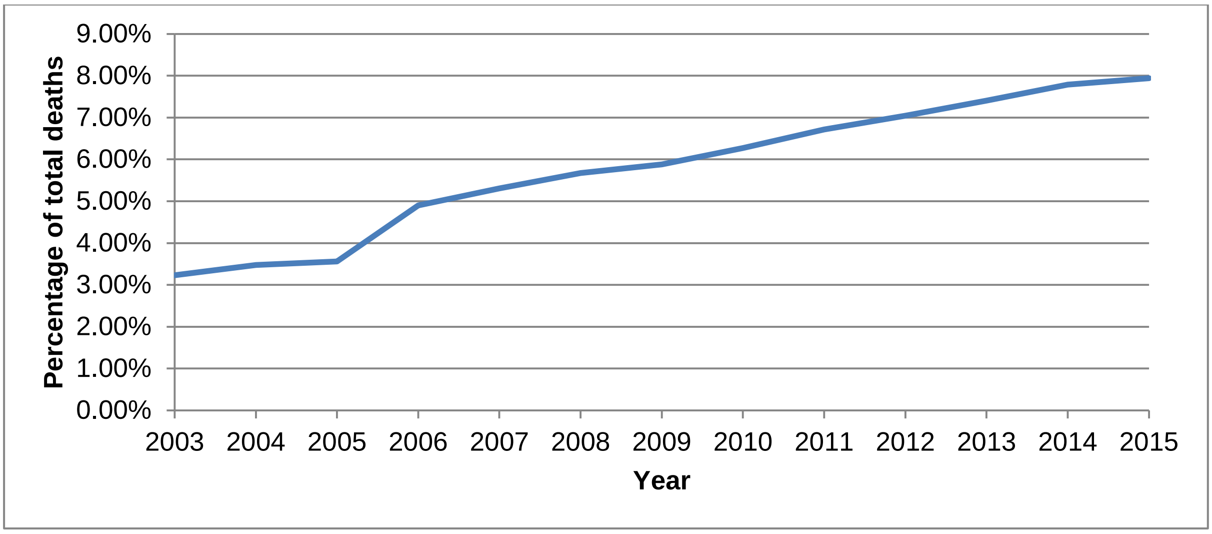


Figure 1-3 Deaths from dementia as a percentage of total deaths in Australia from 2003-2015 (Australian Bureau of Statistics, 2014, 2016)

Deaths from dementia in Australia have been steadily climbing over recent years, and females are more highly affected than males (Figure 1-2). Between 2003 and 2015, deaths from dementia in Australia increased from 3 per cent of total deaths to 8 per cent of total deaths, as illustrated in Figure 1-3. This is likely an under-representation of the true value, as dementia is known to be under-diagnosed and under-reported (Department of Health, 2013).

To illustrate the progressive nature of dementia, an example of symptoms associated with each stage of Alzheimer’s disease is presented in Table 1-2. Mild symptoms can include things such as forgetting the names of people who were just introduced and having difficulty with finances or travel to new locations. Moderate stages can include further memory loss as well as the development of delusions or hallucinations, increased anxiety, sleeping during the day and staying awake at night. In the most severe stages common symptoms include the loss of all speech, urinary and bowel control, and the ability to walk. People in the later stages of Alzheimer’s disease typically become bedridden and often die from sepsis or pneumonia. These descriptions are taken from the Functional Assessment Staging (FAST) scale which is an Alzheimer’s disease-specific assessment scale which stages the disease based on a person’s functional ability and activities of daily living (ADL) (Reisberg, 1988).

Table 1-2 Example of symptoms associated with the typical progression of Alzheimer's disease. Source: Functional Assessment Staging (FAST) scale

Mild	Moderate	Severe
• unable to remember names of persons just introduced to them • difficulty with finances, counting money, and travel to new locations • knowledge of current and recent events decreases	• may not know the date/ year or where they live; begin to forget the names of family members or friends • more assistance with activities of daily living (i.e. bathing, toileting, eating) • may develop delusions, hallucinations, or obsessions • may show increased anxiety and may become violent • begin to sleep during the day and stay awake at night	• all speech is lost • lose urinary and bowel control • lose the ability to walk

Source: Reisberg (1988)

In the absence of treatments to slow or stop the progression of dementia, the care and treatment for people living with dementia largely focuses on preserving their abilities, well-being, and quality of life. Research has shown a capacity for people with dementia to comprehend and interact through verbal and non-verbal communications (Annear et al., 2015). An important priority of dementia care research is therefore to improve the quality of life of people living with dementia and their carers.

1.1.4 Quality of life in dementia

The perspectives of people with dementia are central to measuring the impact of service innovations in dementia care (Alzheimer Europe, 2011). Researchers in health economics and other disciplines are increasingly recognising quality of life as an important outcome measure to capture a multi-dimensional perspective of the impact of interventions which includes dimensions such as emotional well-being and social relationships, as well as more traditional health-related outcomes (O'Rourke, Duggleby, Fraser, & Jerke, 2015; Rabins & Black, 2007). A systematic review of factors associated with quality of life of people living in residential aged care facilities highlighted depressive and behavioural symptoms as important factors influencing residents' quality of life (Beerens, Zwakhalen, Verbeek, Ruwaard, & Hamers, 2013).

Assessment of quality of life is a key requirement for quality assessment in residential aged care facilities, as well as being a key component of economic evaluations. Researchers have developed a number of methods in an attempt to capture and quantify an individual's quality of life (John Brazier, Ratcliffe, Salomon, & Tsuchiya, 2016). Typical methods used in health economics include the use of descriptive systems or instruments to classify and measure an individual's quality of life state and/or visual analogue scales to provide an overall quality of life rating. For evaluation of new health technologies, cost utility analyses, using a generic-preference based quality of life measure as the key outcome measure is recommended as the preferred method by a number of government and non-government bodies (Commonwealth of Australia, 2016a; Husereau et al., 2013; National Institute for Health and Care Excellence, 2004, 2008). A key component of the use of generic-preference based quality of life measures is the use of 'off the shelf' preference weighted scoring algorithms for health states described by the measure, based usually on general population preferences for one quality of life state over another (with values typically elicited on the 0=dead to 1=full health quality adjusted life years (QALY) scale) (John Brazier et al., 2016). The weighted scoring algorithm can then be applied to individual's responses to the descriptive system to produce a quality of life score for each individual respondent that reflects the public's view of the value attached to that state.

Dementia presents unique challenges when it comes to measuring and valuing quality of life. Traditionally, measuring quality of life is a subjective assessment, and instruments designed to measure an individual's quality of life are completed by the individual themselves. There is ongoing debate, however, surrounding the ability of people with cognitive impairment and dementia to self-report their own quality of life (Berwig, Leicht, & Gertz, 2009; Conde-Sala, Turró-Garriga, Garre-Olmo, Vilalta-Franch, & Lopez-Pousa, 2014). This issue is of particular importance for economic evaluations conducted in a residential aged care setting, where the majority of residents are living with cognitive impairment and dementia (Australian Institute of Health and Welfare, 2012b; Harris-Kojetin, Sengupta, Park-Lee, & Valverde, 2013; Hoffmann, Kaduszkiewicz, Glaeske, van den Bussche, & Koller, 2014; Stewart et al., 2014).

Economic evaluation, which is explained further in the theoretical framework section below, requires the measurement of changes over time and in response to an intervention under investigation in resource use, costs and quality of life outcomes. As such, it is necessary for suitable quality of life measures to be sensitive enough to be able to capture changes in quality of life over time. As cognitive decline progresses, loss of insight, reduced capacity to make judgements, and reduced ability to form new memories are typical symptoms of dementia, as well as reduced verbal fluency and ability to read and respond to written questions. The validity of self-rated responses thus becomes uncertain as cognition declines (Berwig, Leicht, & Gertz, 2009; Conde-Sala, Turró-Garriga, Garre-Olmo, Vilalta-Franch, & Lopez-Pousa, 2014). Richard Trigg et al. (2014) conducted a longitudinal study following 145 people with Alzheimer's disease over a period of 18 months. Despite disease progression (according to clinical assessments of cognition, dependence, and behavioural symptoms) between baseline and follow-up measurements, no changes in quality of life scores were evident for the subsample of 70 participants who self-reported their own quality of life. In contrast, proxy-reported quality of life measures did indicate changes in quality of life during this time period and the direction and magnitude of these changes mirrored those indicated by clinical assessment.

Proxy responses may be sought from a family member, carer, or friend on behalf of the person with dementia as an alternative to self-assessment. Proxies may be asked to complete a quality of life measure with responses that reflect the proxy's perception of the person with dementia's quality of life (proxy-proxy report) (Pickard & Knight, 2005). Alternatively, proxies may be asked to provide responses which reflect the answer they believe the person with dementia would give if they were able to answer themselves (proxy-patient report) (Pickard & Knight, 2005). A recent systematic review found proxy ratings (as opposed to self ratings) to be most acceptable across the entire range of Alzheimer's disease severity in terms of validity and reliability and for the assessment of change over time (Shearer, Green, Ritchie, & Zajicek, 2012). However a number of issues have also been noted in the literature, for instance that proxies have a tendency to give lower quality of life ratings than the individual themselves would give (Jönsson et al., 2006; Sheehan et al., 2012; Sitoh et al., 2003), and tend to report differences in quality of life outcomes depending on whether the proxy is a carer or clinician (Coucill, Bryan, Bentham, Buckley, & Laight, 2001). Proxy responses have also been found to be more reflective of physical symptoms such as dependency and behavioural disturbances, while self-rated responses are more reflective of subjective attributes such as mood (Beerens et al., 2013). A study on proxy bias by Arons, Krabbe, Scholzel-Dorenbos, van der Wilt, and Rikkert (2013) found carers tend to project assessments of their own quality of life onto the individual with dementia for whom they are responding. The authors of this study went on to recommend that for these reasons proxy ratings should not be used as a direct substitute for self-rated measures.

In addition to the self versus proxy dilemma, no consensus has yet been reached with regard to the most appropriate measurement scales or instruments for application in cognitive decline and dementia (Bowling et al., 2015). Quality of life measures can have either a generic or a condition-specific focus (John Brazier et al., 2016). A 2013 review of dementia-specific health-related quality of life measures identified 15 dementia-specific measures with commonly assessed dimensions including mood, self-esteem, social interaction and enjoyment of activities (Perales, Cosco, Stephan, Haro Abad, & Brayne, 2013). None of these dementia-specific measures, however, at that time were suitable for use in economic evaluation as they did not incorporate preference-weighted scoring algorithms. A 2012 review of health state values for use in economic evaluations for Alzheimer's Disease identified three preference-based generic measures suitable for economic evaluation in this context: the EQ-5D, the Health Utilities Index, and the Quality of Well-Being scale (Shearer et al., 2012). Since that time, the first dementia-specific preference based quality of life measures have been developed: the DEMQOL-U and the DEMQOL-Proxy-U (B. Mulhern et al., 2013).

Another aspect of quality of life of particular relevance when talking about dementia is the issue of carer quality of life, which typically relates to family or friends taking on an informal carer role for the person with dementia. While outside the scope of this thesis, the quality of life of informal carers is an important topic, and one that has been researched extensively (for instance, see Dow et al., 2018; Kerpershoek et al., 2017; Laver, Milte, Dyer, & Crotty, 2017; Liu, Sun, & Zhong, 2017; Parkinson, Carr, Rushmer, & Abley, 2017). In a community setting in particular, carer characteristics, including quality of life, play a role in the decision to admit family members to residential aged care facilities whether for temporary respite or permanent placement (Australian Institute of Health and Welfare, 2012a).

In a residential aged care setting, in which there are high rates of cognitive impairment and dementia, as well as high rates of physical disability, a consensus has not yet been reached with regard to the most appropriate method to collect quality of life information. Questions remain with regard to the appropriate measurement instrument/s, as well as the appropriate respondent in terms of self or proxy ratings, or a combination of these.

1.1.5 Economic impact

The economic impact of caring for the aging population is wide-ranging. Government projections in this area explore the implications for labour supply, economic output, infrastructure requirements, and government budget (Productivity Commission, 2013). This thesis focuses more specifically on the government budget impact. The Australian government is the primary funder of residential aged care. In 2015, $10.8 billion, or approximately 0.9 per cent of GDP was spent on residential aged care in Australia (Steering Committee for the Review of Government Service Provision (SCRGSP), 2016). Residents themselves pay a basic daily fee equal to 85 per cent of the single person rate of the basic

Age Pension. Additional co-payments from residents towards accommodation costs and costs of care are subject to income and assets testing.

Beyond residential aged care, the ageing population also has an impact on the broader health care system, from appointments with general practitioners or specialists, to pharmaceutical prescriptions, to hospitalisations. The Australian health care system is funded by three levels of government – including federal, state and territory, and local – and is further supported by optional private health insurance.

Medicare is the foundation of the health care system in Australia. Citizens may choose whether to have Medicare coverage only, or a combination of Medicare and private health insurance. Broadly, Medicare covers hospital, medical, and pharmaceutical costs for all Australians.

In terms of hospital costs, Australians can choose to be treated in a public hospital at no charge, in which case the entire cost is covered by the Australian Commonwealth and State governments. Alternatively, Australians with private health insurance may choose to be treated in a private hospital, in which case the cost is covered through a combination of Medicare, private insurance, and possibly a gap fee, or excess, payable by the individual depending on the policy.

Outside of hospitals, other medical services covered by Medicare are listed on the Medicare Benefits Schedule (MBS), and include General Practitioner (GP) and specialist visits, as well as numerous medical tests, examinations, and procedures. Medicare will cover or reimburse 100 per cent of the MBS fee for a GP visit, and 85 per cent for a specialist with additional gap fees in some cases. Residents of residential aged care facilities may also be eligible for some allied health services when coordinated through a GP.

Government-funded pharmaceuticals are listed on the Pharmaceutical Benefits Scheme (PBS) and are partly covered by Medicare. The amount paid by an individual varies depending on the drug, up to a standard maximum. Drugs which are not listed on the PBS must be paid for out-of-pocket.

The other method by which the Australian government provides health care funding, though outside the scope of this thesis, is through the Department of Veterans’ Affairs (DVA). Veterans who have served in Australia's defence force may be eligible for health cover through the DVA. Similar to Medicare, the DVA covers costs relating to hospitalisations, medical treatments, and pharmaceuticals.

Globally, annual expenditure on dementia care is estimated at US$818 billion, or roughly 1 per cent of global GDP (Wimo et al., 2017). While this thesis is focused primarily on the Australian setting, the economic impact of dementia is highly significant internationally and the methods applied in this thesis have potential applicability for residential care settings in other countries.

1.2 Theoretical Framework

1.2.1 Economic evaluation

Health economic analyses are increasingly being applied in the health and aged care sectors in an effort to promote efficiency in the design and delivery of services (Boorsma, Van Hout, Frijters, Ribbe, & Nijpels, 2008; K. S. Goldfeld, Hamel, & Mitchell, 2013; Grabowski, 2006; Mason et al., 2007). Economic evaluation is the most prevalent form of health economic analysis and is defined as the comparative analysis of alternative interventions in terms of both their costs (resource use) and outcomes (Drummond, Schulpher, Torrance, O'Brien, & Stoddart, 2005). Economic evaluation provides a systematic, transparent and robust consideration of the factors involved in a decision to commit resources – such as people, time, facilities, equipment, and knowledge – to one use instead of another in terms of both costs and outcomes (Drummond et al., 2005).

The economic principles of scarcity, choice and opportunity cost are fundamental to the discipline of economics. Resources such as land, labour and capital are limited, or scarce, and thus decisions must be made with regard to their use. By choosing to allocate resources to a particular use, we give up the opportunity to use them for a different purpose. As a result, it is necessary to set priorities in order to guide efficient resource allocation. The opportunity cost of investing resources in a particular health intervention is the benefit forgone from not using those resources for the next best alternative.

While the overarching aim of health economics is to maximise the health of the population, this may not be the only goal or priority when choosing how to allocate health care resources. Ethics and equity issues are also important considerations and indeed are a common consideration in aged care (Coast, 2004; Culyer, 2001).

In an economic evaluation, costs are expressed in terms of the benefit received, typically in the form of an incremental cost-effectiveness ratio (ICER). For example, in a cost-utility analysis, results are presented as the cost per quality-adjusted life year (QALY) gained in which the unit of effect is a 'year in full health' (Drummond et al., 2005). Outcomes can also be measured in ‘natural’ units, such as life-years gained or the number of units of blood-pressure reduction, which can be incorporated into a cost-effectiveness analysis.

Governmental agencies in healthcare, such as the Medical Services Advisory Committee (MSAC) and Pharmaceutical Benefits Advisory Committee (PBAC) in Australia, and the National Institute for Health and Care Excellence (NICE) in the UK, require cost-effectiveness evidence in order to appraise new medical services and new pharmaceuticals, where possible, in the form of incremental cost per QALY (Commonwealth of Australia, 2016a, 2016b, 2016c; National Institute for Health and Care Excellence, 2004, 2008).

Quality-adjusted life years combine quality and quantity of life lived whereby the length of time lived in a particular health state is adjusted for the quality of life during that time period. The quality-adjusted life year is the most widely used approach for estimating quality of life benefits in economic evaluations. QALY gains may be achieved both by increasing or maintaining quality of life, and by extending life.

In economic evaluations, quality of life is typically captured using a preference-based quality of life measure. Health states are described (reflecting varying levels of impairment for the dimensions included within the descriptive systems of the respective instruments), and then a value is ascribed to that health state based on how the general population values that particular health state. This health state value is also commonly referred to as a utility score. Utility scores are anchored on a scale of zero to one where a value of one indicates a health state equal to full health and a value of zero is indicates a health state equivalent to death. Negative values are also possible, indicating that, on average a health state is perceived by the general population to be worse than death.

Generic preference-based measures are the most widely used method for generating health state values, or utility scores. They are typically easy to administer – the EQ-5D, for instance, has only five questions and on average takes less than five minutes to complete – and are widely accepted by policy-makers (John Brazier et al., 2016). A common criticism of generic preference-based measures is their lack of ability to detect changes in particular conditions, such as behavioural symptoms of dementia for example (Hounsome, Orrell, & Edwards, 2011). Condition-specific measures may improve sensitivity to changes by focusing on dimensions of health which have been found to be influential on quality of life for that particular condition. In recent years, a number of condition-specific preference-based measures have been developed for various conditions including asthma, urinary incontinence and dementia (John Brazier et al., 2016). A criticism of condition-specific preference-based measures is that they add to the heterogeneity of utility scores and thus reduce the comparability between quality-adjusted life years calculated with different measures.

There are currently no medications available which can substantially alter or slow the progression of dementia. As such, the life-years gained component of a quality-adjusted life year will not vary substantially across different interventions. It can therefore be argued that the calculation of a QALY, and by extension, economic evaluations of dementia services and interventions, become highly dependent on health and/or quality of life utility scores (Oremus, Tarride, Clayton, Canadian Willingness-to-Pay Study, & Raina, 2014). Hence, this observation adds to the central importance of the measurement and valuation of quality of life in this context.

1.3 Rationale for thesis

As outlined in this chapter, the residential aged care sector is an important area for research. With Australia's ageing population, increasing numbers of people living with dementia and seeking care services, and the significant economic impact, particularly in the health and aged care sectors, decision-makers need high quality, timely, and accurate information in order to inform resource-allocation decisions.

The ultimate goal of residential aged care is to improve the quality of life of older people residing in these facilities. It follows that, wherever possible, quality of life assessments should be sought from aged care residents themselves as this is a key requirement both for economic evaluation and the quality assessment of residential aged care facilities. Furthermore, the inclusion of people with dementia is vital in any robust evaluation of residential aged care services given their ubiquity in this setting.

1.3.1 Objectives

The main objectives of this thesis were to provide a detailed assessment of the costs of care and quality of life in an Australian residential aged care setting, and highlight the key issues and implications for economic evaluation methodology and practice in this sector.

These main objectives were addressed with a series of specific aims listed below.

AIM 1: Identify the extent to which economic evaluations have been conducted in a residential aged care setting and their impact on our knowledge of aged care.

AIM 2: Determine how residents with dementia have been included in existing economic evaluations.

AIM 3: Compare the performance of generic versus condition-specific preference-based measures of health-related quality of life in a population of older adults living in residential aged care.

AIM 4: Explore the relevant costs of residential aged care in Australia at both a facility and system-level, specifically whether differences exist between regional and metropolitan facilities.

AIM 5: Determine the main factors which contribute to system-level costs in an Australian residential aged care setting.

AIM 6: Examine whether quality of life differs in regional and metropolitan aged care facilities.

AIM 7: Explore factors which contribute to resident quality of life in an Australian residential aged care setting.

There are five inter-related components to this research. The first step was to conduct a systematic literature review to identify the extent to which economic evaluations had been conducted in residential aged care settings in Australia and internationally, the extent to which residents with dementia had been included in existing economic evaluations and where residents with dementia have been included what mechanisms have been used to facilitate their inclusion. This systematic review is presented in Chapter 2 and informed the research objectives of this thesis.

The final four components are empirical studies using data collected from the INSPIRED study. The first empirical study explores the measurement of quality of life in residential aged care for use in economic evaluations conducted in this setting. Chapter 4 presents an empirical comparison of three preference-based measures for capturing quality of life in dementia –the EQ-5D-5L, a generic measure, and the DEMQOL-U and DEMQOL-Proxy-U, condition-specific measures.

The next two studies analyse the costs of care. Chapter 5 focuses on the residential aged care sector, drawing on facility-level operating and capital costs of residential aged care organisations around Australia. The analysis focuses on the key variables that contribute to the running costs of Australian residential aged care facilities. Chapter 6 focuses upon the broader health-care system. Costs to the health system, including medical, pharmaceutical, and hospital costs, are captured for a subset of the INSPIRED cohort, and comparisons are made in health system costs between regional and metropolitan facilities.

The final empirical study, presented in Chapter 7, combines information on both costs and outcomes in order to examine the factors which contribute to residents' quality of life. The implications of results for researchers and decision-makers are considered, as are opportunities for future research in this area.

This thesis explores quality of life and costs of care in a residential aged care setting, and the implications for economic evaluation. This introductory chapter has provided background to residential aged care and dementia in Australia, described the framework of economic evaluation, and laid out the aims of this thesis. The following chapter further extends these concepts and presents a review of economic evaluations in residential care conducted to date.

CHAPTER 2: LITERATURE REVIEW

The introduction to this thesis presented an overview of Australian research and reforms in residential aged care. Two key issues that emerged from this summary were the financial viability of aged care providers, and the quality of life of aged care residents. Both of these issues can be studied from a health economics perspective, which this thesis set out to do.

The first step was to conduct a systematic review of the literature to identify the extent to which economic evaluations had been conducted in residential aged care settings around the world. The review also sought to determine the extent to which residents with dementia had been included in existing economic evaluations.

The purpose of this review was two-fold. Firstly, an overview of the existing research in this space provides context in terms of understanding what evidence currently exists to inform resource allocation decisions in residential aged care. Secondly, methodological limitations were fleshed out through critical appraisal of the existing literature. Together, an understanding of the existing literature and the methodological issues of conducting economic evaluations in residential aged care were used to inform the study objectives of this thesis.

The following chapter details the methods and results of this systematic review. It then discusses the theoretical and empirical gaps that have been identified, outlines the scope of the problem and lays out the research objectives for the remainder of this thesis. The work in this chapter has resulted in two publications (Easton, Milte, Crotty, & Ratcliffe, 2016, 2017).

2.1 Methods

2.1.1 Protocol and registration

This review was conducted in accordance with the Joanna Briggs Institute (JBI) guidance for the systematic review of economic evaluation evidence (Gomersall et al., 2015). A protocol for this systematic review was registered with the PROSPERO International Prospective Register of Systematic Reviews on 30 January 2015 (http://www.crd.york.ac.uk/PROSPERO; registration number CRD42015015977).

2.1.2 Eligibility criteria

Study designs

Eligible studies included full economic evaluations (e.g. cost-effectiveness analyses, cost-utility analyses, cost-benefit analyses), partial economic evaluations (e.g. cost analyses, cost minimisation analyses, cost consequences analyses), and randomised trials reporting more limited information, such as estimates of resource use or costs of interventions. All studies pertained to organisational and environmental characteristics, and structures and processes of care, aimed at improving the quality of care for older adults in a residential aged care setting.

Partial economic evaluations with no comparator were excluded (e.g. outcome description studies, cost-description studies, cost-outcome descriptions), as were efficacy or effectiveness analyses with no analysis of costs, burden of disease studies, cost-of-illness studies, and aged care financing models.

Participants/population

The eligible population was older adults residing in a long-term residential aged care setting (e.g. residential aged care facility, nursing home, and other country-specific terminology for comparable levels of long-term institutional care). For the purpose of the review, no specific age was specified. Eligibility was determined on the basis of residency in an aged care facility.

Studies including older adults residing in the community were excluded, as were residential facilities for younger adults (e.g. group homes) and long-term residential settings that provided a lower level of care than nursing homes, such as congregate housing, assisted living, and extra-sheltered housing.

Interventions

Studies of interventions were included which pertained to organisational characteristics, environmental characteristics, structures of care, and/or processes of care aimed at improving the quality of care for older adults. The included interventions applied to the entire facility or unit.

Organisational characteristics related to the overall business structure of the aged care provider, and included attributes such as demographics, proprietary status, size, and affiliation. *Environmental characteristics* referred to the physical setting and included tangible attributes such as private rooms, access to outdoors, familiar home-like components, and secure units. *Structures of care* were defined as the workforce and its operations, and included level of staffing, expertise of staff, hours of care per resident per day, continuity of care, etc. *Processes of care* included activity programs and services implemented in the context of care provision.

Interventions that took place outside of the residential care setting (e.g. required the individual to leave the facility) were excluded, such as in-home care and community services. Pharmaceutical interventions were also excluded, as were targeted individual interventions that did not apply at a facility or unit level (e.g. feeding tubes).

Comparator(s)/control

For inclusion, studies possessed at least one alternative intervention or control for comparison. The specific intervention was not defined as an inclusion criterion. Studies that did not include a comparison were excluded.

Outcomes

Included studies reported a cost analysis that included the cost of the service configuration or intervention measured as monetary units or resources.

Timing/Context

There were no restrictions based on the timing of the study or the length of follow-up. There were no restrictions based on date of publication. Studies were selected for inclusion only if undertaken in a long-term residential aged care setting (e.g. residential aged care facilities, nursing homes, and care homes). There were no restrictions applied by region or country. Excluded settings were hospital and community-based, such as in-home, day centres, and foster homes. Included articles were limited to English.

2.1.3 Information sources

Eight electronic bibliographic databases were searched from inception to 8 October 2014, including AgeLine, the Cumulative Index of Nursing and Allied Health Literature (CINAHL), Econlit, Informit (databases in Health; Business and Law; Social Sciences), Medline, ProQuest, Scopus, and Web of Science. An update search was run on 14 December 2015. The reference lists of included studies were hand searched for additional studies.

2.1.4 Search strategy

The search strategies were developed and reviewed with two Health Sciences Librarians with expertise in systematic review searching. The search strategy was developed for Medline using medical subject headings (MeSH) and text words, and then adapted for use with the other bibliographic databases. The strategy combined terms relating to nursing homes, economics, and older people. Search terms for adolescents, children, and infants were excluded using the NOT boolean operator. Only quantitative studies were sought. Studies were limited to English. No study design or date limits were imposed on the search. The Medline search strategy is included in Appendix I.

Due to the large number of results retrieved when searching the multidisciplinary database ProQuest, limits to source type (scholarly journals, reports, dissertations and theses, conference papers and proceedings, and working papers) were applied to this database that were not part of the original search strategy. Newspapers, trade journals, wire feeds, magazines, other sources, books, and encyclopaedias and reference works were excluded.

2.1.5 Study records

Data management

Literature search results were imported to EndNote, a reference-management software. EndNote libraries were used in each stage of screening to organise and track included and excluded citations.

Selection process

Titles and abstracts of studies retrieved were reviewed in full by the primary author (T.E.). A second reviewer (see Acknowledgements) independently screened 10 per cent of the titles and abstracts (L.P.L). Full text reports were retrieved for all citations that appeared to meet the inclusion criteria. All full text reports retrieved were reviewed independently by the primary author and second reviewer (T.E. and L.P.L.). Disagreement was resolved through discussion and consultation with a third reviewer (R.M.). Reasons for excluding studies were documented. The reference lists of included studies were hand searched for additional studies by the primary author (T.E.).

Data collection process

The Joanna Briggs Institute Data Extraction Form for Economic Evaluations was used to extract data from the included studies (The Joanna Briggs Institute, 2014) (see Appendix II). The primary review author extracted all data. Neither the study selection nor the data extraction was blinded.

2.1.6 Data items

Standardised data items extracted included descriptive data about the study and analysis including (i) study population/participants, intervention, comparator(s) and outcomes; (ii) study methods including prices and currency used for costing, time period, sensitivity analyses and measures of resource use; (iii) study context (geographical, health care and broader service delivery setting and culture); (iv) analysis methods. Results for the resource use and/or cost and/or cost effectiveness measures and the author conclusions were also extracted.

2.1.7 Outcomes and prioritisation

The primary outcome of interest was a cost analysis that included the cost of the service configuration or intervention measured as monetary units or resources. Accordingly, measures of resource use of interventions compared to comparators were the top priority.

2.1.8 Critical appraisal

Critical appraisal of studies was undertaken using the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Economic Evaluations (The Joanna Briggs Institute, 2014) (Appendix III), adapted from the Drummond checklist (Drummond et al., 2005), which addressed: the study question; description of alternatives; identification of costs and outcomes; establishment of clinical effectiveness; accuracy, credibility and timing of costs and outcomes; incremental analysis; sensitivity analyses; and generalizability. Studies were rated as ‘yes’, ‘no’, or ‘unclear’ in terms of their compliance with each quality criterion in light of the objective of the study. For instance, a study which was designed to focus only on costs would by definition not have considered outcomes and so it may still score a ‘yes’ on item 3 which considers whether all relevant costs and outcomes have been identified. A study which was designed as a full economic evaluation on the other hand would need to identify both costs and outcomes to meet this criterion. As the search strategy did not impose date limits, the purpose of this appraisal was not to exclude studies that pre-dated the use of current economic evaluation methods. Rather the purpose of appraisal was to identify methodological issues with the study design that may result in biased measures of cost and/or effect in order to inform the interpretation of study results.

The JBI Critical Appraisal Checklist for Economic Evaluations was chosen for the current study as it covers the same ten items as the Drummond checklist with the addition of an eleventh item which addresses the generalizability of results to the setting of interest for the review [31]. The appraisal was conducted by the primary author (T.E.) and ratified by a second reviewer (R.M.). Disagreements were resolved through discussion between the primary and secondary reviewer.

2.1.9 Data synthesis

Data extracted from included studies were analysed and synthesized in a narrative summary to address the stated review objectives. No meta-analysis was conducted due to significant heterogeneity of service configurations in the included studies. The results section first presents a summary of the search and study selection process, followed by an overview of the included studies. Next, key findings are presented for each of the following categories: organisational characteristics; environmental characteristics; structures of care; and processes of care. Critical appraisal results are then highlighted in terms of methodological issues to inform the interpretation of study results. This review was prepared in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009).

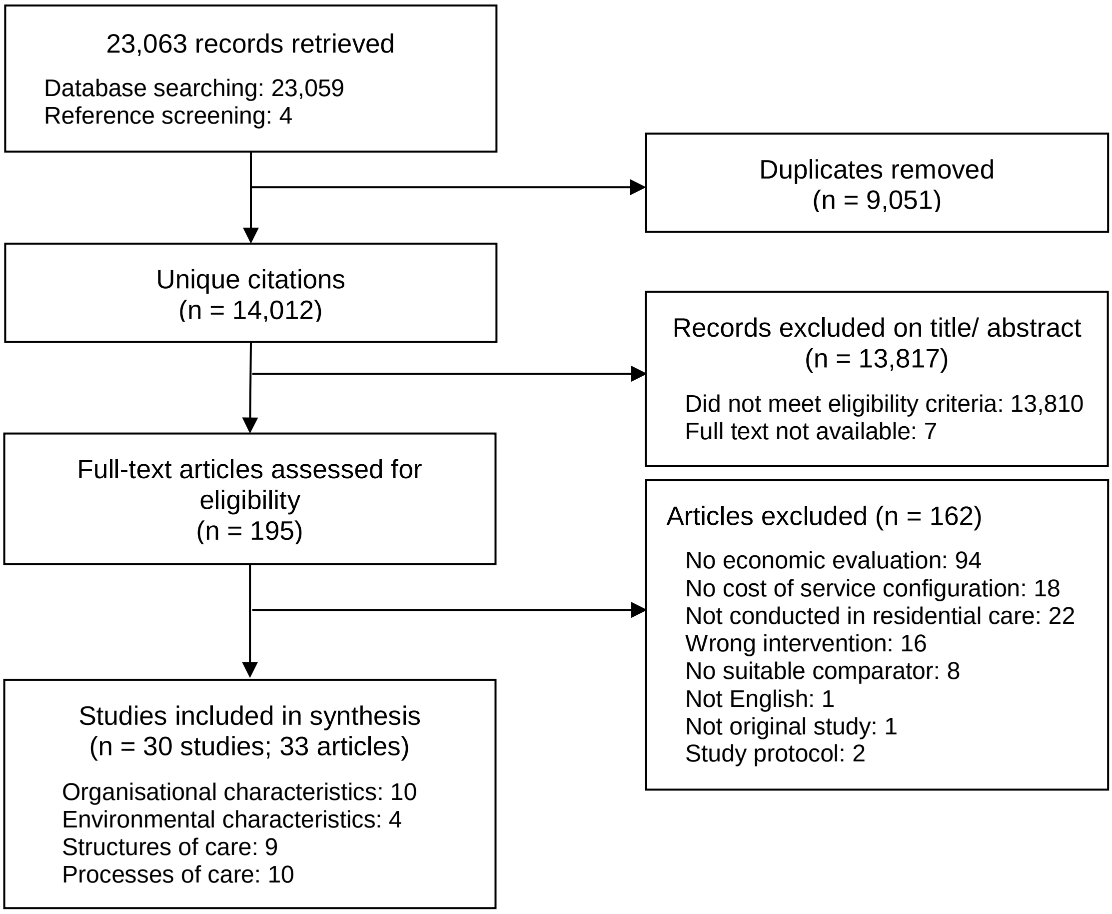
2.2 Results

2.2.1 Search and study selection

The study selection process is presented in Figure 2-1. The electronic database search yielded a total of 23,063 citations; an additional 4 citations were identified through searches of reference lists of included studies. A total of 14,012 unique citations were identified after duplicate removal. Full text reviews were conducted for 196 articles and 30 studies, from 33 publications, met the inclusion criteria. Seven studies (Bader, 2014; Bott et al., 1999; Hendrickson & Gustafson, 1979; Knapp, Fenyo, & Montserrat, 1990; Rupprecht, Engel, & Lang, 2008; Ullmann, Bekele, Holtmann, &

Teicher, 1983; Wilson & Chapman, 1987) were excluded as the full texts were not available. The chance-corrected agreement between the abstracts selected by the primary and secondary reviewers was almost perfect with a kappa statistic of 0.88 (Landis & Koch, 1977).

Figure 2-1 Flow diagram of study selection



2.2.2 Overview of studies

Table 2-1 presents the main characteristics of studies included in the review. Twenty-three out of 30 studies contained a partial economic evaluation in the form of a cost analysis. Only seven of the included studies contained full economic evaluations, which evaluate service configurations through the linkage of both their costs and consequences. The majority of studies (n=21) were evaluated from an institutional perspective (single institution n=2; multiple institutions n=19), and only costs occurring within the facility itself were considered. Three studies were evaluated from a health care perspective, with resource use and costs calculated for items including e.g. drugs, hospitalisations and outpatient visits. Four studies were evaluated from a societal perspective, which implies that wider costs for resources consumed in all relevant sectors such as the residential facility, the heath care sector, and by the residents and family members themselves were taken into account. One study took a health and social services perspective, which included resources consumed in the health care sector as well as social services such as audiology, chiropody, and speech therapy. Two studies were undertaken from an insurance provider perspective.

Nineteen (63 per cent) of the included studies were conducted in the United States, three in the Netherlands, two in Canada, two in Australia, two in the UK, one in Germany, and one in Switzerland. Ten of the studies involved interventions pertaining to processes of care, while four focused on environmental characteristics, nine examined structures of care, and ten evaluated specific organisational characteristics. Six studies identified examined dementia-specific service configurations.

Study designs were varied. The most frequent study design was cross-sectional (n=12), followed by cluster-randomised controlled trial (n=7), randomised controlled trial (n=2), and quasi-experimental (n=2). Other study designs included a Markov-based simulation model, a bedroom plan analysis, controlled before-and-after, cross-sectional time series, non-randomised experimental trial, prospective cohort, and retrospective cohort.

The number of participating facilities per study ranged from 1 to 3,492 (mean: 222; median: 38). Of the 14 studies that recruited resident participants, sample sizes ranged from 44 to 6,663 (mean: 1,018; median: 310). Fifteen studies that did not recruit resident participants collected facility-level data only, such as operating costs or staff time, while a study containing a Markov-based simulation model sourced all input data from existing published literature.

Table 2-1 Characteristics of included studies

Source	Country	Service configuration	Intervention / Comparator	Facility n	Participant n	Study design	Type of economic evaluation	Analytic viewpoint	Dementia specific	Setting
Arling, Nordquist, and Capitman (1987)	USA	O	Chain vs. independent for-profit vs. public/not for profit ownership types	150	N/A	Cross-sectional	Cost analysis	Institutional	No	ICF
R. Bland, Bland, Cheetham, Lapsley, and Llewellyn (1992)	United Kingdom	O	Local authority (government) vs. private vs. voluntary sectors	Phase 1: 100 Phase 2: 6	Phase 1: 2,405 Phase 2: 156	Cross-sectional	Cost analysis	Institutional	No	RH
Calkins and Cassella (2007)	USA	E	Private room vs. enhanced shared rooms vs. traditional shared rooms	N/A	189 (bedrooms)	Bedroom plan analysis	Cost analysis	Institutional	No	NH
Chenoweth et al. (2014)	AUS	P; E	Person-centred care vs. person-centred environment vs. both vs. usual care	38	601	Cluster RCT	Cost analysis	Institutional	Yes	High-care RACF
Chenoweth et al. (2009) Norman et al. (2008)	AUS	P	Person-centred care vs. dementia-care mapping vs. usual care	15	289	Cluster RCT	Cost-effectiveness analysis	Institutional	Yes	RACF
Davis (1993)	USA	O	For profit vs. not for profit	178	N/A	Cross-sectional	Cost analysis	Institutional	No	NH
Dorr, Horn, and Smout (2005)	USA	S	30 to 40 minutes of RN direct care time per resident per day vs. less than 10 minutes	82	1,376	Retrospective cost study	Cost-benefit analysis	Societal; Institutional	No	NH
Farsi and Filippini (2004)	CHE	O	Not for profit: private vs. public	36	N/A	Cross-sectional time series	Cost analysis	Institutional	No	NH
Grabowski and O'Malley (2014)	USA	S	Off-hours physician coverage via telemedicine vs. on-call physician	11	N/A	Cluster RCT	Cost-benefit analysis	Insurance provider (Medicare)	No	NH
Holmes (1996)	USA	O	Chain vs. proprietary non-chain vs. freestanding not for profit vs. government-owned vs. hospital-based	393	N/A	Cross-sectional	Cost analysis	Institutional	No	NH
Jenkens, Sult, Lessell, Hammer, and Ortigara (2011)	USA	S; E	Green House model vs. usual care	7	N/A	Cross-sectional	Cost analysis	Institutional	No	SNF
Maas, Specht, Weiler, Buckwalter, and Turner (1998); Swanson, Maas, and Buckwalter (1993); Swanson, Maas, and Buckwalter (1994)	USA	S; E	Special care unit vs. traditional unit	1	44	Prospective cohort study	Cost analysis	Health care	Yes	NH
MacNeil Vroomen et al. (2012)	NED	P	Multidisciplinary Integrated Care model vs. usual care	10	301	Cluster RCT	Cost-effectiveness analysis	Societal	No	RH
Mehr and Fries (1995)	USA	S	Special care units vs. traditional units	177	6,663	Cross-sectional	Cost analysis	Institutional	Yes	NH
Molloy et al. (2000)	CAN	P	Advance Directive program vs. usual care	6	1,292	Cluster RCT	Cost analysis	Health care	No	NH
Müller, Borsi, Stracke, Stock, and Stollenwerk (2015)	DEU	P	Multifactorial fracture prevention program vs. usual care	N/A	N/A	Markov-based simulation model	Cost-utility analysis;	Insurance provider	No	NH

Ouslander et al. (2011)	USA	P	INTERACT II tools (Interventions to Reduce Acute Care Transfers)	36	N/A	Controlled before-and-after	Cost analysis	Institutional	No	Community NH
Paulus, van Raak, and Maarse (2008)	NED	P	Integrated care vs. traditional care	2	342	Quasi-experimental	Cost analysis	Societal	No	NH
Przybylski et al. (1996)	CAN	S	Physical Therapy & Occupational Therapy staffing levels: 1.0 FTE PT and 1.0 FTE OT per 50 beds vs. 1.0 FTE PT and 1.0 FTE OT per 200 beds	1	115	RCT	Cost analysis	Institutional	No	NH
Rantz et al. (2012)	USA	P	Multilevel intervention with expert nurses vs. monthly info packs on ageing and physical assessment	58	N/A	Cluster RCT	Cost analysis	Institutional	No	SNF
Rovner, Steele, Shmuely, and Folstein (1996)	USA	P	A.G.E. dementia care program (activities, medication guidelines, educational rounds) vs. usual care	1	81	RCT	Cost analysis	Institutional	Yes	ICF
Schneider, Duggan, Cordingley, Mozley, and Hart (2007)	GBR	S	1.0 FTE occupational therapist vs. usual care	8	190	Non-randomised experimental trial	Cost analysis	Health & social services	No	CH
Sharkey, Hudak, Horn, James, and Howes (2011)	USA	S	Green House model vs. traditional skilled nursing facilities	27	240	Cross-sectional	Cost analysis	Institutional	No	SNF
H. L. Smith, Piland, and Fisher (1992)	USA	O	Rural vs. urban nursing facilities	52	N/A	Cross-sectional	Cost analysis	Institutional	No	NH
Sulvetta and Holahan (1986)	USA	O	Hospital-based vs. freestanding nursing homes	3,492	N/A	Cross-sectional	Cost analysis	Institutional	No	SNF
Teresi et al. (2013)	USA	S	Implementation of an evidence-based education and best practice program: Training staff vs. training staff and nursing home inspectors vs. usual training	45	N/A	Quasi-experimental	Cost-benefit analysis	Societal	No	NH
Ullmann (1984)	USA	O	For profit vs. not for profit vs. government	308	N/A	Cross-sectional	Cost analysis	Institutional	No	SNF
Ullmann (1986)	USA	O	Independent vs. chain-affiliated facilities	265	N/A	Cross-sectional	Cost analysis	Institutional	No	SNF
Ullmann (1987)	USA	O	For profit vs. not for profit vs. government	494	N/A	Cross-sectional	Cost analysis	Institutional	No	SNF
van de Ven et al. (2014)	NED	P	Dementia-care mapping vs. usual care	11	318	Cluster RCT	Cost-minimisation analysis	Health care	Yes	NH

Countries: AUS, Australia; CAN, Canada; CHE, Switzerland; DEU, Germany; GBR, United Kingdom; NED, Netherlands; USA, United States.
Service configurations: O, organisational characteristics; E, environmental characteristics; S, structures of care; P, processes of care.
Study designs: RCT, randomised controlled trial.
Settings: CH, care home; ICF, intermediate care facility; SNF, skilled nursing facility; NH, nursing home; RACF, residential aged care facility; RH, residential home.

2.2.3 Organisational characteristics

Interventions reported in studies pertaining to organisational characteristics fell into four broad categories: proprietary status, affiliation, size, and location.

Proprietary status

Of the seven studies that focused upon proprietary status, six compared for-profit facilities to one or more alternative proprietary status, and all studies indicated that for-profit facilities provided care at the lowest cost (Arling et al., 1987; R. Bland et al., 1992; Davis, 1993; Holmes, 1996; Ullmann, 1984, 1987). One study compared private not-for-profits to public (i.e. government-owned) not-for-profits and found no significant cost differences (Farsi & Filippini, 2004). In three of the studies, clinical and process-related outcomes were utilized as markers for the quality of care provided (Davis, 1993; Holmes, 1996; Ullmann, 1984). These proxy measures of care quality varied widely and included rates of decubitus ulcers, catheterisation, physical restraints, chemical restraints, drug error, number of regulatory deficiencies, skill level of persons in charge of nursing shifts, range of therapies provided, and number of people waitlisted. One study sourced quality measures from a state-wide composite rating scale which combined three quality assessment tools administered by interdisciplinary survey teams to evaluate compliance with the state hospital code, federal regulations, and individual resident medical reviews (Ullmann, 1987) to give an overall rating of either “very good”, “good”, “needs improvement”, or “unsatisfactory”. Results indicated a distinct lack of variation amongst the quality ratings for the 494 facilities included in the study, with over 95 per cent of facilities receiving a rating of “good” for overall quality.

A study by Bland and colleagues (1992) attempted to link costs to quality across Scottish residential homes for older people in three sectors: public (government-owned), for-profit and not-for-profit. The study concluded that there were no readily identifiable patterns of trade-offs between cost and quality across the three sectors. However, through a comparison of operating costs, the study suggested that the for-profit sector was a low-cost operator, the not-for-profit sector operated in the mid-range for costs, and the public sector operated at the highest cost. Analysis of quality of care data found that larger facilities (within respective sectors) and government-owned facilities (between sectors) were associated with better care. Quality of care was assessed on 130 primary variables through a combination of interview with the facility’s officer-in-charge and researcher observation. The quality of care scale was classified into 8 groups: building; procedures; regime; medical care; promotion of continence; care of dementia sufferers; general services; and interviewer-observation.

Affiliation, size and location

Affiliation refers to both hospital-based facilities and facilities owned as part of a chain, as compared with freestanding or independent facilities. Freestanding facilities are those which are not part of a hospital. Independent facilities are those which are not affiliated with a chain. Chain affiliation is defined as membership in a group of facilities operating under one authority or ownership. The minimum number of facilities required to meet this definition varied between studies ranging from three or more facilities (Arling et al., 1987) to five or more facilities (Holmes, 1996) while a third study did not specify a particular number (Ullmann, 1986). While there is some evidence to suggest hospital-based facilities have relatively lower capital costs compared with non-hospital based (freestanding) facilities (Holmes, 1996), both operating costs and total costs were found to be higher in hospital-based facilities when compared with freestanding institutions (Holmes, 1996; Sulvetta & Holahan, 1986). Three studies evaluated the effects of chain-affiliations on operating and total costs, with conflicting results reporting chain-affiliated facilities as having no difference in costs (Arling et al., 1987), higher costs (Holmes, 1996), and lower costs (Ullmann, 1986) when compared with independent facilities.

Out of four affiliation studies identified by this review (Arling et al., 1987; Holmes, 1996; Sulvetta & Holahan, 1986; Ullmann, 1986), process-related outcome measures designed to give an indication of the quality of care provided at the facility were examined in three of the studies and included number of regulatory deficiencies (Holmes, 1996), presence of rehabilitation services and nurse-to-bed ratios (Sulvetta & Holahan, 1986), and facility age, number of therapies provided, and the facility's wait-list size (Ullmann, 1986). Chain and free-standing facilities had the highest average annual deficiencies, while hospital-based facilities had the least (Holmes, 1996). Hospital-based facilities were also found to have more rehabilitation services and higher nurse-to-bed ratios (Sulvetta & Holahan, 1986), which was suggested to indicate higher quality care.

One study compared rurally located nursing homes (n=34) with urban-based facilities (n=18) and found no significant cost differences (H. L. Smith et al., 1992). No effectiveness data were collected; rather comparisons were made based on facility profits. A second study reported urban-based facilities as having higher total costs than rural facilities (Sulvetta & Holahan, 1986). Process-related outcome measures of quality in this study found rural facilities to have higher nurse-to-bed ratios but fewer rehabilitation services.

Only one study was identified which specifically focused on the costs associated with the size of facility. Marginally lower average costs were reported for facilities with 100-199 beds compared with 0-49 beds, 50-99 beds, and 200 or more beds (Ullmann, 1984). No effectiveness or quality data were reported.

2.2.4 Environmental characteristics

Interventions reported in studies pertaining to environmental characteristics fell into two broad categories, functional modifications and home-like environments.

Functional modifications

Two studies examined the effects of functional modifications on residents with dementia. Interventions consisted of adjustments to existing spatial configurations with the aim of improving the safety, accessibility and utility of both indoor and outdoor spaces. One study undertook a cluster-randomised controlled trial examining the effects of both person-centred care and person-centred environments for residents with dementia (Chenoweth et al., 2014). Modifications varied between participating facilities (n=38), and included changes such as extending activity spaces, modifying internal walls to increase visual access to bedrooms and activity spaces, increasing ease of access to courtyards and gardens, building partitions to reduce overstimulation in large group spaces, and improving gardens and landscaped exteriors with paving, new sitting areas, and covered spaces. It was estimated that all environmental modifications (implemented between 2009 and 2011) cost less than 10,000 Australian dollars per facility to implement, with the average facility spending 9,198 Australian dollars.

Outcome measures collected included: quality of life (DEMQOL and DEMQOL-Proxy), agitation (CMAI - Cohen Mansfield Agitation Inventory), emotional responses (Emotional Responses to Care instrument), and quality of care interactions (QUIS instrument). Results for outcome measures were inconsistent although small statistically significant improvements were found for some participants in levels of agitation, with CMAI scores decreasing from 65 pre-intervention to 55 at the 8-month follow-up in the environmental intervention group compared with the control group which reported CMAI scores of 52 and 51 at pre-intervention and follow-up respectively (p=0.04) (Chenoweth et al., 2014).

A cost analysis of special care units (SCUs) for residents with dementia conducted by Maas and colleagues (1998) provided data on SCU construction and remodelling costs. In this study, participants with dementia were matched by age and cognitive function, and randomly assigned to the SCU or one of the traditional units at the same facility. Modifications to the SCU included redecorating, door modifications and installation of a security system, new walls in the lounge and dining areas, bedroom privacy curtains and special furniture, and installation of a fence in the outdoor area. Total remodelling costs on the SCU (home to 37 residents) were 89,700 US dollars (date of cost data unknown).

Effectiveness measures from the SCU study were examined in two additional publications (Swanson et al., 1993, 1994). Primary outcome measures included cognitive status (Alzheimer’s Disease Assessment Scale) and functional abilities (Functional Abilities Checklist and the Geriatric Rating Scale). No significant differences in cognition or function were found between residents on the SCU, and those in the traditional units (Swanson et al., 1994). However, the number of catastrophic reactions reduced significantly on the SCU compared with traditional units with the number of reactions decreasing from 156 pre-intervention to 48 at the 12-month follow-up in the

SCU group compared with the control group which reported catastrophic reactions of 82 and 46 at pre-intervention and follow-up respectively (p=0.035) (Swanson et al., 1993). A catastrophic reaction in dementia is defined as an excessive reaction to a seemingly normal, non-threatening situation (e.g. a question asked of the person, bathing, dressing) and is characterised by mood changes or reactions such as weeping, blushing, anger, or agitation (Swanson et al., 1993). Catastrophic reactions were recorded for each resident on an Individual Incident Record by nursing staff.

Home-like environments

Two studies examined costs associated with providing more home-like care environments. An analysis of bedroom plans conducted by Calkins and Cassella (2007) examined room size and construction cost differences between private rooms, shared rooms, and enhanced shared rooms (designed to give the resident a well-defined and generally exclusive territory within the shared room). Findings indicated that private rooms cost more to construct on a per resident basis than shared or enhanced shared rooms. No quantitative quality measures were included in the study. Rather the authors examined the effectiveness of private rooms through a systematic review, interviews and focus groups, the results of which indicated better outcomes associated with private rooms, with evidence indicating that older adults have a strong preference for private bedrooms (Calkins & Cassella, 2007; Lawton & Bader, 1970). Clinical outcomes associated with private rooms, identified as part of the authors’ systematic review, included reduced risk of infection such as influenza and gastroenteritis (Fune, Shua-Haim, Ross, & Frank, 1999; Pegues & Woernle, 1993).

One study examined the Green House model, which is an alternative living environment to the traditional skilled nursing facilities in the United States that aims to provide a more person-centred, consumer-driven environment. In the Green House model, ten to twelve residents live in a self-contained residence designed to look and feel like a private home. Each resident has a private bedroom and bathroom, and each residence has an open kitchen, living room, and dining room, as well as access to outdoors through a patio or balcony. An analysis of capital costs conducted by Jenkens and colleagues (2011) concluded that the Green House model incurred slightly higher capital costs than traditional skilled nursing facilities largely as a result of the increased square foot requirements (an additional 300 square feet per resident, on average). Facility type, size, labour rates, and site-specific preparation costs were found to be the primary drivers of capital costs. No quality or outcome measures were included alongside the measurement of costs assessed in this study.

2.2.5 Structures of care

Interventions reported in studies pertaining to structures of care fell into two broad categories: staffing levels, and staff education.

Staffing levels

Four studies evaluated the costs and effects of enhanced staffing levels, including increasing the amount of direct nursing care time for each resident (Dorr et al., 2005), employing a full-time occupational therapist (Schneider et al., 2007), increasing the staffing level of both physical and occupational therapists (Przybylski et al., 1996), and implementing off-hours physician coverage via telemedicine (Grabowski & O'Malley, 2014). Results suggest that enhanced staffing levels, whilst being associated with increases in staffing costs, provide the potential for cost savings in other areas. For example, one study found that increasing registered nurse staffing in nursing homes to ensure 30-40 minutes of direct care time per resident per day reduced the incidence of pressure ulcers, hospitalisations, and urinary tract infection rates resulting in a net societal benefit of US$3,191 per resident per year (Dorr et al., 2005). Similarly, another study reported that increasing the staff to resident ratio for physical therapists and occupational therapists was more effective at promoting, maintaining, or limiting decline in functional status. The resulting reduction in required care delivery resources was estimated to provide an annual cost saving to the institution of $283 per resident (Przybylski et al., 1996). A third study which evaluated the benefit of a full-time occupational therapist reported a significant reduction in secondary health care costs (including hospital admissions) and an increase in the use of social services, though the cost of providing occupational therapy was not offset by the savings in health care (Schneider et al., 2007). Finally, a fourth study found that increasing the availability of physician care during the off-hours via a dedicated telemedicine service decreased annual hospitalisations by 11.3 per cent annually (Grabowski & O'Malley, 2014). Based on an average nursing home size of 113 beds, net savings to US Medicare were estimated to be $120,000 per annum for facilities which utilised the telemedicine service to a greater extent (Grabowski & O'Malley, 2014).

Another important finding from this review was the assimilation of currently available evidence relating to the costs and effectiveness of staffing levels in specialised models of residential care, including Green House facilities and dementia special care units (Jenkens et al., 2011; Maas et al., 1998; Mehr & Fries, 1995; Sharkey et al., 2011). Green House facilities provide a small, home-like model of care as an alternative living environment to the traditional skilled nursing facilities in the United States. In the Green House model, ten to twelve residents live in a self-contained residence designed to look and feel like a private home. Dementia special care units (SCUs) are separate units within a residential care facility that have been adapted specifically for people living with dementia.

Three out of four studies which evaluated staffing levels in specialised models of care (Green House facilities and dementia special care units) reported that these types of specialised models generally provided more direct care time to residents compared to traditional facilities (Jenkens et al., 2011; Maas et al., 1998; Sharkey et al., 2011). Resource use and cost implications associated with staffing levels in specialised models of care, however, were conflicting across studies with no clear results. With regard to special care units, one study reported no difference in resource use once adjusted for case mix (Mehr & Fries, 1995), while the other reported higher resource use but made no adjustments for case mix (Maas et al., 1998). Of the two studies on Green House facilities, one reported lower staffing requirements than traditional units (Sharkey et al., 2011) while the other reported increased staffing requirements of 2.0 to 2.5 per cent compared with traditional facilities (Jenkens et al., 2011). None of the studies evaluating staffing levels in specialised facilities established clinical effectiveness. Swanson, Maas and Buckwalter (1993) did report significant results found with indirect outcome measures in the form of reduced catastrophic reactions and increased social interactions on special care units with the number of reactions decreasing from 156 pre-intervention to 48 at the 12-month follow-up in the SCU group compared to the control group which reported catastrophic reactions of 82 and 46 at pre-intervention and follow-up respectively (p=0.035).

Staff education

One study evaluated the implementation of an evidence based staff education and best practice program targeting ‘vision awareness’ to improve staff knowledge of visual impairments and to reduce the incidence of falls (Teresi et al., 2013). It was estimated that the intervention resulted in a reduction in the number of annual falls between 5 and 12 in a typical 200-bed nursing home in New York State. Depending on estimates used for the cost of falls, the net societal benefit ranges between a net loss of US$26,000 and a net saving of US$52,000 calculated in 2008 US dollars.

2.2.6 Processes of care

Interventions reported in studies pertaining to processes of care fell into three broad categories: dementia-specific care, integrated care, and quality improvement initiatives.

Dementia-specific care

Four studies evaluated dementia-specific care interventions compared to usual care. These interventions included person-centred care implemented through staff training (Chenoweth et al., 2014; Chenoweth et al., 2009; Norman et al., 2008) or dementia-care mapping (Chenoweth et al., 2009; van de Ven et al., 2014), and a dementia care program which aimed to reduce behaviour disorders (Rovner et al., 1996).

Supporting personhood has been identified as a foundation for quality care for people living with dementia (R. Milte et al., 2016). Person-centred care centres on relationships with others and the theory that warm and compassionate care interactions should increase well-being, while disrespectful and disengaged care interactions are thought to lead to decreased well-being and increased agitation (Kitwood & Bredin, 1992). Person-centred care can be implemented at residential care facilities in different ways.

Two methods of implementing person-centred care were evident from the identified studies. One method, which researchers called ‘person-centred care’ involved off-site staff training followed by a period of on-site supervision and telephone support (Chenoweth et al., 2014; Chenoweth et al., 2009). The second, more resource-intensive method was dementia-care mapping which required selected staff members to become certified through basic and advanced training. The certified mappers then completed systematic observation of residents with dementia, from which feedback was given to care staff and managers in order to assist with planning, implementation and assessment of person-centred care (Chenoweth et al., 2009; van de Ven et al., 2014). Chenoweth and colleagues (2009) found that the first method of training and support dominated dementia-care mapping, as their results showed dementia-care mapping to be more expensive and less effective. Van de Ven and colleagues (2014) on the other hand, found dementia-care mapping to be a cost-neutral endeavour.

The most common primary outcome assessed in this subgroup was agitation using the Cohen Mansfield Agitation Inventory (CMAI) (Chenoweth et al., 2014; Chenoweth et al., 2009; van de Ven et al., 2014). Van de Ven (2014) and Chenoweth (2009) both found that dementia-care mapping had no significant effect on agitation with study follow-up times of 18 months and 8 months respectively. Two studies by Chenoweth and colleagues (Chenoweth et al., 2014; Chenoweth et al., 2009) reported small statistically significant decreases in agitation as a result of their person-centred care intervention, with follow up conducted at 14 months and 8 months.

Other outcomes assessed (and measurement tools used) across this subgroup included emotional responses in care (ERIC), quality of life (DEMQOL, DEMQOL-Proxy, Qualidem, EQ-5D, and QUALID), care interaction quality (Quality of Interactions Schedule), psychiatric symptoms (neuropsychiatric inventory), behavioural symptoms (Psychogeriatric Dependency Rating Scale Behaviour Subscale), antipsychotic drug and restraint use, cognition (mini-mental state examination, MMSE), level of nursing care (resource utilisation groups, RUG-II), and activity participation rates. Some small improvements were found in quality of care interactions, resident care responses, and quality of life measured with the DEMQOL-Proxy (Chenoweth et al., 2014).

Rovner and colleagues (1996) evaluated a dementia care initiative consisting of organised ‘day-care’ activities from 10AM-3PM daily, combined with psychotropic medication guidelines, and educational rounds performed by a psychiatrist. In contrast to the person-centred care interventions, the dementia care program was not based exclusively on relationships but was developed to provide structure and stimulation through scheduled activities such as music and games. While the study did not find any cost reductions to offset the intervention costs, the authors did report that intervention residents were over 10 times more likely to participate in activities than the comparison group. The intervention was also found to decrease the prevalence of behaviour disorders and the use of antipsychotic drugs and restraints.

Integrated care

Two studies evaluating integrated care delivery found higher costs in the intervention group compared to usual care (MacNeil Vroomen et al., 2012; Paulus et al., 2008). Integration strategies aim to provide a level of service that is more individualised and sensitive to the personal circumstances of the resident (Gröne & Garcia-Barbero, 2001), and can be applied to residential care at a number of levels (Reed, Cook, Childs, & Mccormack, 2005).

Paulus and colleagues (2008) examined integrated care in the sense of integration between residents and care staff. Residents lived in smaller-scale facilities with increased levels of social activities, more flexibility in daily routines, and the opportunity to engage in daily activities such as cooking, cleaning and laundry. Integrated care was shown to have lower informal care costs (care provided by family and friends) when compared to traditional care, while both the costs of formal care (provided by staff) and total average costs were higher in integrated care.

MacNeil Vroomen and colleagues' (2012) integrated care model focused on the integration of health disciplines through case-conferencing. The intervention included a quarterly assessment of all residents by nursing assistants, multidisciplinary meetings with a primary care physician, nursing home physician, nurse, psychotherapist, and other disciplines involved in resident care, and a multidisciplinary consultation for those residents with more complex health needs. Three outcomes were measured: quality of care, functional health, and quality of life. This study found that for functional health and quality-adjusted life years (utility scores calculated from the SF-6D), integrated care was not cost-effective compared to usual care. However, for patient-related quality of care, the probability that integrated care was cost-effective compared to usual care was 0.95 or more for ceiling ratios greater than €129.

Quality improvement initiatives

Four studies conducted facility-level interventions aimed at improving the quality of care (Molloy et al., 2000; Müller et al., 2015; Ouslander et al., 2011; Rantz et al., 2012). Interventions included an advance directive program to educate and assist residents with a written expression of their wishes to guide family and health care workers in their care choices (Molloy et al., 2000), an intervention to reduce acute care transfers through the early identification, assessment, communication, and documentation of changes in resident status (Ouslander et al., 2011), a quality improvement intervention involving monthly visits and support by expert nurses (Rantz et al., 2012), and a fracture prevention program for all residents upon admission to a residential care facility (Müller et al., 2015). The advance directive program (Molloy et al., 2000), the intervention to reduce acute care transfers (Ouslander et al., 2011), and the multifactorial fracture prevention program (Müller et al., 2015) were all found to reduce hospitalisation rates, resulting in cost savings from a broader health care perspective. The quality intervention with expert nurses was found to improve quality of care (measured with the Observable Indicators of Nursing Home Care Quality (OIQ) instrument.), and reduce the incidence of pressure ulcers and weight loss (Rantz et al., 2012). In all four studies, the increased costs associated with implementation of the interventions were borne by the aged care facility.

2.2.7 Critical appraisal

Table 2-2 presents the results of the assessment of methodological quality of the included studies. The methodological quality of included studies was varied. Some notable deficiencies were found in two of the four studies which indicated their analysis was undertaken from a societal viewpoint. A societal viewpoint is the broadest perspective that can be taken for an economic evaluation and resources consumed in all relevant sectors should ideally be captured using this approach. In an evaluation of enhanced Registered Nurse time, costs beyond the aged care facility e.g. informal carer time or social services consumption were excluded (Dorr et al., 2005). In a study evaluating the integration of residents with care staff via increased participation in daily activities (e.g. cooking), Paulus and colleagues (2008) included costs for formal (staff) and informal (family and friends) care time, but did not include other relevant costs such as medications or hospitalisations.

In a study evaluating a multidisciplinary integrated care model, MacNeil Vroomen and colleagues (2012) also chose a societal viewpoint. This study provides an example of a well-conducted robust analysis that captures all relevant resource use items and costs incurred in all relevant sectors including general practitioner, physical therapy, psychosocial therapy, medical specialists, admission to hospital, informal care, as well as intervention-specific implementation costs.

In terms of the reporting of resource use and costs there were notable deficiencies in a number of studies. Four studies reported mean costs but did not provide a measure of variation or dispersion in the cost results (e.g. standard deviation) (Calkins & Cassella, 2007; Chenoweth et al., 2014; Maas et al., 1998; Sulvetta & Holahan, 1986). Seven of the included studies did not disclose the date for their cost data collection (Calkins & Cassella, 2007; Maas et al., 1998; Mehr & Fries, 1995; Molloy et al., 2000; Paulus et al., 2008; Rantz et al., 2012; Rovner et al., 1996). Four studies did not disclose the source of their cost data (Maas et al., 1998; MacNeil Vroomen et al., 2012; Przybylski et al., 1996; Ullmann, 1987), and one study also failed to disclose the currency used in the analysis (Przybylski et al., 1996). There were also deficiencies in the source of cost data in two studies (Teresi et al., 2013; van de Ven et al., 2014). In a study of dementia-care mapping, Van de Ven and colleagues (2014) calculated nursing home staff costs for their analysis of 11 nursing homes based on the gross costs of a single nursing home. In this scenario, it is unclear whether the costs from a single facility can reliably be generalised to the 11 nursing homes which were included in the study. In an implementation study of evidence based education, Teresi and colleagues (2013) were unable to obtain site-specific data for the 45 facilities that participated. Aggregated local estimates combined with cost data from published literature were utilised in lieu of site-specific data, which may not have been representative of the facilities included in the analysis.

Further methodological issues identified included: a failure to establish clinical effectiveness in any of the studies pertaining to organisational and environmental characteristics (though it should be noted that the study perspectives were institutional, rather than health system focussed), the absence of incremental analysis of costs and consequences in all but three studies, and a lack of sensitivity analyses (n=25) to assess the robustness of the base case results to variations in key parameters. Overall, a high level of uncertainty was found in the generalisability and transferability of findings.

Five studies conducted sensitivity analyses (Chenoweth et al., 2009; Dorr et al., 2005; MacNeil Vroomen et al., 2012; Müller et al., 2015; Norman et al., 2008; Teresi et al., 2013). Eight studies were undertaken over a time horizon greater than one year (Grabowski & O'Malley, 2014; Molloy et al., 2000; Müller et al., 2015; Paulus et al., 2008; Przybylski et al., 1996; Rantz et al., 2012; Teresi et al., 2013; van de Ven et al., 2014), of which one study made adjustments for differential timing of costs over the study period (Müller et al., 2015).

Table 2-2 Critical appraisal results for included studies using the JBI Critical Appraisal Checklist for Economic Evaluations

Source	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11
	Well-defined question	Comprehensive description of alternatives	All important and relevant costs and outcomes for each alternative identified	Clinical effectiveness established	Costs and outcomes measured accurately	Costs and outcomes valued credibly	Costs and outcomes adjusted for differential timing	Incremental analysis of costs and consequences	Sensitivity analyses conducted	Study results include all issues of concern to users	Results are generalizable
Arling et al. (1987)	Yes	Yes	Yes	No	Unclear	Yes	N/A	No	No	Yes	No
R. Bland et al. (1992)	Yes	Yes	Yes	No	Yes	Yes	No	No	No	Yes	Unclear
Calkins and Cassella (2007)	Yes	Yes	Yes	No	Yes	Unclear	No	No	No	No	Yes
Chenoweth et al. (2014)	Yes	Yes	Yes	Yes	Yes	Yes	N/A	Yes	Yes	Yes	Yes
Chenoweth et al. (2009); Norman et al. (2008)	Yes	Yes	No	No	Unclear	Yes	N/A	No	No	No	Unclear
Davis (1993)	Yes	Yes	Yes	No	Yes	Yes	N/A	No	No	Yes	No
Dorr et al. (2005)	Yes	Yes	No	Yes	No	Yes	N/A	No	Yes	No	Yes
Farsi and Filippini (2004)	Yes	Yes	Yes	No	Yes	Yes	No	No	No	Yes	Unclear
Grabowski and O'Malley (2014)	Yes	Yes	Yes	Yes	No	Unclear	No	No	No	No	Unclear
Holmes (1996)	Yes	Yes	Yes	No	Yes	Yes	N/A	No	No	Yes	No
Jenkens et al. (2011)	Yes	Yes	Yes	No	Yes	Yes	N/A	No	No	Yes	Yes
Maas et al. (1998); Swanson et al. (1993); Swanson et al. (1994)	Yes	Yes	Yes	No	Unclear	Unclear	N/A	No	No	No	Unclear
MacNeil Vroomen et al. (2012)	Yes	Yes	Yes	Yes	Unclear	Yes	N/A	Yes	Yes	Yes	Unclear
Mehr and Fries (1995)	Yes	Yes	Yes	No	Yes	Unclear	N/A	No	No	Yes	Unclear
Molloy et al. (2000)	No	Yes	Yes	No	Yes	Unclear	No	No	No	Yes	Unclear
Müller et al. (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Ouslander et al. (2011)	No	Yes	Yes	Yes	Yes	Yes	N/A	No	No	Yes	Unclear
Paulus et al. (2008)	Yes	Yes	No	No	Yes	Unclear	Unclear	No	No	No	Unclear
Przybylski et al. (1996)	Yes	Yes	Yes	Yes	Unclear	Unclear	No	No	No	Yes	Unclear
Rantz et al. (2012)	Yes	Yes	No	Yes	No	Unclear	No	No	No	No	No
Rovner et al. (1996)	Yes	Yes	Yes	Yes	Unclear	Unclear	N/A	No	No	Yes	Unclear
Schneider et al. (2007)	No	Yes	Yes	No	Yes	Yes	N/A	No	No	Yes	No
Sharkey et al. (2011)	Yes	Yes	Yes	No	Yes	Yes	N/A	No	No	No	Unclear
H. L. Smith et al. (1992)	Yes	Yes	Yes	No	Yes	Yes	N/A	No	No	Yes	Unclear
Sulvetta and Holahan (1986)	Yes	Yes	Yes	No	Yes	Yes	No	No	No	No	Unclear
Teresi et al. (2013)	Yes	Yes	No	Yes	No	Unclear	Unclear	No	Yes	No	No
Ullmann (1984)	Yes	Yes	Yes	No	Yes	Yes	N/A	No	No	Yes	Unclear
Ullmann (1986)	Yes	No	Yes	No	Yes	Yes	N/A	No	No	Yes	Unclear
Ullmann (1987)	Yes	Yes	Yes	No	Unclear	Yes	N/A	No	No	Yes	Unclear
van de Ven et al. (2014)	No	Yes	Yes	Yes	Yes	Unclear	No	No	No	Unclear	Unclear

2.3 Discussion

In comparison with the health care sector, where economic evaluations are common practice for pharmaceuticals and medical technologies, this review identified a total of 30 studies containing economic evidence in the residential aged care sector. A total of 14 studies pertaining to organisational and environmental characteristics in residential care were identified by this review, all of which contained partial economic evaluations in the form of cost analyses. Nineteen studies were identified which related to structures and processes of care, including 12 cost analyses, one cost-minimisation analysis, one cost-utility analysis, two cost-effectiveness analyses, and three cost-benefit analyses. The quality of study designs varied across the included studies, and as such study results should be treated with caution.

Formalising these issues within the framework of a systematic review has highlighted the paucity of evidence in this area. The usefulness of studies containing only partial economic evaluations is limited for policy and decision makers, in that they do not present the case on whether the costs of a course of action is worthwhile in terms of benefits provided to improve quality of care, leaving this aspect up to the reader to decide. The studies identified by this review provide a starting point from which to develop future economic studies and the methodological issues discussed throughout this section emphasize the need to do a better job of collecting and reporting data that are helpful for decision makers.

2.3.1 Key findings pertaining to organisational and environmental characteristics

In terms of organisational factors, the available literature suggests that for-profit facilities operate at lower costs than not-for-profit and government-owned facilities, while hospital-based facilities may have lower running costs than free-standing facilities. It is important that these results be interpreted with caution firstly because the cost data presented in these studies are dated, having been collected between 1976 and 1989. Secondly, all but one of the studies addressing proprietary status and affiliation were conducted in the United States and therefore their transferability to other aged care systems around the world is unclear. That being said, the value of investigating the cost-effectiveness of organisational characteristics should not be dismissed. While the evidence pointing to cost differences may be dated, there is current literature which identifies variation in outcomes based on organisational factors. For instance, for-profit facilities have been associated with higher staff turnover (Banaszak-Holl & Hines, 1996; Castle & Engberg, 2006), lower nursing staff levels (Castle & Engberg, 2006), and lower quality care overall (Harrington, Olney, Carrillo, & Kang, 2012). A recently published systematic review conducted in the United States found that prioritising resident well-being and care quality over profit maximisation was a key factor in not-for-profit facilities providing a higher quality of care than their for-profit counterparts (Godby, Saldanha, Valle, Paul, & Coustasse, 2017). Given the available literature indicating differences in both costs and effectiveness, future research which aims to link quality measures with cost data for differing proprietary status may provide insight into questions such as whether additional resources allocated in a not-for-profit organisation are producing better outcomes, or if perhaps these organisations are operating less efficiently.

There is a paucity of evidence regarding the impact of location or size on the running costs and cost-effectiveness of residential care facilities. This review found only two studies related to locality and one study which investigated facility size and thus it is difficult to draw conclusions. There have been a number of studies, however, which have looked at associations between these organisational factors and clinical outcomes. For instance, in a study investigating the use of feeding tubes among residents with advanced cognitive impairment, residents living in urban facilities and residents living in facilities with more than 100 beds were found to have an increased likelihood of having a feeding tube despite empirical data suggesting that feeding tubes are not beneficial in this population (Mitchell, Teno, Roy, Kabumoto, & Mor, 2003). Facilities with more than 100 beds have also been linked to higher staff turnover which has been found to be detrimental to overall quality of care (Castle & Engberg, 2006). In light of evidence which links quality outcomes to size and location, future economic evaluation studies are warranted.

The body of evidence examining the impact of the physical environment on people with dementia has been well documented, and environmental design interventions have been shown to affect behaviour, function, well-being, social abilities, orientation, and care outcomes (Marquardt, Bueter, & Motzek, 2014). SCUs have been linked to lower hospitalisation rates (Intrator, Castle, & Mor, 1999) and lower likelihood of using feeding tubes (Mitchell et al., 2003). However, economic evaluations of environmental characteristics and dementia-specific facility designs are scant; this review identified only four studies in this domain. Environmental modifications in the identified studies included homelike environments (e.g. single bedrooms, private bathrooms, decorating, and access to outdoors) and functional modifications (e.g. increasing visual access to bedrooms and activity rooms, extending activity spaces, and building partitions to reduce overstimulation). The economic evidence in this review indicates that environmental modifications come at an additional cost, but are weakly associated with better outcomes in the form of reduced agitation and improved social interactions. It is important for future studies investigating the effectiveness of a particular environmental intervention to conduct economic evaluations alongside these trials in order to build a more robust evidence base surrounding the value of investing in specialised designs.

2.3.2 Key findings pertaining to structures and processes of care

Despite the heterogeneity of interventions and outcome measures pertaining to structures and processes of care, synthesis of study results revealed several common themes. Results from three studies suggest a potential for cost savings to the health care sector by increasing the amount of direct care time provided to each resident (Dorr et al., 2005; Przybylski et al., 1996; Schneider et al., 2007). Benefits reported were wide ranging from reductions in the frequency of hospitalisations to improved functional status for the residents. The best means of achieving these outcome improvements is unclear, however, as the included studies focused on a disparate array of staff positions including registered nurses, occupational therapists, and physiotherapists. These positive results highlight an opportunity for future research to explore cost-effective methods of increasing the amount of direct care time to residents, and the optimal skill set and configuration of staff (e.g. nurses, allied health professionals, and other aged care workers) needed to achieve the best outcomes for individual residents.

Interestingly, increased levels of direct care time were found in the small, home-like ‘Green House’ model, as well as the dementia special care units. While we would expect to see cross-sectoral benefits (beyond the aged care sector and into the health care sector) similar to those reported in the enhanced staffing interventions, none of the studies actually measured costs in the health care sector. Three of the four did not report any effectiveness measures (Jenkens et al., 2011; Mehr & Fries, 1995; Sharkey et al., 2011), while the fourth found no effect on cognitive or functional abilities (Swanson et al., 1994). By not including costs from all relevant sectors, these studies may be underestimating the potential value of specialised care settings.

Another aspect of residential care that was shown to create cost savings from a broader health care perspective was quality improvement initiatives, such as activity programs and interventions aimed at reducing health care utilisation and hospitalisations. While quality improvement initiatives tend to come at a cost to the facility in terms of planning and implementation, the flow-on effects of improving care quality is likely to extend to other areas of health services. Many of these initiatives, however, such as the quality improvement projects evaluated by Ouslander and colleagues (2011), and Rantz and colleagues (2012), along with more than half of included studies in this review, focused cost analyses on intervention and care costs incurred by the facility only.

The remaining studies are difficult to generalize, largely due to differing implementation methods. In terms of caring for individuals with dementia, recent research into person-centred care suggests its potential to reduce agitation and aggression (Chenoweth et al., 2014; Chenoweth et al., 2009), though this was not a unanimous conclusion (van de Ven et al., 2014). Despite the sound methodological quality of these three studies, disparate implementation methods render it difficult to draw any definitive conclusions. For instance, of the two studies that considered dementia care mapping, one study had two experienced, accredited researchers as well as two care staff from each facility to conduct the mapping (Chenoweth et al., 2009) while the second study used two care staff from each facility but no researchers (van de Ven et al., 2014). These disparities raise questions about the conclusions drawn, as the two studies described reported higher costs and cost-neutrality respectively.

The concept of integrated care is not well-defined, and is therefore difficult to generalize. Two studies identified by this review defined integrated care in terms of integration between staff and residents (Paulus et al., 2008), and integration across disciplines (MacNeil Vroomen et al., 2012). Both integrated care interventions reported limited cost-saving potential, although further research in this area is needed which links costs to outcomes. The study of integrated care between staff and residents (Paulus et al., 2008) considered only the costs of care, with no attempt to measure outcomes. The multidisciplinary integrated care method, which conducted full cost-effectiveness analyses, found that for resident-related quality of care, the probability that the intervention was cost-effective compared to usual care was 0.95 or more for ceiling ratios greater than €129, while the same intervention was not cost-effective in terms of functional health or quality adjusted life years.

2.3.3 Scope of problem

The inclusion of health and quality of life effects

One very prominent methodological issue that emerged from this review was the heterogeneous range of outcomes that have been used. Some of the direct outcomes measured included agitation, improved social interactions, quality of life, behaviour, function, well-being, depressive symptoms, quality of care, rates of decubitus ulcers, catheterisation, physical restraints, and chemical restraints. Other outcomes, which could be presumed to impact on health, included drug errors, number of regulatory deficiencies, skill level of persons in charge of nursing shifts, range of therapies provided, and number of people waitlisted. The development of guidance towards a more consistent methodology for economic assessment of residential aged care infrastructure is needed, specifically with the inclusion, where possible, of the health and quality of life benefits measured from the perspective of the residents themselves including people with dementia.

There have been numerous instruments developed to measure health benefits such as behaviour, function, well-being, care outcomes, and health-related quality of life, for example. Consequently, it is important for the chosen outcome to be an appropriate measure of achievement for the desired objective. For instance, the desired objective of aged care infrastructure may be to improve the quality of life for the residents who live there. The question then becomes what is the most reliable outcome measure to capture improvements in the lives of residents?

One approach may be to present an array of outcome measures for each alternative, allowing the decision-makers to make their own trade-offs between measures of effectiveness. This is commonly known as a cost-consequences analysis. It may be argued that a focus on quality of life is more meaningful in this context than hard clinical indicators. As such, another possibility would be to incorporate a generic measure of incremental benefit, such as the QALY. The main benefit of utilising QALYs as an outcome measure (as opposed to clinical indicators) is their generic nature and therefore their potential applicability to all aged care residents, which would allow decision makers to make comparisons across differing programs. Cost-utility analyses, which use QALYs as the outcome measure, are the recommended economic evaluation in national guidelines developed by government agencies in healthcare such as NICE in the UK (National Institute for Health and Care Excellence, 2004, 2008), and the Canadian Agency for Drugs and Technologies in Health in Canada (Canadian Agency for Drugs and Technologies in Health, 2006). While these guidelines were originally developed for economic evaluations of health technologies, they could potentially be applied to aged care infrastructure, for instance where meaningful differences in health-related quality of life between the intervention and comparator have been demonstrated. NICE has published a manual for developing guidelines which covers health and social services in a broader context. In describing the role of economic evidence in guideline development, the manual notes that 'significant methodological developments in this area are anticipated' (National Institute for Health and Care Excellence, 2014), In 2015, NICE published social care guidelines for older people with multiple long-term conditions, in which it noted a lack of economic evidence pertaining to service delivery models in residential care, and recommended that future research capture health-related quality of life along with other outcome measures in order to build a body of economic evaluation evidence from which to base guidelines (National Institute for Health and Care Excellence, 2015).

It may also be worthwhile to consider a social context, rather than a health context, as potentially more appropriate in a residential care setting. Current research has acknowledged factors outside of health status such as dignity, independence, and having control over their daily lives as important contributors to residents' quality of life (C. M. Milte et al., 2014; J Ratcliffe et al., 2015). A recent systematic review of instruments for measuring outcomes in economic evaluations within community aged care recommends the use of a generic preference based measure of health related quality of life such as the EQ-5D to obtain QALYs in combination with an instrument with a broader quality of life focus to capture dimensions of social well-being, such as the Adult Social Care Outcomes Toolkit (ASCOT) designed to evaluate interventions in social care, or the ICEpop CAPability measure for Older people (ICECAP-O) which measures capability in older people (Bulamu, Kaambwa, & Ratcliffe, 2015). Ultimately, it is important that the chosen method is sensitive enough to measure changes for this population, and broad enough to allow comparisons to be made at a service planning level.

The inclusion of residents with dementia

Twenty-one studies identified by this review did not disclose whether residents with dementia had participated. While it is uncertain whether these studies included participants with dementia, the omission suggests that no specific consideration was given to this subgroup during study design. One study specified that residents were only approached to participate if judged by staff to be capable of self-completing the study questionnaire (R. Bland et al., 1992), which suggests cognitively impaired residents were excluded. When designing economic evaluations, it must be ensured that the study sample is representative for the population being assessed. The quality of an economic evaluation is highly dependent on the source of data used, and its ability to be transferred to other settings. In residential care settings, the exclusion of residents with dementia raises serious concerns regarding the representativeness of data given that over 50 per cent of those residing in aged care facilities have a recorded diagnosis of dementia (Australian Institute of Health and Welfare, 2012b; Harris-Kojetin et al., 2013).

Generalizability of findings, and transferability to an Australian setting

A key issue affecting the generalizability of findings is the geographic concentration of research in the United States. Research conducted outside of the United States is sparse. More than half of the included studies were conducted in the United States, while the remaining third were split between the Netherlands, Germany, Canada, Australia, and the United Kingdom. In the Australian context, this review identified only one group of researchers to have published an economic evaluation pertaining to residential aged care. While these findings are consistent with a recent systematic review of randomised controlled trials in care homes, which reported that 50 per cent of the randomised controlled trials undertaken in care homes were from the United States (Gordon et al., 2012), they do highlight a need for research in a wider array of countries and health systems to increase the generalizability and transferability of results.

2.3.4 Strengths and limitations of the review

This systematic review had a broad scope in order to provide a comprehensive summary of the evidence, and as such it provides a detailed overview of studies undertaken from a health economics perspective in the residential aged care sector. The main strength of this review was the systematic and transparent approach that, in combination with the breadth of the objective, allowed for a thorough synthesis of existing economic evaluations conducted in a residential aged care setting. The review was conducted to a high methodological standard and met the quality standards set within the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement. Critical appraisal of studies was undertaken using the JBI Critical Appraisal Checklist for Economic Evaluations which is a well-recognised and highly regarded checklist for assessing the quality of economic evaluation studies previously utilised in other high quality systematic reviews (Davy et al., 2015; Reilly et al., 2016). The broad scope of this review and the incorporation of economic evidence meant that it was necessarily time-intensive, requiring more resources for the search process, data extraction, and analysis compared with a narrow scope review. This review had limitations to analysis imposed by the heterogeneity of interventions, methods, and outcomes in the included studies. A meta-analysis was not possible; rather the review relied on a narrative analysis of the included studies. This is a reflection of the research that has been conducted to date, and again highlights the need for future evaluation research to be carefully planned such that the data collected and reported are useful for decision makers. In the Australian context, it should be noted that while the national Aged Care Financing Authority has published a number of studies pertaining to the costs of residential aged care in Australia, these reports did not meet the inclusion criteria for this systematic review, as they are descriptive in nature, and do not contain interventions or comparators (Aged Care Financing Authority, 2014; 2015). Nonetheless, a number of these reports contain findings relevant to the studies undertaken in this thesis. Therefore, while they have not been reviewed in depth in this chapter, they have been included in the discussion of results throughout this thesis.

2.4 Conclusions

This review provides the first comprehensive summary of the existing economic evidence pertaining to infrastructure, workforce structures and care processes in residential care, and highlights an urgent need for robust economic evaluations to inform future service development in this area. In order to fully capture the impact of an intervention or model of care in a residential aged care setting, it is important to take a broad perspective when conducting economic evaluations. The inclusion of broader health care costs in economic evaluations of interventions in residential care, in particular the use of hospitals, is critical for ensuring the value of the intervention is not underestimated.

There are number of unresolved methodological issues that have the potential to impact the results of economic evaluations in this sector. The practical application and transferability of findings would benefit from identifying appropriate and meaningful outcome measures that can be used at a service planning level. In addition, the representativeness of data would improve by increasing and ensuring the inclusion of residents with dementia. Economic evidence is essential to the promotion of efficiency, facilitating future policy directions within the aged care sector and will assist in identifying and quantifying the cross-sectoral impacts of new innovations in terms of both the costs and benefits provided.

The following chapter describes the methods for the INSPIRED study as well as an overview of the analyses conducted for each empirical study contained in this thesis.

CHAPTER 3: OVERVIEW TO THE INSPIRED STUDY

The INSPIRED (Investigating services provided in the residential care environment for dementia) study collected a range of data on costs, quality of life, and health status for a large sample of residents living in residential care facilities around Australia. These data provided an opportunity to explore the costs of providing care and the quality of life of older people living with cognitive decline in an Australian residential aged care setting. The data utilised for each of the studies contained in chapters 4 to 7 were derived from the INSPIRED study. This chapter provides an overview of the recruitment, data collection, data management, and research ethics for the INSPIRED study as a whole.

3.1 The INSPIRED study

The INSPIRED study was a cross-sectional, observational study to evaluate the specialised dementia services provided at residential aged care facilities in Australia. Data were collected from 17 residential aged care facilities across four states over a 14-month time period from January 2015 to February 2016. There were two levels of recruitment and data collection: (1) recruitment at the organisational level and (2) recruitment at the individual level. Copies of the study information sheets can be found in Appendix IV.

3.1.1 Organisational participants and recruitment

The National Health and Medical Research Council (NHMRC) Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People (the Cognitive Decline Partnership Centre or CDPC) was formed in 2012 to coordinate significant research efforts to contribute to improved quality of care for older people with dementia and their carers, as well as better information for service providers and decision makers. The CDPC’s participating partners consist of the NHMRC, Alzheimer’s Australia, and three residential aged care providers: Brightwater Care, HammondCare and Helping Hand. The partners were integrally involved in the development of the project.

The INSPIRED study recruited five residential aged care provider participants from four states of Australia (NSW, SA, WA and QLD) for the project. Facilities known to be dementia-specific as well as those with a high proportion of residents with dementia were intentionally approached for recruitment. Characteristics differed subtly between facilities, such as the number of residents per living unit, independent access to outdoor areas, allocation of care staff to specific living units or to the entire facility, and meals cooked in the units versus centrally prepared.

At the organisational level, with written CEO approval, data collection took the form of a paper-based survey which was distributed to residential aged care facilities to determine the costs to operate each facility, the facility profile and services, and the facility's capital structure. A staff member, typically a finance manager, from each organisation with knowledge of the participating facility's services, staffing, and financial structures was recruited to complete the survey. Data collection for this survey was done in person or via telephone as per the preference of the participating finance manager. Organisations were reimbursed for the time of the participating finance manager.

After CEO approval had been received and financial data collected, individual resident recruitment and data collection was coordinated with facility managers at each participating residential aged care facility.

3.1.2 Individual participants and recruitment

Residents were eligible if they (1) were permanent residents of the facility; (2) had been residing in the facility for at least 12 months; (3) were not in immediate palliative care; (4) had no complex medical or family issues which would impede their participation; and (5) had a proxy (i.e. usually a family member) willing to participate on their behalf if the resident themselves was unable to provide informed consent due to the presence of significant cognitive impairment.

The Psychogeriatric Assessment Scales - Cognitive Impairment Scale (PAS-Cog) was used to ascertain an eligible resident's level of cognitive impairment. Using previous PAS-Cog scores and/or advice from facility care staff, residents were separated into two separate consent profiles based on their likely ability to give informed consent and an appropriate recruitment approach was undertaken for each group. Residents with mild to no cognitive impairment were approached by a trained researcher, who sought consent to conduct a PAS-Cog. Residents who scored between 0 and 9 on the PAS-Cog (indicating no to mild cognitive impairment) were then provided with information on the full INSPIRED study, and given time to consider whether they wished to participate.

Proxy consent from a family member was sought for all eligible residents with moderate to severe cognitive impairment, or where the researcher had doubt regarding a resident's ability to self-consent. Family members were initially sent study information via post and then contacted by telephone to determine whether they were interested in participating on behalf of the resident. Wherever possible, the proxy consent was done by a family member, spouse, or friend empowered with legal decision-making authority.

All outcome measures were collected in-person through face-to-face interviews undertaken at the resident's facility where possible, with residents as well as proxy respondents. If a face-to-face interview was not possible with proxy respondents, questionnaire packs were sent to the proxy via post with contact details of the research team, and follow-up via telephone to offer assistance with completion.

3.1.3 Data collection

The INSPIRED study collected cost data as well as a comprehensive set of outcome measurements, including cognitive function, generic and condition-specific measurements of health-related quality of life, dementia severity, physical function, and neuropsychiatric symptoms. An overview of the measurement instruments from INSPIRED which have been used in this thesis is provided in Table 3-1 and described in more detail in the section below. A full copy of the questionnaires used can be found in Appendix V.

Table 3-1 Overview of data collected and data sources utilised

Data type	Variable	Source
Cost data	Average per diem facility cost	Facility Cost Survey
	12-month cost of medical consultations, procedures & tests	Medicare claims history
	12-month cost of prescription medications	Pharmaceutical Benefits Scheme (PBS) claims history
	12-month cost of hospitalisations	Hospital inpatient and emergency department separations
Quality of Life data	Health-related quality of life	EQ-5D-5L EQ-5D-5L-Proxy DEMQOL DEMQOL-Proxy
Controls	Sex, age, marital status, education, dementia diagnosis	Demographic Questionnaire
	Cognitive impairment	PAS-Cog
	Severity of dementia	Dementia Screening Scale (DSS) Functional Assessment Staging (FAST) scale
	Physical functioning	Modified Barthel Index (MBI)
	Neuropsychological symptoms	Neuropsychiatric Inventory Questionnaire (NPI-Q)

Facility Cost Survey

A facility-level cost survey was designed to facilitate data collection for the first costing component of the INSPIRED project. Routinely collected data were obtained from participating residential aged care facilities with the assistance of facility financial staff and business service records. Data collection took the form of a paper-based survey which collected data on the costs to operate each facility, the facility profile and services, and the facility's capital structure. Data were collected for the 2012/13 and 2013/14 financial years.

The survey contained three sections. The *Costing* section of the survey was designed to collect data relating to the quantities of resource use as well as unit costs or prices. The *Facility Profile & Services* section of the survey collected information on the service models of each residential aged care facility, with questions relating to room configuration, age of facility, staff training, continuity of care, resident amenities, social activities, construction and fit-out costs, and future building plans. The *Capital Structure* section of the survey collected information on borrowing rates (the cost of debt) as well as information on the type of debt (i.e. accommodation bonds vs interest bearing debt) and the tax status of the facility.

To ease the burden on residential aged care facilities participating in the INSPIRED study, participating organisations were able to submit facility reports for the StewartBrown Aged Care Financial Performance Survey to satisfy the revenue and expense portion of the *Costing* section in the Facility Cost Survey. StewartBrown is a chartered accountancy firm in Australia which conducts a quarterly Aged Care Financial Performance Survey (StewartBrown, 2014). This survey provides an opportunity for participating aged care organisations to benchmark their performance against others in the industry, and attracts wide participation from over 190 aged care organisations in Australia, representing over 900 aged care facilities, or roughly one-third of the residential aged care sector.

Demographic Questionnaire

A demographic questionnaire was designed to obtain information on each participant's age, sex, marital status, level of education, presence of a diagnosis of dementia, current Aged Care Funding Instrument (ACFI) level, and current comorbid conditions and medications.

The ACFI is an instrument used to determine the level of funding to be allocated to an aged care provider for an individual aged care resident based on their overall relative care needs (Commonwealth of Australia, 2013). It focuses on three areas which have been determined to differentiate care needs among residents: activities of daily living (ADL), behaviour (BEH), and complex health care (CHC). The ACFI consists of 12 questions regarding an individual's assessed care needs, each rated A, B, C, or D, with A corresponding to the lowest level of care needs and D corresponding with the highest level of care needs. Each question's A, B, C, or D response has a score. Scores are summed for each of the three categories (ADL, BEH, and CHC), and individuals are assigned a needs rating of high, medium, low, or nil based on the summed score in each category. Funding in the form of basic care subsidies are then provided according to the four levels in each of these categories (see Table 6-1). The daily subsidy paid for a resident comprises the sum of the amounts payable for each of the three care categories (ADL + BEH + CHC).

PAS-Cog

The Psychogeriatric Assessment Scales (PAS) are a collection of six scales which provide an assessment of dementia and depression in older adults (Jorm et al., 1995). The Cognitive Impairment scale consists of nine questions administered in the form of an interview to test the cognitive functioning and memory of the subject. The resulting score ranges between 0 and 21, with 0 indicating that no impairment was detected by the scale and 21 indicating severe cognitive impairment.

EQ-5D-5L

The EQ-5D-5L is a generic, preference-based measure which captures health-related quality of life using five levels of severity in five dimensions (Herdman et al., 2011). The EQ-5D-5L can be completed by the subject or by a proxy, and collects subjective assessments of mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Self-reporting of the EQ-5D-5L was encouraged for all participating residents with a PAS-Cog score less than or equal to 11, based on evidence of its appropriateness in people with mild to moderate dementia (Hounsome et al., 2011; Orgeta, Edwards, Hounsome, Orrell, & Woods, 2015). For participants who declined or were unable to complete the EQ-5D-5L and for those with a PAS-Cog score greater than 11, a proxy-assessment via a family member was sought. Proxies were asked to respond as they thought their relative would (proxy-patient perspective). Health state utility values were generated from a scoring algorithm based on the time trade off (TTO) and discrete choice experiment approaches in a UK general population sample (Devlin, Shah, Feng, Mulhern, & van Hout, 2016). Utility scores were bounded from -0.281 to 1 where health states with a score less than 0 are considered worse than death. A cognition bolt-on question, which was originally developed for the 3-level version (Krabbe, Stouthard, Essink-Bot, & Bonsel, 1999), was added to the questionnaire. The bolt-on was not incorporated in the utility scoring algorithm. The EQ-5D-5L descriptive system is illustrated in Figure 3-1.

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

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

USUAL 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

PAIN / DISCOMFORT
☐ 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

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

COGNITION
☐ I do not have any problems with cognitive functioning
☐ I have slight problems with cognitive functioning
☐ I have moderate problems with cognitive functioning
☐ I have severe problems with cognitive functioning
☐ I have extreme problems with cognitive functioning

Figure 3-1 EQ-5D-5L descriptive system with cognition bolt-on

DEMQOL and DEMQOL-Proxy

The DEMQOL and DEMQOL-Proxy are health-related quality of life measures designed specifically for use in people with dementia (S. C. Smith et al., 2005). The conceptual framework used in their development focused on the dimensions of health and well-being, cognitive functioning, social relationships, daily activities, and self-concept. The DEMQOL is a self-report instrument containing 28 items plus an overall quality of life rating and is appropriate for use in people with mild to moderate dementia. The DEMQOL-Proxy, which contains 31 items plus the overall quality of life rating, is designed for completion by a family member or carer and is recommended for all levels of dementia, from mild to severe. The DEMQOL-Proxy asks proxies to provide responses to the instrument that most closely approximate the responses that they think their relative would provide (proxy-patient perspective). In accordance with the developers' guidelines, both a DEMQOL and DEMQOL-Proxy were sought for all participants with a PAS-Cog score below 18, while only the DEMQOL-Proxy was completed for residents with a PAS-Cog score greater than or equal to 18.

The original DEMQOL system does not allow the calculation of health state utility values; rather it uses a simple summative scoring system. In 2012, Mulhern and colleagues developed a health state classification system based on the DEMQOL questionnaires which could then be used in economic evaluations (Brendan Mulhern et al., 2012). This involved first using factor analysis to determine the number of different dimensions captured by the DEMQOL and DEMQOL-Proxy questionnaires, followed by Rasch analysis (a logit modelling technique) to select the most appropriate item for each of the identified dimensions. These health state classification systems were subsequently called the DEMQOL-U and DEMQOL-Proxy-U. For the INSPIRED study, all DEMQOL and DEMQOL-Proxy responses were converted to health state utility values using the

DEMQOL-U and DEMQOL-Proxy-U scoring algorithms derived using the TTO approach in a UK general population sample (B. Mulhern et al., 2013). The DEMQOL-U consists of four levels of severity in five dimensions: positive emotion, memory, relationships, negative emotion, and loneliness. The DEMQOL-Proxy-U consists of four levels of severity in four dimensions: positive emotion, memory, appearance, and negative emotion. Utility scores for the DEMQOL-U are bounded from 0.243 to 0.986, while the DEMQOL-Proxy-U are bounded from 0.363 to 0.937 (B. Mulhern et al., 2013). The DEMQOL-U and DEMQOL-Proxy-U descriptive systems are presented in Figure 3-2.

DEMQOL-U	DEMQOL-Proxy-U
POSITIVE EMOTION I feel cheerful a lot I feel cheerful quite a bit I feel cheerful a little I do not feel cheerful at all	**POSITIVE EMOTION** I feel lively a lot I feel lively quite a bit I feel lively a little I do not feel lively at all
MEMORY I do not worry at all about forgetting things that happened recently I worry a little about forgetting things that happened recently I worry quite a bit about forgetting things that happened recently I worry a lot about forgetting things that happened recently	**MEMORY** I do not worry at all about forgetting what day it is I worry a little about forgetting what day it is I worry quite a bit about forgetting what day it is I worry a lot about forgetting what day it is
RELATIONSHIPS I do not worry at all about making myself understood I worry a little about making myself understood I worry quite a bit about making myself understood I worry a lot about making myself understood	**APPEARANCE** I do not worry at all about keeping myself looking nice I worry a little about keeping myself looking nice I worry quite a bit about keeping myself looking nice I worry a lot about making keeping myself looking nice
NEGATIVE EMOTION I do not feel frustrated at all I feel frustrated a little I feel frustrated quite a bit I feel frustrated a lot	**NEGATIVE EMOTION** I do not feel frustrated at all I feel frustrated a little I feel frustrated quite a bit I feel frustrated a lot
LONELINESS I do not feel lonely at all I feel lonely a little I feel lonely quite a bit I feel lonely a lot	

Figure 3-2 DEMQOL-U and DEMQOL-Proxy-U descriptive systems

Dementia Screening Scale (DSS)

The DSS is a proxy dementia rating scale designed and validated for use by nursing staff in residential aged care facilities (Köhler, Weyerer, & Schäufele, 2007). The 7-item instrument provides a score between 0 and 14, with a higher score indicating a higher level of impairment, and can differentiate between residents with severe dementia. Resulting scores can be classified into three levels with scores of 0 to 3 indicating no cognitive impairment, 4 to 7 indicating mild-severe impairment, and 8 to 14 indicating very severe impairment. Questions relate to the recognition of family and carers and the resident’s orientation in their environment.

Functional Assessment Staging (FAST) scale

The FAST scale is an Alzheimer's disease-specific assessment scale which stages the disease based on a person's functional ability and activities of daily living (ADL) (Reisberg, 1988). The FAST scale has seven stages ranging from normal adult (stage 1) to severe dementia (stage 7). The instrument is completed by a carer and is useful for detecting changes at the more severe end of the scale where cognitive assessments such as the PAS-Cog are no longer able to detect meaningful changes (Sclan & Reisberg, 1992).

Modified Barthel Index (MBI)

The MBI is a functional assessment scale which measures a person's level of independence across a range of ADL functions (Shah, Vanclay, & Cooper, 1989). Consisting of 10 items, the MBI is scored on a range from 0 to 100, with 0 indicating full physical dependence in all categories and 100 indicating full independence.

Neuropsychiatric Inventory Questionnaire (NPI-Q)

The NPI-Q, a brief version of the original Neuropsychiatric Inventory, is a validated instrument for assessing psychopathology in dementia (Kaufer et al., 2000). There is both a 10-item and 12-item version. The 10-item NPI-Q was completed by care staff for each participating resident in the INSPIRED study. Each of the 10 items were rated by the care staff as 0 to 3 points according to levels of increasing severity with 0 indicating no symptoms were present in the past month for that item, and 3 indicating severe symptoms were present.

Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) claims

A second participant consent form was used to consent to release of MBS and PBS claims history for the 12-month period prior to the INSPIRED data collection. Costs were calculated by applying the schedule fee for the relevant time period to each to each claim item. The total MBS cost for each participant was calculated as the sum of all MBS items' schedule fees for that individual. The total PBS cost for each participant was calculated as the total of the item costs (patient contribution + net benefit) for each prescription. The time period of the costs was the retrospective 12-month period from the start date of data collection at each facility. This period was chosen to more closely align with the facility-level cost data which were collected for the 2012/13 and 2013/14 financial years.

Missing data could either mean that consent was not received, that the linked data were not available, or that no claims were made for that participant. In some instances, claims may have gone through the Department of Veterans' Affairs (DVA) instead of Medicare; however DVA claims data were not collected for this study.

Hospital inpatient and emergency department separations

Hospital inpatient and emergency department separations data were also collected for the 12-month period prior to the INSPIRED data collection. In Australia, hospital admissions are classified into diagnostic-related groups (DRGs). Each DRG then has a payment weight assigned to it based on the average resources used to treat patients in that DRG. No hospitalisation data was assumed to mean the participant did not visit hospital. Consent for hospitalisation data was included on study consent form. Data on hospital outpatient visits were not captured in this dataset.

3.1.4 Research ethics

Ethics approval was obtained from Flinders Social and Behavioural Research Ethics Committee (SBREC) in October 2014 for the Facility Cost Survey (SBREC project number 6594) and in December 2014 for the individual-level portion of the INSPIRED study (SBREC project number 6732).

3.2 Overview of analytical plan

Analyses to address the stated research objectives outlined in Chapter 1 were divided into the following four areas:

1. Quality of life in dementia
2. Facility-level costs
3. Health system costs
4. Synthesis of costs and quality of life

These four areas of analysis have each been allocated a dedicated chapter. Table 3-2 provides an overview of each of these chapters along with the primary objective, study sample and variables used for each analysis.

In chapter three I have provided a description of the design and collection of data as part of the large-scale INSPIRED study. This thesis now moves into the individual empirical studies and presentation of results. Chapter 4 presents an investigation into the performance of two preference-based measures of health-related quality of life in a residential aged care setting.

Table 3-2 Overview of analytical plan

Results Chapter	Primary objective	Sample for analysis	Variables
Chapter 4: Quality of life in dementia	Empirical comparison of two preference-based measures: one generic and one condition specific	Full INSPIRED cohort; individual level (n=541)	Age; Sex; Diagnosis of dementia; EQ-5D-5L; EQ-5D-5L-Proxy; DEMQOL-U; DEMQOL-Proxy-U; Pas-Cog; DSS; FAST; MBI; NPI-Q
Chapter 5: Facility-level costs	Present the results of the Facility Cost Survey, including primary cost categories, cost drivers, and sources of cost variation related to the operation of residential aged care facilities	Full INSPIRED cohort; facility level (n=17)	Operating costs; Locality; Total number of physical beds; Number of secure dementia beds; Number of extra services beds; Average annual resident turnover; Resident case-mix; Agency rate; Proportion of staff on casual contracts; Annual staff turnover; Average number of volunteers; Proportion of multi-bed rooms; Average room size; Number of floors in facility; Age of facility; RN Level 1 wage rate (as proxy for cost of living)
Chapter 6: Health system costs	Determine the main factors which contribute to system-level costs in an Australian residential aged care setting from the perspective of the government	Subsample from 5 facilities in South Australia for whom MBS, PBS, and hospitalisation data were available; individual level (n=180)	Facility characteristics: locality, facility size, facility costs Resident Characteristics: age, sex, dementia diagnosis, PAS-Cog, MBI, NPI-Q, MBS costs, PBS costs, hospitalisation costs
Chapter 7: Synthesis of costs and outcomes	Explore the factors which contribute to resident quality of life in an Australian residential aged care setting	Subsample from 5 facilities in South Australia for whom Medicare, PBS, and hospitalisation data were available; individual level (n=180)	Facility characteristics: locality, facility size, facility costs Resident Characteristics: age, sex, dementia diagnosis, PAS-Cog, MBI, NPI-Q, MBS costs, PBS costs, hospitalisation costs

CHAPTER 4: MEASURING QUALITY OF LIFE FOR PEOPLE WITH DEMENTIA

Using the INSPIRED study cohort, this chapter presents an empirical study to compare the performance of (1) self-reported responses for the EQ-5D-5L with the DEMQOL-U; (2) proxy-reported responses for the EQ-5D-5L with the DEMQOL-Proxy-U; and (3) self-reported responses for the DEMQOL-U with proxy-reported responses for the DEMQOL-Proxy-U. The analyses reported in this chapter are amongst the first empirical analyses to compare the recently developed DEMQOL-U and DEMQOL-Proxy-U health state classification systems with the EQ-5D-5L in a residential aged care setting and thus provide a novel and important contribution to the field. The work in this chapter has been accepted for publication (Easton, Milte, Crotty, & Ratcliffe, 2017b).

4.1 Methods

The INSPIRED study collected health-related quality of life data using both the EQ-5D-5L and DEMQOL group instruments for a large sample of residents living in residential care facilities around Australia. These data provided an opportunity to further explore the acceptability and empirical validity of these preference-based measures and explore their appropriateness for use in a residential care setting. The primary aim of this empirical study was to compare the performance of two preference-based measures – the generic EQ-5D-5L and the condition-specific DEMQOL-U (and their proxy versions) – in an Australian residential aged care setting. This aim is in line with Objective 3 of this thesis.

Brazier and colleagues propose three main criteria to compare the performance of preference-based measures: practicality, reliability, and validity (J. Brazier, Deverill, Green, Harper, & Booth, 1999). Practicality refers to an instrument's acceptability to respondents, and relates to characteristics such as the length of the questionnaire and its complexity. Reliability refers to the ability of a measure to produce the same value on two separate administrations when there is no change in health. Reliability can be examined in terms of inter-rater reliability and test-retest reliability. Inter-rater refers to two people, such as an individual and their carer, both rating the health of the same individual. Test-retest refers to the same questionnaire repeated on two separate occasions when there has been no change in health. The final criteria, validity, refers to the extent that an instrument measures the right concept (Streiner, Norman, & Cairney, 2015). Assessment methods for examining the validity of the health state descriptive system include content validity (the extent to which dimensions of health are covered), face validity (the extent to which items are sensible to respondents), construct validity (the extent of agreement with other measures of health), and responsiveness to change (the ability to capture changes in health over time).

From a clinical perspective, comparison between instruments can be useful in providing some context and meaning when interpreting or using quality of life results (Symonds, Berzon, Marquis, & Rummans, 2002). For instance, understanding how each instrument converges with other measures of health (construct validity) may assist in choosing which instrument is most relevant for use in a particular population. Similarly, knowledge of the practicality of each instrument is also important when planning quality of life assessments, to ensure the measure is suitable to the population.

In accordance with the main objective of the study to compare the performance of the EQ-5D-5L, DEMQOL-U, and their proxy versions, the analyses focused on assessing the practicality and validity of each instrument. An overview of the assessment criteria to compare the performance of preference-based measures and the associated method used to assess each criterion is presented in Figure 4-1. Inter-rater and test-retest reliability could not be assessed as the instruments were administered on a single occasion only and no repeated measures were collected. Content validity, which relates to the comprehensiveness of an instrument, and face validity, which considers whether the individual items are appropriate, were not within the scope of this study. While data limitations meant that reliability, content validity, and face validity could not be directly assessed in this thesis, previous studies have focused on these criteria and found good results for the EQ-5D-5L, the DEMQOL-U and the DEMQOL-Proxy-U (Herdman et al., 2011; B. Mulhern et al., 2013).

The main analyses for this chapter were performed utilising three subgroups from the full INSPIRED study sample:

1. **Self-rated subgroup** comprising a subsample of participants who completed two self-rated health-related quality of life measures: EQ-5D-5L and DEMQOL.
2. **Proxy-rated subgroup** comprising a subsample of participants for which the two proxy-rated health-related quality of life measures were completed: EQ-5D-5L-Proxy and DEMQOL-Proxy.
3. **Self versus Proxy subgroup** comprising a subsample of participants for which dyad (both a self-rated DEMQOL and a proxy-rated DEMQOL-Proxy) assessments were completed.

The purpose of analysing the subgroups outlined above was to facilitate direct comparisons between the various instruments. Dyadic comparisons allow for analyses to determine agreement between instruments in the case of the first two subgroups, and agreement between person (self and proxy) perception in the case of the third subgroup (J. M. Bland & Altman, 1986). Dyads also facilitate the examination of issues such as whether the various instruments are interchangeable (i.e. substitutes) or capturing different information (i.e. complements). Statistical analysis was undertaken using IBM SPSS Statistics Version 22 (IBM Corp, Released 2013).

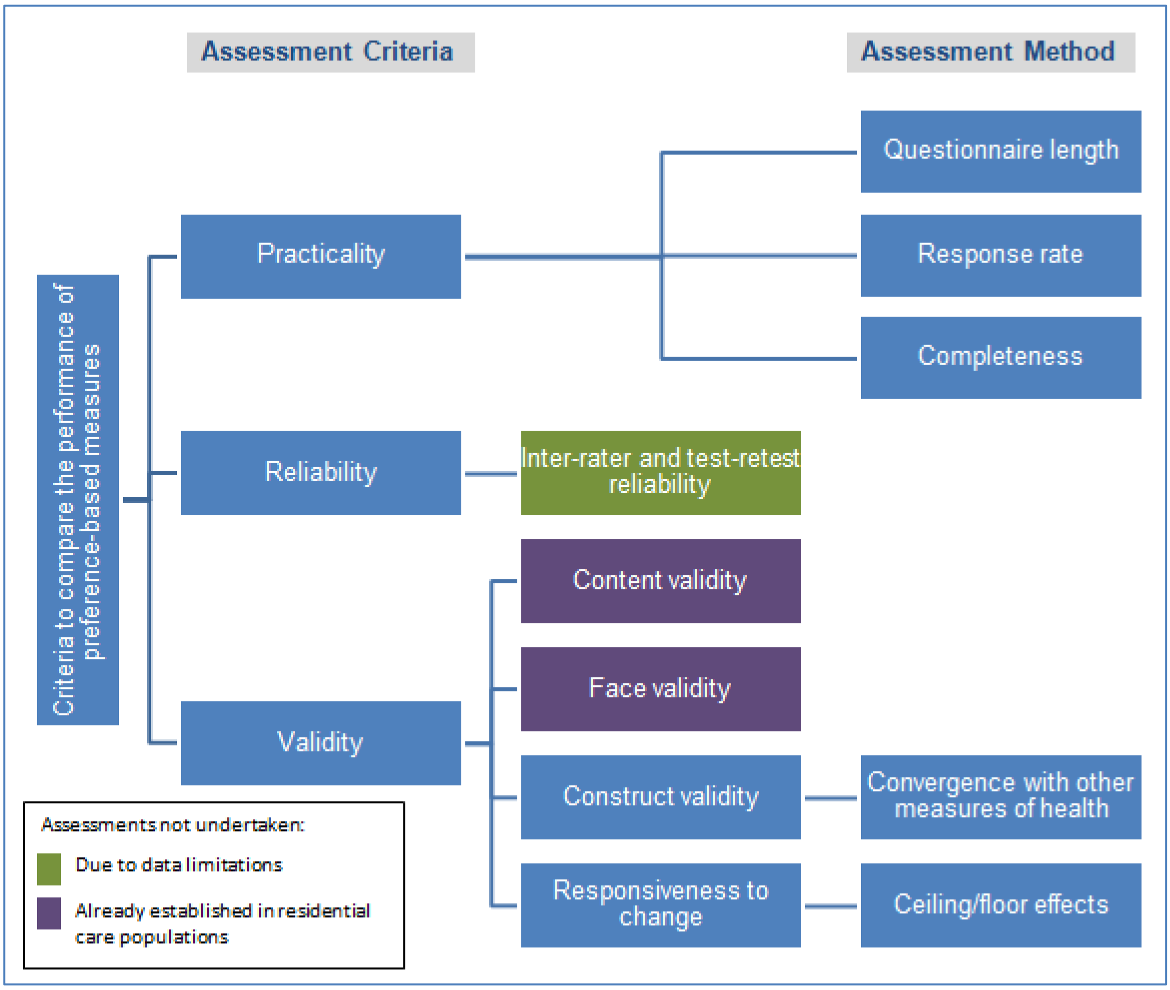


Figure 4-1 Overview of assessment criteria and methods used to compare the performance of the EQ-5D-5L, DEMQOL-U, and their proxy versions

4.1.1 Descriptive statistics

Summary statistics of the full INSPIRED study sample as well as each of the three subsamples were calculated for all demographic and outcome measures. Variables included (1) participant characteristics including age, sex, and the existence of a dementia diagnosis; (2) self-rated health-related quality of life utility scores for the EQ-5D-5L and DEMQOL-U; (3) proxy-rated health-related quality of life utility scores for the EQ-5D-5L-Proxy and DEMQOL-Proxy-U; and (4) clinical outcome measures for cognitive function (PAS-Cog), severity of dementia (DSS, FAST), physical function (MBI), and neuropsychiatric symptoms (NPI-Q). Summary statistics included sample size, mean, standard deviation, and range. The distributions of each variable were assessed for normality using the Kolmogorov-Smirnov test with Lilliefors significance correction and the Shapiro-Wilks test. Utility distributions were plotted for the EQ-5D-5L, EQ-5D-5L-Proxy, DEMQOL-U, and DEMQOL-Proxy-U.

The next phase of the descriptive analysis focussed solely on the three subgroups. The Mann-Whitney U test and the Kruskal-Wallis test were used to compare utility scores in terms of participant characteristic groups: age, sex, and dementia diagnosis. The Mann-Whitney U test was used to test for differences between two independent groups on a continuous measure. This test was appropriate to determine whether males and females differed in terms of utility scores. Similarly, it was appropriate to determine whether utility scores differed between those with a diagnosis of dementia and those without. The Kruskal-Wallis test was used to compare the scores of a continuous variable with three or more groups. To determine whether utility scores differed by age group, participants were grouped based on age quartiles. This resulted in four categories of age which facilitated use of the Kruskal-Wallis test. For both the Mann-Whitney U test and the Kruskal-Wallis test, a resulting significance level below 0.05 indicates a statistically significant difference in utilities across groups.

4.1.2 Practicality

Practicality refers to an instrument's acceptability to respondents, and relates to characteristics such as the length of the questionnaire and its complexity (John Brazier, Ratcliffe, Salomon, & Tsuchiya, 2007). To examine the practicality of the EQ-5D-5L, the EQ-5D-5L-Proxy, the DEMQOL, and the DEMQOL-Proxy, the following data were tabulated: (1) the number of items on the questionnaire; (2) the response rate; and (3) the completeness or level of missing data for those who completed the survey.

4.1.3 Validity

Validity was assessed in terms of construct validity and responsiveness to change. Construct validity assesses the extent to which the dimensions of a utility measure correlate with other indicators of health, or health-related quality of life in the population of interest. Responsiveness to change considers the ability of an instrument to measure changes in health status.

Construct validity

The strength of association between the dimensions of the EQ-5D-5L and DEMQOL-U were evaluated using Spearman's rank order correlations and index-level correlations were graphically represented with scatterplots. Correlations sizes below 0.3 were considered negligible, those from 0.3 to 0.5 were considered low, and those from 0.5 to 0.7 were considered moderate (Hinkle, Wiersma, & Jurs, 2003). The level of agreement between the EQ-5D-5L and DEMQOL-U was also graphically presented using a Bland-Altman plot (J. M. Bland & Altman, 1986). Differences in individual-level utility scores were plotted on the y-axis, and average utility scores were plotted on the x-axis. These analyses were repeated for EQ-5D-5L-Proxy and DEMQOL-Proxy-U (proxy-rated subgroup), as well as for the DEMQOL-U and DEMQOL-Proxy-U (self vs. proxy subgroup).

Convergent validity for the EQ-5D-5L and the DEMQOL-U was assessed by examining the mean distributions of DEMQOL-U index scores by EQ-5D-5L dimensions. This was repeated for both the proxy-rated subgroup and self vs. proxy subgroup. Convergent validity was also assessed between each health-related quality of life measure and three common clinical outcome measures for dementia: cognitive function, physical function, and neuropsychiatric symptoms. Bivariate correlation coefficients were calculated for each health-related quality of life dimension with the respective clinical outcome measures (PAS-Cog, DSS, FAST, MBI, and NPI-Q).

For the comparison of self-rated DEMQOL-U with proxy-rated DEMQOL-Proxy-U dyads, the association between common dimensions of both measures (positive emotion, memory, and negative emotion) was tested using the Wilcoxon Signed Ranks test. The Wilcoxon Signed Ranks test is designed for use with repeated measures, either when each subject is measured on two occasions, or when each subject is measured under two different conditions. It is the non-parametric alternative to the repeated measures t-test. As the quality of life for each participant in the self vs. proxy subgroup was measured by the individual and their proxy, measurement under two conditions was satisfied and the Wilcoxon Signed Ranks test was appropriate.

Responsiveness to change

Responsiveness is typically assessed statistically using effect size calculations. This was not possible given the cross-sectional nature of the INSPIRED data. Instead the potential sensitivity to change was examined in terms of floor and ceiling effects. For each dimension of each health-related quality of life measure, the percentage of respondents who answered the best response (ceiling) and worst response (floor) was tabulated.

This approach was chosen because an instrument’s responsiveness depends, in part, on the distribution of responses across the levels of the dimensions (John Brazier et al., 2016). For example, the EQ-5D has been commonly reported to have a high ceiling effect with the implication being, if a large number of respondents report themselves at the best possible level, improvements to population health from developments in care cannot be captured (Herdman et al., 2011).

4.2 Results

The INSPIRED study assessed a total of 1,323 people living in 17 residential care facilities across four Australian states. The facilities belonged to five not-for-profit aged care organisations. Of the total resident pool, 901 met eligibility requirements and 541 consented to participate in the study. A total of 24 per cent of study participants self-consented, whilst proxy consents were obtained for 76 per cent. The mean age of participants was 85.5 years. Descriptive statistics for the INSPIRED study sample as well as the three subgroups are presented in Table 4-1.

In general, consent rates were poorer at sites that (anecdotally) had been exposed to a lot of research activity or where the residents had very severe cognitive impairment and dementia-associated behaviours as their family members did not visit as often or feel that they could respond on behalf of the resident. More specifically, the main reasons for declining to participate were:

- Family didn’t respond to approach by letter or phone message (a cap on 3 approaches to family members was applied).
- Facility did not have current contact details for family members
- Lack of interest (residents and family)
- Too busy (residents and family)
- Not willing to speak on residents behalf (family)
- Did not return postal questionnaires and consents despite follow up calls (postal surveys ranged from 0 to 7 at each site, on average 63 per cent did not return.)

4.2.1 Practicality

A summary of measures to assess the practicality of the four health-related quality of life measures is presented in Table 4-2. The EQ-5D-5L questionnaire and its proxy version contained six items each including a cognition bolt-on. The DEMQOL and DEMQOL-Proxy questionnaires contained 29 and 32 items respectively. The proxy-rated questionnaires had near-perfect response rates with 100 per cent of those approached completing the EQ-5D-5L-Proxy and 99.8 per cent completing the DEMQOL-Proxy. Response rates for the self-rated questionnaires were lower, with 67.4 per cent of people approached completing the EQ-5D-5L and 76.5 per cent completing the DEMQOL. Missing data were low across all questionnaires ranging from no data missing on the EQ-5D-5L to 2 per cent missing on the DEMQOL. Missing data on the proxy-rated questionnaires were similar for both the EQ-5D-5L-Proxy and DEMQOL-Proxy (0.42 and 0.47 per cent respectively).

Table 4-3 provides a summary of participants who were unable to complete the DEMQOL instrument. The primary reason for absence of a valid DEMQOL was a PAS-Cog score of 18 or above (n=239), which was outside the developer’s recommended guidelines for the DEMQOL, and thus these participants were not asked to complete the DEMQOL instrument. Of those participants with a PAS-Cog score less than 18, the most common reasons cited for non-completion were ‘participant unable’ (n=21); ‘family refused’ (n=15); and ‘participant refused’ (n=13). This information was not collected for the EQ-5D-5L instrument.

Table 4-1 Sample characteristics and summary statistics for the INSPIRED study sample, self-rated subgroup, proxy-rated subgroup, and self versus proxy subgroup

	INSPIRED study sample			**Self-rated subgroup**			**Proxy-rated subgroup**			**Self versus Proxy subgroup**		
Variable	N	Mean (SD) or %	Range	N	Mean (SD) or %	Range	N	Mean (SD) or %	Range	N	Mean (SD) or %	Range
Participant characteristics												
Age (years)	541	85.5 (8.5)	48 to 104	143	85.7 (8.8)	49 to 99	387	85.5 (8.3)	48 to 104	225	86.2 (8.5)	49 to 102
Female	403	74. 5	-	103	72.0	-	290	74.9	-	159	70.7	-
Diagnosis of dementia	345	64.0	-	35	24.5	-	299	77.3	-	77	34.2	-
Self-rated HRQoL utility values												
EQ-5D-5L	145	0.66 (0.28)	-0.28 to 1.00	143	0.66 (0.28)	-0.28 to 1.00	-	-	-	-	-	-
DEMQOL-U	225	0.85 (0.12)	0.30 to 0.99	143	0.87 (0.12)	0.39 to 0.99	-	-	-	225	0.85 (0.12)	0.30 to 0.99
Proxy-rated HRQoL utility values												
EQ-5D-5L-Proxy	390	0.48 (0.29)	-0.28 to 1.00	-	-	-	387	0.48 (0.29)	-0.28 to 1.00	-	-	-
DEMQOL-Proxy-U	536	0.69 (0.13)	0.36 to 0.94	-	-	-	387	0.68 (0.13)	0.36 to 0.94	225	0.72 (0.13)	0.41 to 0.94
Clinical outcome measures												
PAS-Cog score (max 21)	520	13.2 (7.7)	0 to 21	143	3.8 (2.8)	0 to 11	366	16.6 (5.9)	0 to 21	222	5.7 (4.3)	0 to 17
DSS score (max 14)	538	7.8 (4.5)	0 to 14	143	3.2 (3.1)	0 to 13	384	9.4 (3.8)	0 to 14	225	4.3 (3.5)	0 to 14
FAST scale (max 7)	533	5.6 (1.8)	1 to 7	143	3.9 (2.0)	1 to 7	380	6.2 (1.1)	1 to 7	225	4.4 (1.9)	1 to 7
Modified Barthel Index (max 100)	537	40.2 (32.7)	0 to 100	143	63.0 (30.0)	0 to 100	383	32.9 (29.8)	0 to 100	225	59.5 (30.0)	0 to 100
NPI-Q 10 item sum severity (max 30)	538	8.3 (6.4)	0 to 28	143	4.9 (4.7)	0 to 25	384	9.5 (6.5)	0 to 28	225	6.0 (5.3)	0 to 25

Table 4-2 Summary of questionnaire length, response rate, and level of missing data for the EQ-5D-5L, EQ-5D-5L-Proxy, DEMQOL, and DEMQOL-Proxy

Measure	EQ-5D-5L	EQ-5D-5L-Proxy	DEMQOL	DEMQOL-Proxy
Number of items on questionnaire	6	6	29	32
Response rate (frequency and percentage)	145/215 (67.4%)	396/396 (100.0%)	231/302 (76.5%)	540/541 (99.8%)
Missing data (percentage)	0.00%	0.42%	1.99%	0.47%

Table 4-3 Summary of participants who were unable to complete the DEMQOL

Reason	N
PAS-Cog ≥ 18	239
Participant unwell	2
Participant deceased	0
Participant refused	13
Family refused	15
Participant agitated	2
Participant fatigued	2
Participant unable	21
Other	5
Missing (PAS-Cog< 18 but no DEMQOL in file)	17

4.2.2 Self-rated subgroup

In the full INSPIRED study sample (n=541), a measurable level of cognitive impairment was present in 83 per cent of participants and 64 per cent had a recorded diagnosis of dementia. Among the subset of 143 participants who were able to complete both the DEMQOL and EQ-5D-5L instruments, 45 per cent were identified as living with mild or moderate cognitive impairment, and 25 per cent had a diagnosis of dementia. The analyses in this section focus solely on the subgroup of residents who completed both the self-rated EQ-5D-5L and DEMQOL instruments (n=143).

The distributions of EQ-5D-5L utility scores and DEMQOL-U utility scores are presented in Figure 4-2 and Figure 4-3 respectively. Neither the EQ-5D-5L nor DEMQOL-U utility scores produced normally distributed values according to the Kolmogorov-Smirnov test with Lilliefors significance correction and the Shapiro-Wilks test. A negative skew was observed for both instruments. Table 4-4 presents a comparison of utility scores across age, sex, and dementia diagnosis. No significant differences in utility scores were found between males and females for either instrument. EQ-5D-5L utility values tended to increase with age (p=0.033), with the oldest residents reporting higher utility scores on average than younger residents. This age-related trend was not found in DEMQOL-U scores. Mean EQ-5D-5L utility scores were higher for residents with a diagnosis of dementia compared to those without diagnosed dementia (p<0.001). This pattern was also evident for the DEMQOL-U, with slightly higher scores reported on average for those with a diagnosis of dementia, although the difference was not statistically significant (p=0.066).

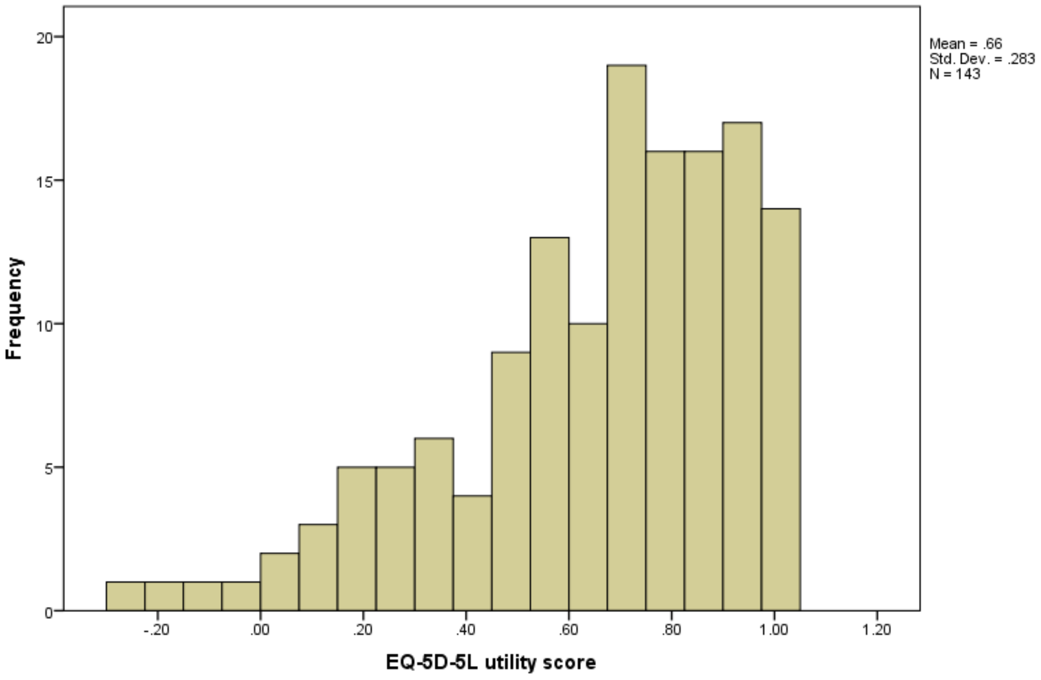


Figure 4-2 Distribution of EQ-5D-5L utility scores in the self-rated subgroup

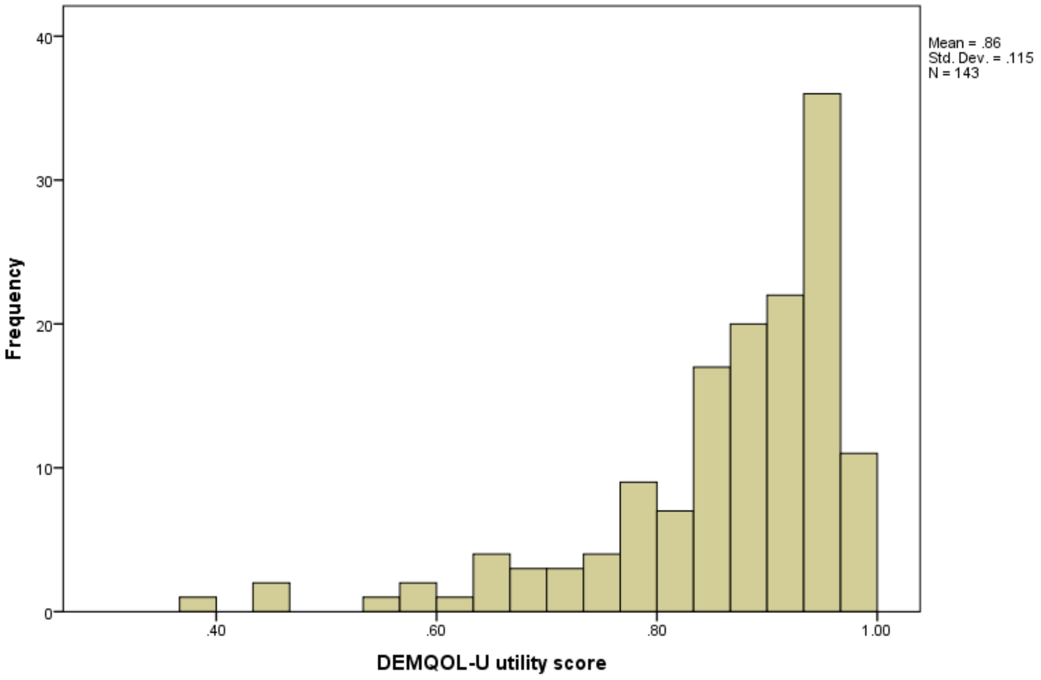


Figure 4-3 Distribution of DEMQOL-U utility scores in the self-rated subgroup

Table 4-4 Test of difference between self-rated utility scores by age, sex, and dementia diagnosis

Characteristic		EQ-5D-5L			DEMQOL-U		
		Mean (SD)	**95% CI**	**Effect size[1]**	**Mean (SD)**	**95% CI**	**Effect size[1]**
Age	49 to 81	0.53 (0.33)	0.42, 0.64	-	0.85 (0.12)	0.81, 0.89	-
	82 to 87	0.68 (0.27)	0.59, 0.77	0.23	0.85 (0.14)	0.80, 0.90	0.06
	88 to 92	0.70 (0.26)	0.62, 0.79	0.01	0.86 (0.10)	0.83, 0.89	0.04
	93 to 99	0.71 (0.27)	0.62, 0.81	0.06	0.89 (0.09)	0.86, 0.93	0.19
	p-value[2]			0.033			0.273
Sex	Male	0.68 (0.28)	0.59, 0.77	-	0.86 (0.12)	0.82, 0.90	-
	Female	0.65 (0.28)	0.60, 0.71	0.05	0.87 (0.11)	0.85, 0.89	0.04
	p-value[3]			0.532			0.623
Dementia diagnosis	Yes	0.80 (0.20)	0.73, 0.87	-	0.89 (0.12)	0.85, 0.93	-
	No	0.61 (0.29)	0.55, 0.67	0.31	0.86 (0.12)	0.83, 0.88	0.15
	p-value[3]			<0.001			0.066

1 Mann-Whitney U test used to calculate z-score. Effect size = z / $\sqrt{n}$

2 Kruskal-Wallis test

3 Mann-Whitney U test

Construct validity for self-rated measures

The Spearman correlation coefficients between the EQ-5D-5L and DEMQOL-U responses are presented in Table 4-5, and graphically in Figure 4-4. Generally speaking, the correlations were low to negligible across all dimensions. In absolute value terms, the correlation between dimensions ranged from a low of 0.05 ("mobility" and "loneliness") to a maximum of 0.37 ("anxiety and depression" and "negative emotion"). Eleven participants described themselves in full health according to the EQ-5D-5L but also with at least some impairment in the DEMQOL-U. In contrast, eight participants described themselves in full health according the DEMQOL-U while their corresponding EQ-5D-5L scores indicated a range of impairments. Three participants reported themselves in full health according to both instruments.

Table 4-5 Spearman correlation coefficients of EQ-5D-5L and DEMQOL-U measures

	Positive emotion	Negative emotion	Loneliness	Memory	Relation-ships	DEMQOL-U index
Mobility	0.150	-0.059	-0.048	-0.154	-0.215**	-0.134
Self-care	0.251**	-0.157	-0.181*	-0.125	-0.191*	-0.267**
Usual activities	0.163	-0.260**	-0.262**	-0.156	-0.324**	-0.351**
Pain and discomfort	0.151	-0.203*	-0.215**	-0.220**	-0.194*	-0.294**
Anxiety and depression	0.278**	-0.371**	-0.204*	-0.253**	-0.177*	-0.374**
Cognition	0.181*	-0.158	-0.120	-0.304**	-0.234**	-0.222**
EQ-5D-5L index	-0.231**	0.255**	0.216**	0.216**	0.321**	0.346**

* Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed)

The agreement between utility scores generated by the EQ-5D-5L and DEMQOL-U are depicted in Figure 4-5. The mean difference for the self-rated instruments was 0.206, with the 95 per cent limits of agreement (L.O.A) ranging from -0.314 to 0.725. The convergence and diamond shape on the right side of the Bland-Altman plot is expected given utility estimates are bounded to 1. This pattern is not as clear on the left side of the plot, as the two instruments have different lower bounds. There is evidence of a higher level of agreement between the two instruments at higher levels of utility, with more responses clustering around the zero mean difference. At lower levels of utility the DEMQOL-U produces consistently higher utility values than the EQ-5D-5L, which again is expected given the lower bounds of each instrument.

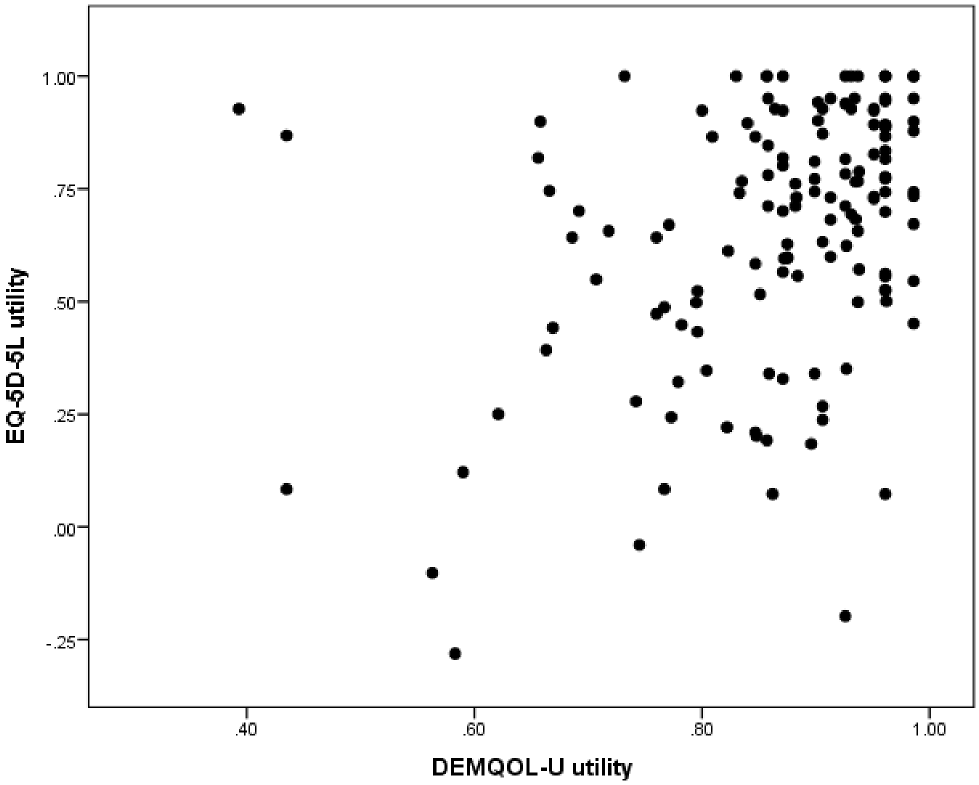


Figure 4-4 Scatterplot of EQ-5D-5L and DEMQOL-U utility values

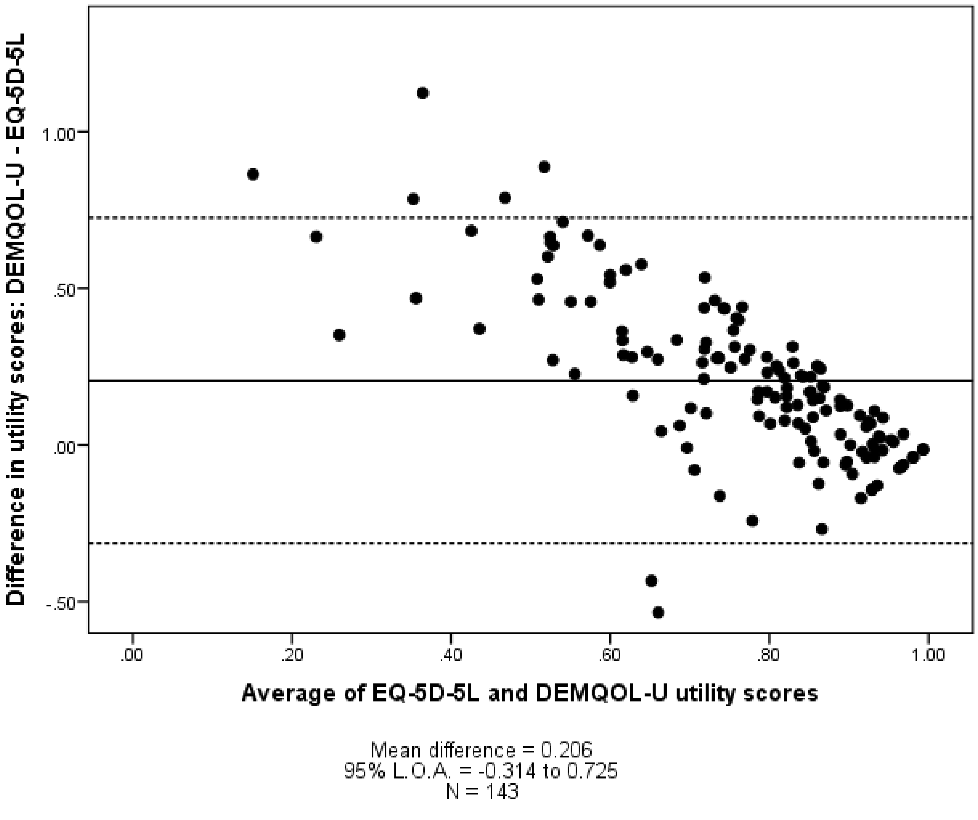


Figure 4-5 Bland-Altman plot analysing agreement between EQ-5D-5L and DEMQOL-U

Agreement was also assessed by examining the distributions of DEMQOL-U index scores by EQ-5D-5L dimensions (Table 4-6). With the exception of the EQ-5D-5L “mobility” dimension, there is a general trend of decreasing DEMQOL-U utilities as the severity of EQ-5D-5L dimensions increase. Two notable exceptions are apparent at the most severe level of “self-care” and “usual activities”, with DEMQOL-U utilities increasing rather than declining between “severe problems” and “unable”.

Table 4-6 Distribution of DEMQOL-U index scores by EQ-5D-5L dimension

		DEMQOL-U index	
		(n = 143)	
EQ-5D-5L Dimension		N	Mean (SD)
Mobility	1 No problems	40	0.87 (0.13)
	2 Slight problems	27	0.88 (0.09)
	3 Some problems	35	0.88 (0.09)
	4 Severe problems	21	0.80 (0.15)
	5 Unable	20	0.87(0.09)
	P value[1]		*0.150*
Self-care	1 No problems	58	0.90 (0.10)
	2 Slight problems	26	0.86 (0.12)
	3 Some problems	24	0.85 (0.10)
	4 Severe problems	15	0.77 (0.16)
	5 Unable	20	0.86 (0.09)
	P value[1]		*0.011*
Usual activities	1 No problems	62	0.90 (0.11)
	2 Slight problems	23	0.89 (0.07)
	3 Some problems	26	0.84 (0.11)
	4 Severe problems	15	0.76 (0.14)
	5 Unable	17	0.85 (0.11)
	P value[1]		*<0.001*
Pain and discomfort	1 No pain or discomfort	49	0.89 (0.10)
	2 Slight pain or discomfort	36	0.88 (0.08)
	3 Moderate pain or discomfort	37	0.85 (0.11)
	4 Severe pain or discomfort	16	0.82 (0.15)
	5 Extreme pain or discomfort	5	0.70 (0.15)
	P value[1]		*0.007*
Anxiety and depression	1 Not anxious or depressed	84	0.89 (0.10)
	2 Slightly anxious or depressed	27	0.85 (0.11)
	3 Moderately anxious or depressed	26	0.81 (0.13)
	4 Severely anxious or depressed	4	0.77 (0.18)
	5 Extremely anxious or depressed	2	0.68 (0.14)
	P value[1]		*<0.001*
Cognition	1 No problems	69	0.88 (0.12)
	2 Slight problems	51	0.87 (0.10)
	3 Moderate problems	20	0.82 (0.12)
	4 Severe problems	3	0.76 (0.16)
	5 Extreme problems	0	-
	P value[1]		*0.034*

1 Kruskal-Wallis test

The correlations between the health-related quality of life dimensions and clinical outcome measures are presented in Table 4-7. Overall, the correlations between the EQ-5D-5L and clinical outcome measures were stronger than between the DEMQOL-U and clinical outcome measures. Physical functioning as measured by the MBI showed a moderately strong correlation with the EQ-5D-5L index, particularly in the dimensions of “mobility”, “self-care”, and “usual activities” with greater impairments being associated with lower reported quality of life. Higher levels of cognitive impairment, as measured by the PAS-Cog, were associated with higher self-rated quality of life as measured by the EQ-5D-5L, particularly in the dimensions of “mobility”, “self-care”, and “pain and discomfort”, although the strength of the correlation (r=0.24) was weak. Behavioural and psychological symptoms, as measured by the NPI-Q, were weakly correlated with the DEMQOL-U index and the dimension of “loneliness” in particular with more severe symptoms associated with higher reported loneliness and lower quality of life overall. There was also a weak correlation between physical function and the “positive emotion” dimension of the DEMQOL-U with better function associated with higher positive emotion. Neither of the dementia severity measures, which included the DSS and FAST scale, was associated with any of the quality of life dimensions for either instrument.

Responsiveness to change for self-rated measures

The distribution of responses across the dimension levels are presented for the EQ-5D-5L in Figure 4-6 and for the DEMQOL-U in Figure 4-7. The percentages of respondents who answered the best response (ceiling) and worst response (floor) for each dimension are presented in Table 4-8. Floor effects for the EQ-5D-5L ranged from zero per cent for “cognition” to 14 per cent for the dimensions of “mobility” and “self-care”. For the DEMQOL-U, floor effects ranged from 2.1 per cent for “positive emotion” to 7.7 per cent for “negative emotion”. High ceiling effects were evident across both instruments, ranging from 28 per cent for “mobility” to 58.7 per cent for “anxiety and depression” on the EQ-5D-5L, and from 23.8 per cent for “positive emotion” to 67.8 per cent for “relationships” on the DEMQOL-U.

Table 4-7 Spearman correlation coefficients of EQ-5D-5L and DEMQOL-U dimensions with clinical outcome measures

		Cognition (PAS-Cog)	Dementia severity (DSS)	Dementia severity (FAST)	Physical function (MBI)	Behavioural and psychological symptoms (NPI-Q)
EQ-5D-5L	Mobility	-0.230**	0.043	0.027	-0.499**	0.018
	Self-care	-0.237**	0.111	0.057	-0.609**	0.069
	Usual activities	-0.087	0.020	0.105	-0.374**	0.140
	Pain and discomfort	-0.194*	-0.146	-0.117	-0.065	0.143
	Anxiety and depression	-0.004	0.050	0.098	-0.050	0.076
	Cognition	0.025	0.065	0.034	-0.039	0.045
	EQ-5D-5L index	0.243**	-0.021	-0.029	0.492**	-0.099
DEMQOL-U	Positive emotion	-0.047	0.060	0.114	-0.183*	0.102
	Negative emotion	0.011	-0.043	-0.118	0.119	-0.116
	Loneliness	0.028	-0.051	0.025	0.010	-0.201*
	Memory	-0.100	-0.025	0.090	0.003	-0.043
	Relationships	-0.062	-0.098	-0.037	0.094	-0.003
	DEMQOL-U index	0.066	-0.053	-0.040	0.105	-0.183*

* Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed)

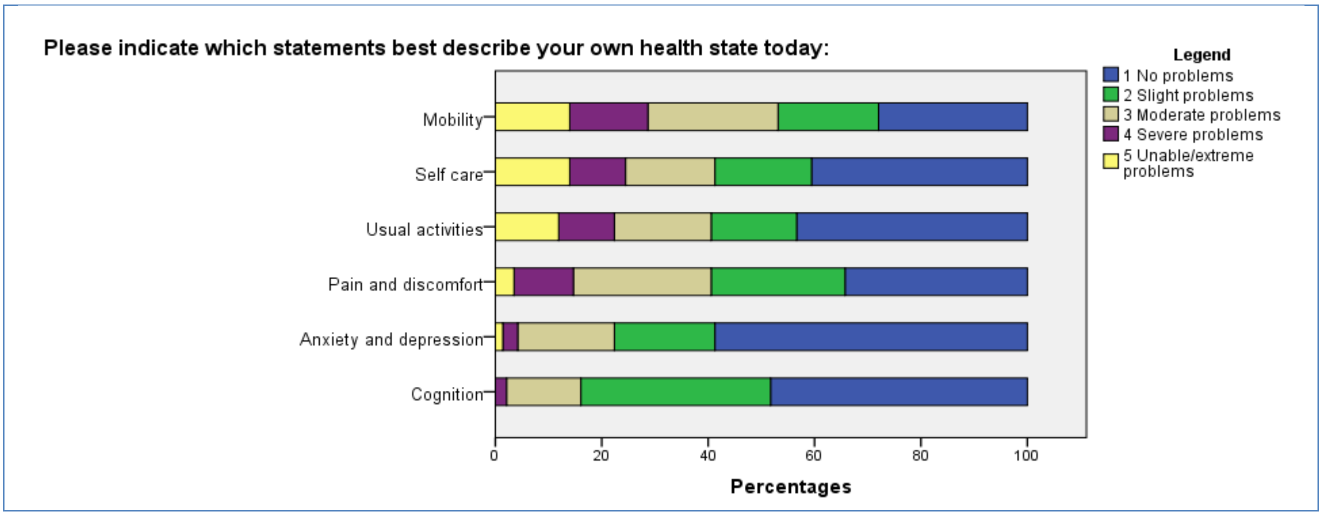


Figure 4-6 Distribution of responses across EQ-5D-5L dimensions

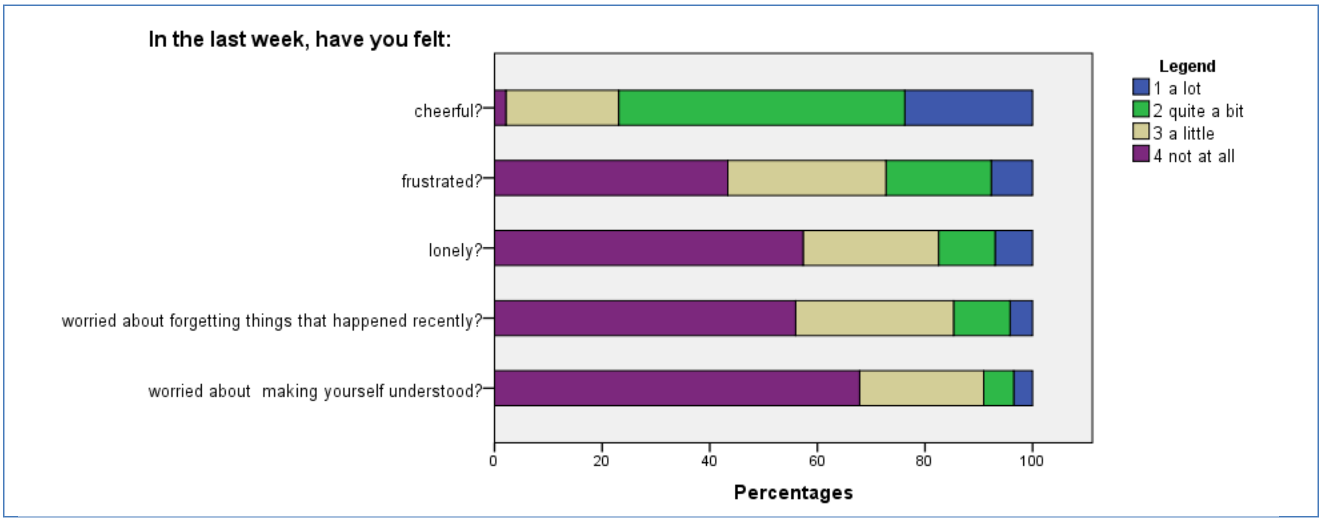


Figure 4-7 Distribution of responses across DEMQOL-U dimensions

Table 4-8 Floor and ceiling effects for the EQ-5D-5L and DEMQOL-U (n = 143)

Measure	Dimension	% floor	% ceiling
EQ-5D-5L	Mobility	14.0	28.0
	Self-care	14.0	40.6
	Usual activities	11.9	43.4
	Pain and discomfort	3.5	34.3
	Anxiety and depression	1.4	58.7
	Cognition	0.0	48.3
	EQ-5D-5L index	0.7	9.8
DEMQOL-U	Positive emotion	2.1	23.8
	Negative emotion	7.7	43.4
	Loneliness	7.0	57.3
	Memory	4.2	55.9
	Relationships	3.5	67.8
	DEMQOL-U index	0.0	7.7

4.2.3 Proxy-rated subgroup

The results of an empirical assessment of the EQ-5D-5L-Proxy responses and the DEMQOL-Proxy-U are presented in this section. Among the subset of 387 participants for which both the DEMQOL-Proxy-U and EQ-5D-5L instruments were completed by proxy, 77 per cent had a diagnosis of dementia compared to 64 per cent in the full study sample of 541. Neither the EQ-5D-5L-Proxy nor DEMQOL-Proxy-U instruments produced normally distributed values according to the Kolmogorov-Smirnov test with Lilliefors significance correction and the Shapiro-Wilks test; however, negative skew was less apparent than with the self-rated measures. The distributions of utility scores completed by proxy are displayed in Figure 4-8 and Figure 4-9.

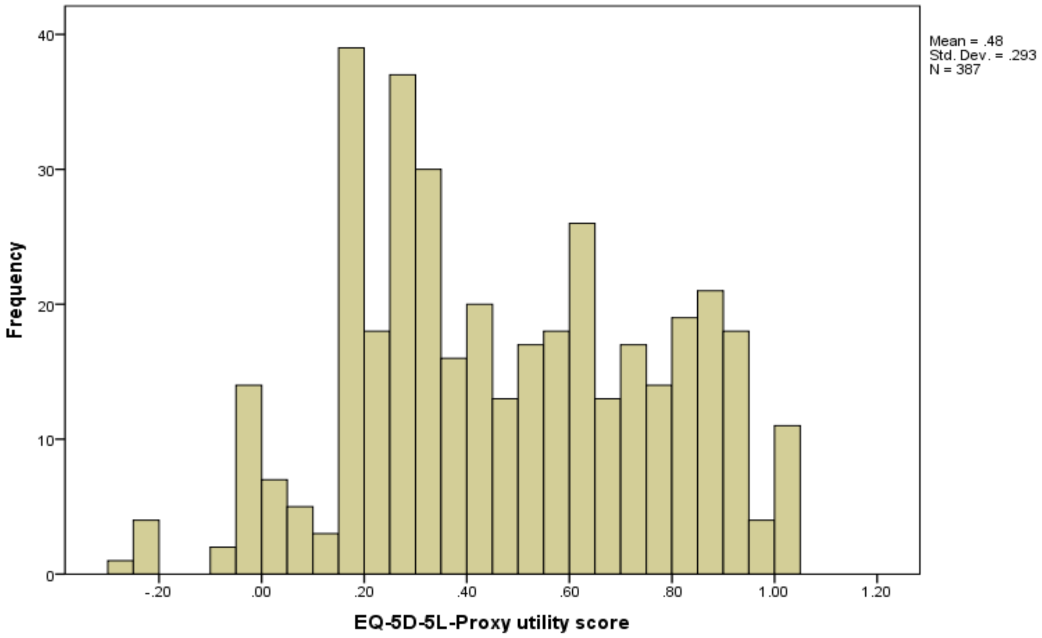


Figure 4-8 Distribution of EQ-5D-5L-Proxy utility scores in the proxy-rated subgroup

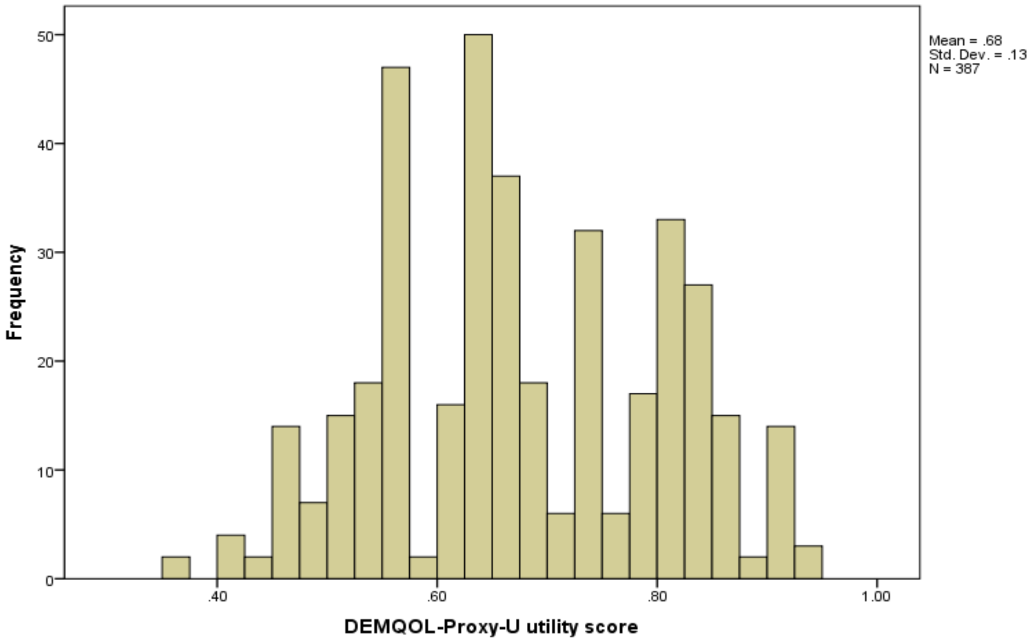


Figure 4-9 Distribution of DEMQOL-Proxy-U utility scores in the proxy-rated subgroup

Table 4-9 Test of difference between proxy-rated utility scores by age, sex, and dementia diagnosis

Characteristic		EQ-5D-5L-Proxy			DEMQOL-Proxy-U		
		Mean (SD)	**95% CI**	**Effect size[1]**	**Mean (SD)**	**95% CI**	**Effect size[1]**
Age	48 to 81	0.46 (0.29)	0.40, 0.52	-	0.70 (0.13)	0.67, 0.72	-
	82 to 87	0.49 (0.33)	0.42, 0.55	0.04	0.68 (0.14)	0.65, 0.71	0.04
	88 to 92	0.49 (0.28)	0.42, 0.55	0.01	0.67 (0.12)	0.65, 0.69	0.06
	93 to 104	0.46 (0.26)	0.40, 0.53	0.04	0.66 (0.12)	0.63, 0.69	0.04
	p-value[2]			0.829			0.195
Sex	Male	0.48 (0.30)	0.42, 0.54	-	0.68 (0.14)	0.65, 0.71	-
	Female	0.48 (0.29)	0.44, 0.51	0.00	0.68 (0.13)	0.66, 0.69	0.01
	p-value[3]			0.934			0.908
Dementia diagnosis	Yes	0.49 (0.30)	0.45, 0.52	-	0.68 (0.13)	0.66, 0.69	-
	No	0.44 (0.29)	0.37, 0.50	0.07	0.68 (0.13)	0.65, 0.71	0.01
	p-value[3]			0.314			0.928

1 Mann-Whitney U test used to calculate z-score. Effect size = z / $\sqrt{n}$

2 Kruskal-Wallis test

3 Mann-Whitney U test

Table 4-9 presents a comparison of utility scores across age, sex, and dementia diagnosis. No significant differences in utility scores were found between males and females for either instrument. No associations were found between utility scores and resident age for either instrument. Mean EQ-5D-5L-Proxy utility scores were slightly higher for residents with a diagnosis of dementia compared to those without diagnosed dementia, but the difference was not statistically significant (p=0.314). Mean DEMQOL-Proxy-U utility scores were the same for residents with and without a diagnosis of dementia.

Construct validity for proxy-rated measures

The Spearman correlation coefficients between the EQ-5D-5L-Proxy and DEMQOL-Proxy-U responses are presented in Table 4-10, and graphically in Figure 4-10. Low correlations were found between four dimension pairs: "pain and discomfort" and "negative emotion"; "anxiety and depression" and "negative emotion"; "self-care" and "positive emotion"; and "usual activities" and "positive emotion". In absolute value terms, the correlation between dimensions ranged from a low of 0.005 ("cognition" and "memory") to a maximum of 0.381 ("anxiety and depression" and "negative emotion"). Eleven participants were described in full health according to the EQ-5D-5L-Proxy but also with at least some impairment in the DEMQOL-Proxy-U. In contrast, three participants were described in full health according the DEMQOL-Proxy-U while their corresponding EQ-5D-5L-Proxy scores indicated a range of impairments. No proxies reported a participant in full health on both instruments.

Table 4-10 Spearman correlation coefficients of EQ-5D-5L-Proxy and DEMQOL-Proxy-U measures

	Negative emotion	**Positive emotion**	**Memory**	**Appearance**	**DEMQOL-Proxy-U index**
Mobility	-0.106*	0.282**	0.049	0.021	-0.265**
Self-care	-0.036	0.307**	0.058	0.055	-0.248**
Usual activities	-0.077	0.344**	0.022	0.058	-0.306**
Pain and discomfort	-0.338**	0.079	-0.131*	-0.136**	-0.249**
Anxiety and depression	-0.381**	0.131**	-0.232**	-0.146**	-0.334**
Cognition	0.025	0.243**	-0.005	0.128*	-0.177**
EQ-5D-5L index	0.251**	-0.325**	0.049	0.027	0.389**

* Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed)

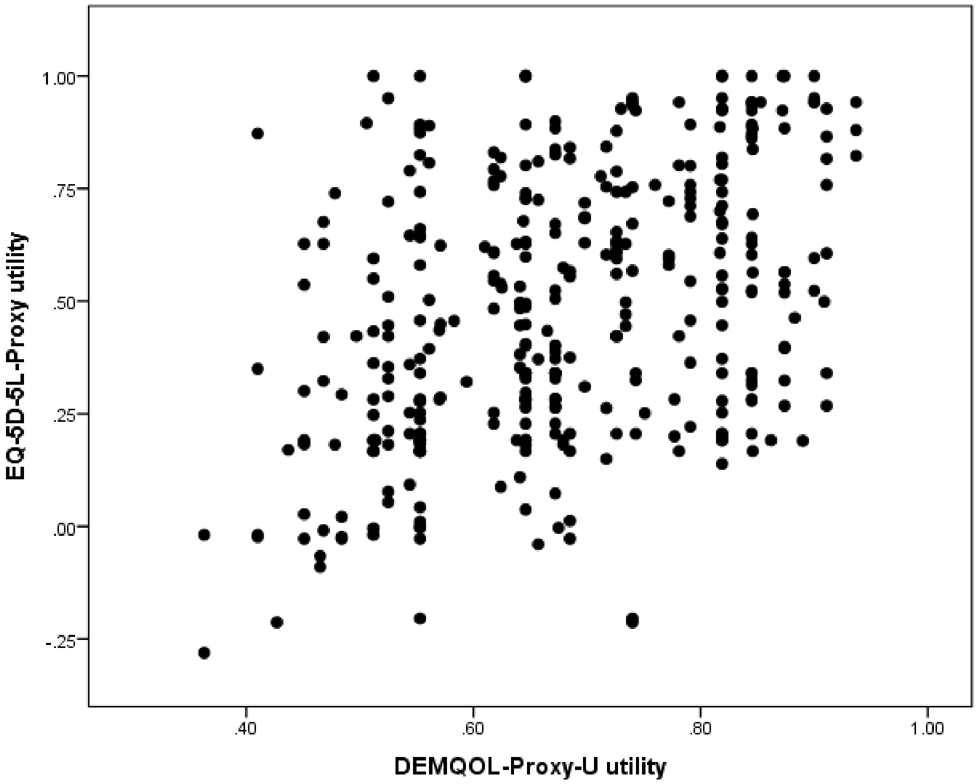


Figure 4-10 Scatterplot of EQ-5D-5L-Proxy and DEMQOL-Proxy-U utility values

The agreement between utility scores generated by the EQ-5D-5L-Proxy and DEMQOL-Proxy-U are depicted in Figure 4-11. The mean difference for the proxy-rated instruments was 0.202, with the 95 per cent limits of agreement (L.O.A) ranging from -0.321 to 0.726. As with the self-rated utility scores, the convergence and diamond shape on the right side of the Bland-Altman plot is expected given utility estimates are bounded to 1. This pattern is not as clear on the left side of the plot, as the two instruments have different lower bounds. There is evidence of a higher level of agreement between the two instruments at higher levels of utility, with more responses clustering around the zero mean difference. At lower levels of utility the DEMQOL-Proxy-U produces consistently higher utility values than the EQ-5D-5L, which again is expected given the lower bounds of each instrument.

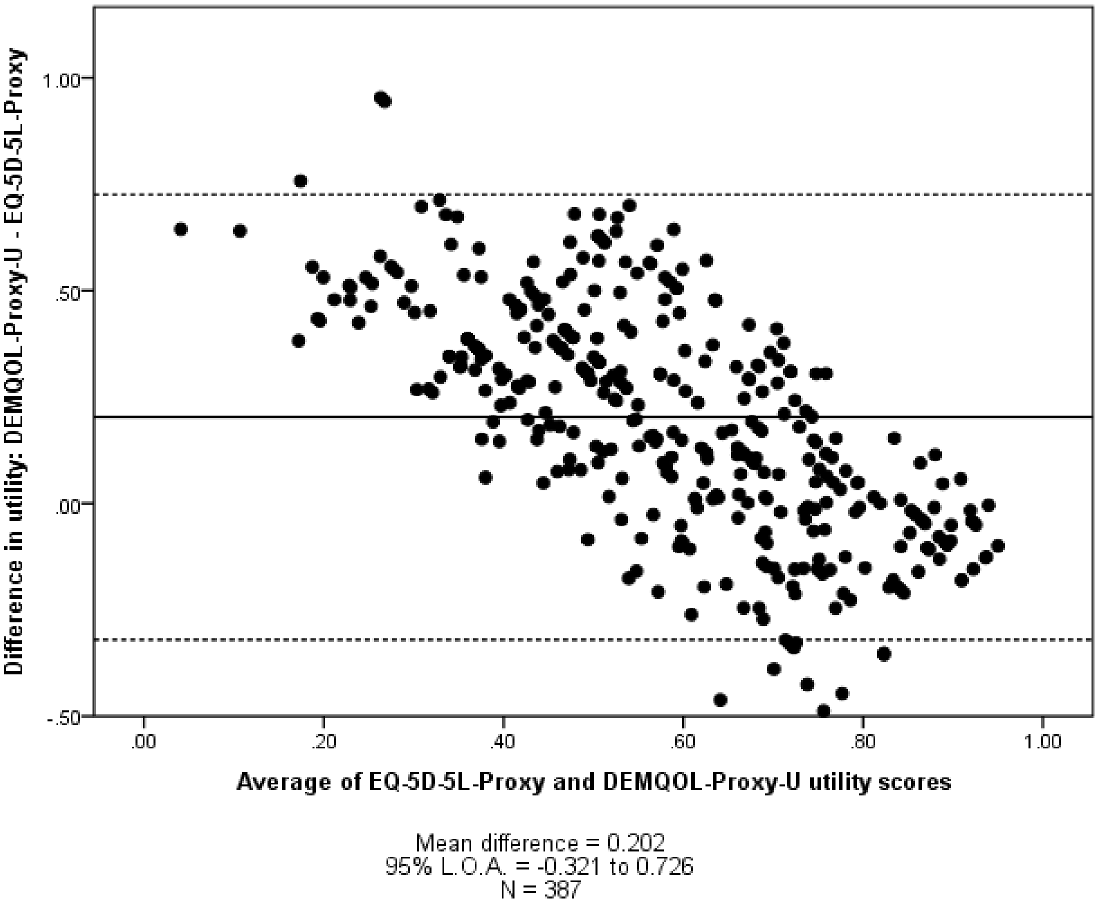


Figure 4-11 Bland-Altman plot analysing agreement between EQ-5D-5L-Proxy and DEMQOL-Proxy-U

Agreement was also assessed by examining the distributions of DEMQOL-Proxy-U index scores by EQ-5D-5L dimensions (Table 4-11). There was a general trend of decreasing DEMQOL-Proxy-U utilities as the severity of EQ-5D-5L-Proxy dimensions increased. However, this trend was less apparent between the two most severe levels the EQ-5D-5L-Proxy, with DEMQOL-Proxy-U utilities increasing rather than declining at the most severe levels of “mobility”, “pain and discomfort”, and “anxiety and depression”. This finding is consistent with the Bland-Altman plot again suggesting better agreement at higher levels of utility.

The correlations between the EQ-5D-5L-Proxy and DEMQOL-Proxy-U dimensions and clinical outcome measures are presented in Table 4-12. Overall, the correlations between the EQ-5D-5L-Proxy and clinical outcome measures were stronger than between the DEMQOL-Proxy-U and clinical outcome measures.

Table 4-11 Distribution of DEMQOL-Proxy-U index scores by EQ-5D-5L-Proxy dimension

		DEMQOL-Proxy-U index	
		(n = 387)	
EQ-5D-5L-Proxy Dimension		N	Mean (SD)
Mobility	1 No problems	71	0.74 (0.14)
	2 Slight problems	48	0.72 (0.11)
	3 Some problems	87	0.68 (0.13)
	4 Severe problems	54	0.64 (0.12)
	5 Unable	127	0.65 (0.13)
	P value[1]		*<0.001*
Self-care	1 No problems	75	0.74 (0.12)
	2 Slight problems	36	0.71 (0.14)
	3 Some problems	72	0.69 (0.12)
	4 Severe problems	38	0.66 (0.14)
	5 Unable	166	0.65 (0.12)
	P value[1]		*<0.001*
Usual activities	1 No problems	72	0.75 (0.12)
	2 Slight problems	45	0.71 (0.12)
	3 Some problems	73	0.68 (0.12)
	4 Severe problems	46	0.65 (0.12)
	5 Unable	151	0.64 (0.13)
	P value[1]		*<0.001*
Pain and discomfort	1 No pain or discomfort	93	0.72 (0.13)
	2 Slight pain or discomfort	118	0.70 (0.12)
	3 Moderate pain or discomfort	128	0.65 (0.13)
	4 Severe pain or discomfort	34	0.63 (0.12)
	5 Extreme pain or discomfort	14	0.64 (0.16)
	P value[1]		*<0.001*
Anxiety and depression	1 Not anxious or depressed	145	0.72 (0.12)
	2 Slightly anxious or depressed	105	0.69 (0.13)
	3 Moderately anxious or depressed	99	0.65 (0.12)
	4 Severely anxious or depressed	21	0.55 (0.12)
	5 Extremely anxious or depressed	17	0.58 (0.14)
	P value[1]		*<0.001*
Cognition	1 No problems	60	0.72 (0.13)
	2 Slight problems	72	0.70 (0.14)
	3 Moderate problems	97	0.67 (0.13)
	4 Severe problems	70	0.68 (0.13)
	5 Extreme problems	87	0.64 (0.12)
	P value[1]		*0.006*

1 Kruskal-Wallis test

Higher levels of cognitive impairment, as measured by the PAS-Cog, were associated with lower proxy -rated quality of life as measured by the EQ-5D-5L-Proxy, particularly in the dimensions of “mobility”, “self-care”, and “usual activities”. A moderately strong correlation was also found between PAS-Cog scores and the EQ-5D-5L-Proxy “cognition” bolt-on question (r=0.495). Dementia severity, as measured by the DSS and FAST scales, showed moderately strong correlation with the EQ-5D-5L-Proxy utility score, with increased severity associated with lower quality of life. At the dimension level, dementia severity was significantly associated with “mobility”, “self-care”, “usual activities”, and “cognition” on the EQ-5D-5L-Proxy. Physical functioning as measured by the MBI showed a moderately strong correlation with the EQ-5D-5L index, particularly in the dimensions of “mobility”, “self-care”, and “usual activities” with greater impairments being associated with lower reported quality of life. Physical function also showed a moderately strong correlation with the “cognition” bolt-on, with better function associated with better cognition.

In terms of the DEMQOL-Proxy-U, the DSS was weakly associated with each of the individual dimensions, however showed no association with the overall utility score. The FAST scale was weakly associated with the dimensions of “negative emotion”, “memory”, and “appearance”, and showed a very weak, yet statistically significant association with the overall DEMQOL-Proxy-U index (r=0.102). With the exception of the FAST scale, none of the other clinical outcome measures showed an association with the DEMQOL-Proxy-U index scores. Weak to negligible correlations were found between cognition and the dimensions of “positive emotion”, “memory”, and “appearance”. Behavioural and psychological symptoms, as measured by the NPI-Q, were weakly correlated with the DEMQOL-Proxy-U dimension of “negative emotion”. There was also a weak to negligible correlation between physical function and the “positive emotion”, “memory”, and “appearance” dimensions of the DEMQOL-Proxy-U.

Table 4-12 Spearman correlation coefficients of EQ-5D-5L-Proxy and DEMQOL-Proxy-U dimensions with clinical outcome measures

		Cognition (PAS-Cog)	**Dementia severity (DSS)**	**Dementia severity (FAST)**	**Physical function (MBI)**	**Behavioural and psychological symptoms (NPI-Q)**
EQ-5D-5L-Proxy	Mobility	0.215**	0.247**	0.348**	-0.555**	-0.177**
	Self-care	0.386**	0.396**	0.522**	-0.627**	-0.063
	Usual activities	0.356**	0.388**	0.479**	-0.577**	-0.083
	Pain and discomfort	-0.067	-0.032	0.026	-0.055	0.006
	Anxiety and depression	-0.043	-0.052	-0.041	0.000	0.160**
	Cognition	0.495**	0.474**	0.496**	-0.488**	0.062
	EQ-5D-5L-Proxy index	-0.261**	-0.285**	-0.409**	0.560**	0.056
DEMQOL-Proxy-U	Positive emotion	0.108*	0.151**	0.058	-0.147**	-0.051
	Negative emotion	0.023	0.105*	0.176**	-0.058	-0.231**
	Memory	0.124*	0.141**	0.109*	-0.131*	-0.069
	Appearance	0.163**	0.212**	0.173**	-0.133**	-0.013
	DEMQOL-Proxy-U index	-0.048	-0.043	-0.102*	0.069	-0.057

* Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed)

Responsiveness to change for proxy-rated measures

The distribution of responses across the dimension levels are presented for the EQ-5D-5L-Proxy in Figure 4-12 and for the DEMQOL-Proxy-U in Figure 4-13. The percentages of respondents who answered the best response (ceiling) and worst response (floor) for each dimension are presented in Table 4-13. As the proxy-rated subgroup consisted of residents with more severe levels of cognitive impairment and dementia than the self-rated subgroup, it was expected that ceiling effects would be less prominent in this subgroup compared with the self-rated subgroup while floor effects would be more prominent. Consistent with this, floor effects for the EQ-5D-5L-Proxy were much more pronounced than found for the self-rated EQ-5D-5L, and ranged from 3.6 per cent for “pain and discomfort” to 42.9 per cent for “self-care”. The highest floor effect found on the self-rated EQ-5D-5L was 14.0 per cent, whereas four of the dimensions on the EQ-5D-5L-Proxy measure indicated floor effects greater than 20 per cent. For the DEMQOL-Proxy-U, floor effects ranged from 8.0 per cent for “appearance” to 49.9 per cent for “positive emotion”. Again, floor effects were much more pronounced for the DEMQOL-Proxy-U than for the self-rated DEMQOL-U in which no floor effect greater than 7.7 per cent was found. In contrast, ceiling effects for the EQ-5D-5L-Proxy were much less pronounced than the self-rated EQ-5D-5L, and ranged from 15.5 per cent for “cognition” to 37.5 per cent for “anxiety and depression”. For the DEMQOL-Proxy-U instrument, ceiling effects ranged from 4.9 per cent for the “positive emotion” dimension to 65.1 per cent for “memory”. The dimensions of “positive emotion” and “negative emotion” showed very low ceiling effects compared to the self-rated DEMQOL-U, whereas the dimensions of “memory” and “appearance” indicated very high ceiling effects in line with the ceiling effects found on the DEMQOL-U instrument.

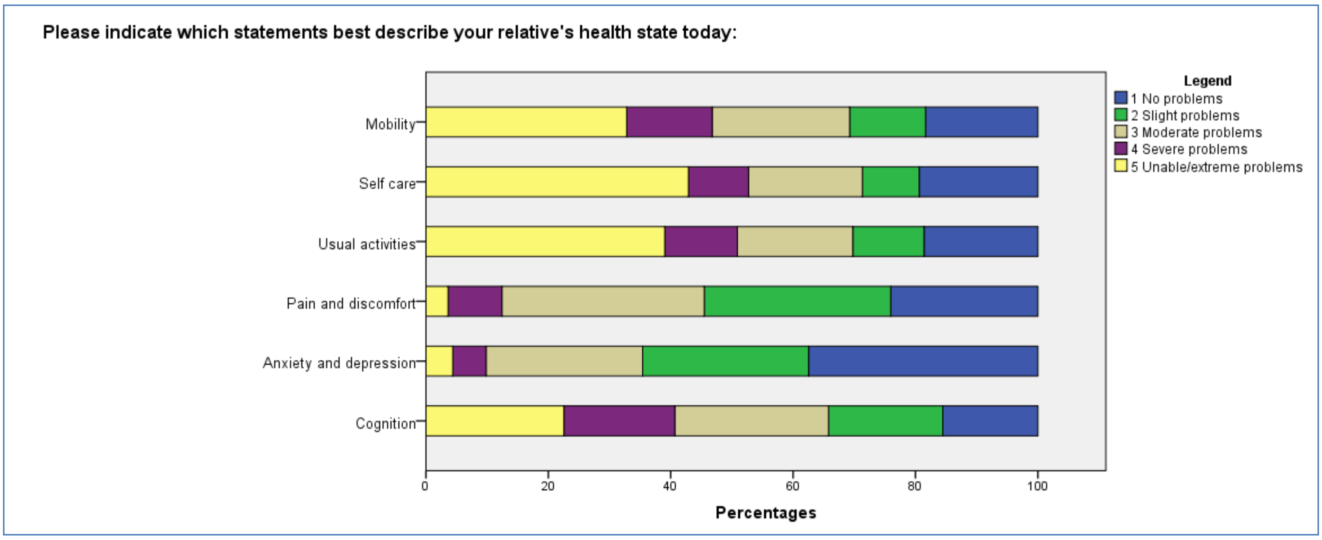


Figure 4-12 Distribution of responses across EQ-5D-5L-Proxy dimensions

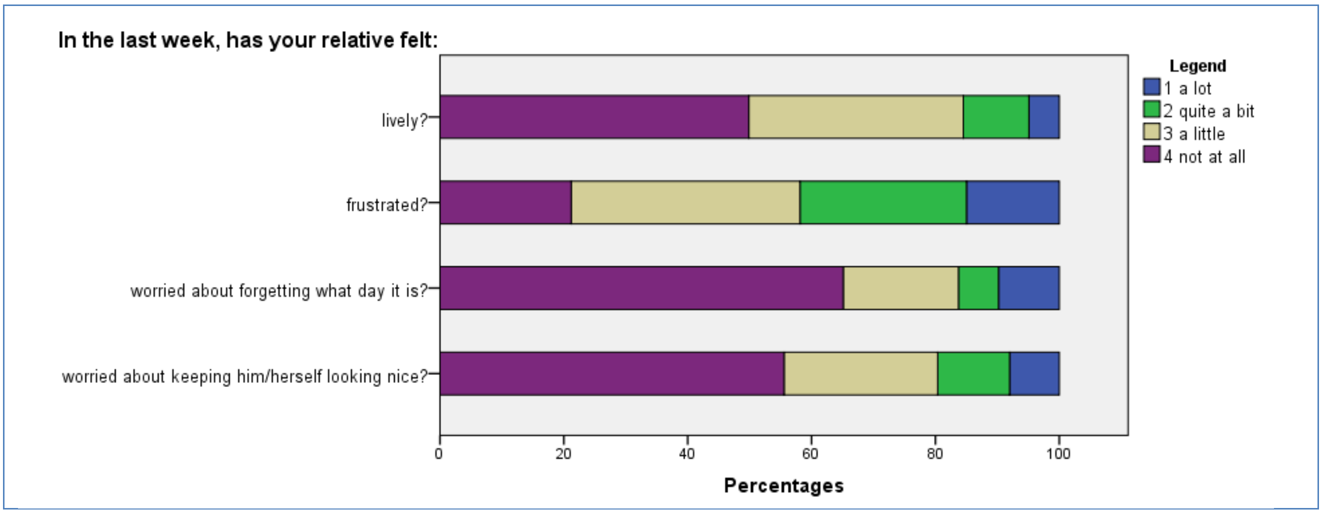


Figure 4-13 Distribution of responses across DEMQOL-Proxy-U dimensions

Table 4-13 Floor and ceiling effects for the EQ-5D-5L-Proxy and DEMQOL-Proxy-U (n = 387)

Measure	Dimension	% floor	% ceiling
EQ-5D-5L-Proxy	Mobility	32.8	18.3
	Self-care	42.9	19.4
	Usual activities	39.0	18.6
	Pain and discomfort	3.6	24.0
	Anxiety and depression	4.4	37.5
	Cognition	22.5	15.5
	EQ-5D-5L-Proxy index	0.3	2.8
DEMQOL-Proxy-U	Positive emotion	49.9	4.9
	Negative emotion	15.0	21.2
	Memory	9.8	65.1
	Appearance	8.0	55.6
	DEMQOL-Proxy-U index	0.5	0.8

4.2.4 Self versus Proxy subgroup

The analyses in this section focus on those participants who had both a DEMQOL and DEMQOL-Proxy questionnaire collected. Out of the total INSPIRED study sample (n=541), 225 participants had both a DEMQOL and DEMQOL-Proxy. Thirty-four per cent of participants in this “Self versus Proxy” subgroup had a diagnosis of dementia and 60 per cent had a measurable level of cognitive impairment. The mean (SD) utility scores for the DEMQOL-U and DEMQOL-Proxy-U were 0.85 and 0.72 respectively.

The distributions of DEMQOL-U and DEMQOL-Proxy-U utility scores are presented in Figure 4-14 and Figure 4-15 respectively. Neither the DEMQOL-U nor its proxy version produced normally distributed values according to the Kolmogorov-Smirnov test with Lilliefors significance correction and the Shapiro-Wilks test.

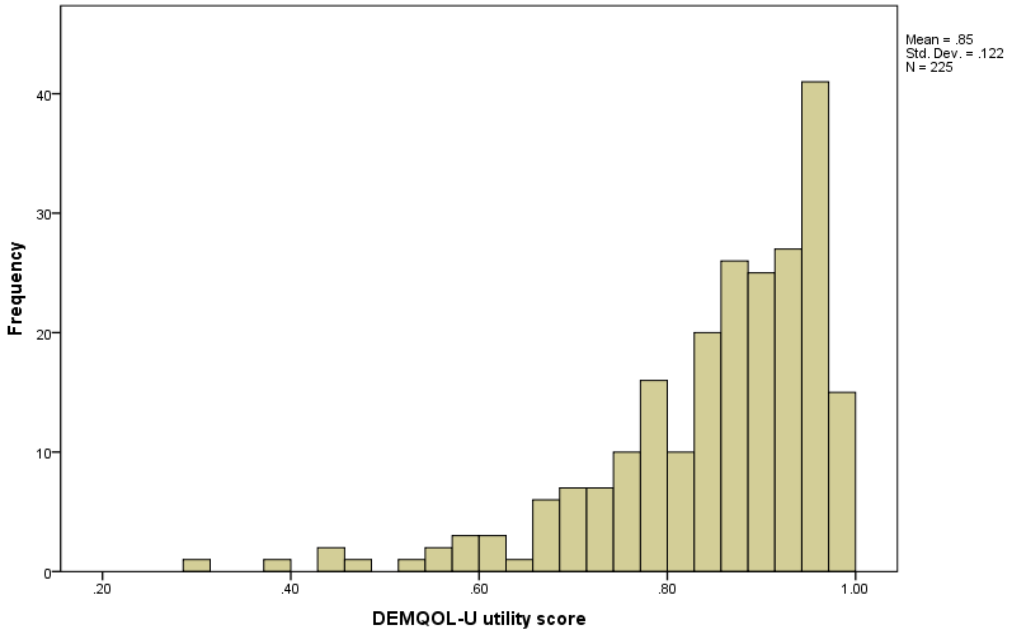


Figure 4-14 Distribution of DEMQOL-U utility scores in the self versus proxy subgroup

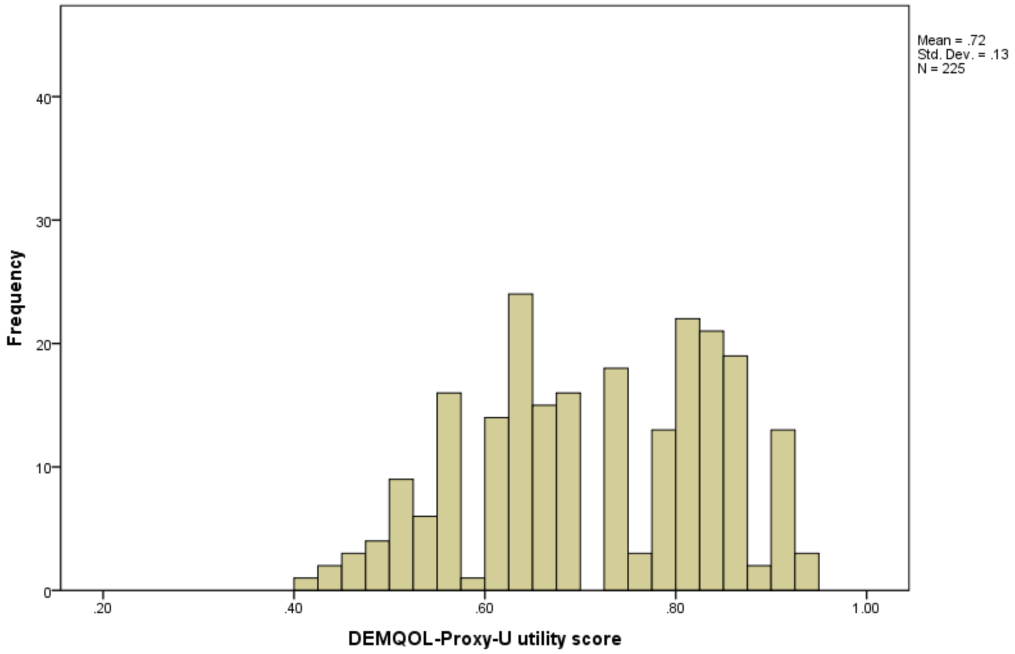


Figure 4-15 Distribution of DEMQOL-Proxy-U utility scores in the self versus proxy subgroup

Table 4-14 Test of difference between self versus proxy-rated utility scores by age, sex, and dementia diagnosis

Characteristic		DEMQOL-U			DEMQOL-Proxy-U		
		Mean (SD)	**95% CI**	**Effect size[1]**	**Mean (SD)**	**95% CI**	**Effect size[1]**
Age	49 to 81	0.83 (0.14)	0.79, 0.87	-	0.72 (0.13)	0.69, 0.76	-
	82 to 87	0.83 (0.14)	0.80, 0.87	0.01	0.72 (0.14)	0.68, 0.75	0.02
	88 to 92	0.87 (0.10)	0.84, 0.89	0.10	0.71 (0.12)	0.68, 0.75	0.01
	93 to 102	0.87 (0.10)	0.84, 0.90	0.03	0.71 (0.13)	0.67, 0.75	0.02
	p-value[2]			0.336			0.971
Sex	Male	0.84 (0.14)	0.80, 0.87	-	0.71 (0.13)	0.68, 0.75	-
	Female	0.86 (0.12)	0.84, 0.87	0.05	0.72 (0.13)	0.70, 0.74	0.02
	p-value[3]			0.472			0.733
Dementia diagnosis	Yes	0.86 (0.13)	0.84, 0.89	-	0.70 (0.14)	0.67, 0.73	-
	No	0.84 (0.12)	0.83, 0.86	0.12	0.73 (0.13)	0.70, 0.75	0.09
	p-value[3]			0.076			0.175

1 Mann-Whitney U test used to calculate z-score. Effect size = z / $\sqrt{n}$

2 Kruskal-Wallis test

3 Mann-Whitney U test

Table 4-14 presents a comparison of utility scores across age, sex, and dementia diagnosis. No significant differences in utility scores were found between males and females for either instrument. No associations were found between utility scores and resident age for either instrument. Mean DEMQOL-U utility scores were slightly higher for residents with a diagnosis of dementia compared to those without diagnosed dementia, though the difference was not statistically significant (p=0.076). Mean DEMQOL-Proxy-U utility scores were marginally higher for residents without a diagnosis of dementia compared with residents with a diagnosis, but this difference did not reach statistical significance (p=0.175).

Construct validity for self-rated DEMQOL-U versus proxy-rated DEMQOL-Proxy-U

The Spearman correlation coefficients between the DEMQOL-U and DEMQOL-Proxy-U responses are presented in Table 4-15, and graphically in Figure 4-16. Generally speaking correlations were weak to negligible across the dimensions. In absolute value terms, the correlation between dimensions ranged from a low of 0.002 (DEMQOL “memory” and DEMQOL-Proxy “Appearance”) to a maximum of 0.213 (DEMQOL “loneliness” and DEMQOL-Proxy “positive emotion”). Fifteen participants described themselves in full health according to the DEMQOL-U but were described by their proxy with at least some impairment in the DEMQOL-Proxy-U. In contrast, three participants were described in full health according the DEMQOL-Proxy-U while their self-rated DEMQOL-U scores indicated a range of mild impairments. No participants were reported in full health on both instruments.

Table 4-15 Spearman correlation coefficients of DEMQOL-U and DEMQOL-Proxy-U measures

	Positive emotion	Negative emotion	Memory	Appearance	DEMQOL-Proxy-U index
Positive emotion	0.138*	-0.169*	-0.162*	-0.086	-0.188**
Negative emotion	-0.010	0.101	0.084	0.056	0.039
Loneliness	-0.213**	0.128	0.104	0.036	0.201**
Memory	-0.116	0.076	0.013	-0.002	0.094
Relationships	-0.087	0.030	0.093	-0.055	0.063
DEMQOL-U index	-0.116	0.162*	0.131	0.029	0.143*

* Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed)

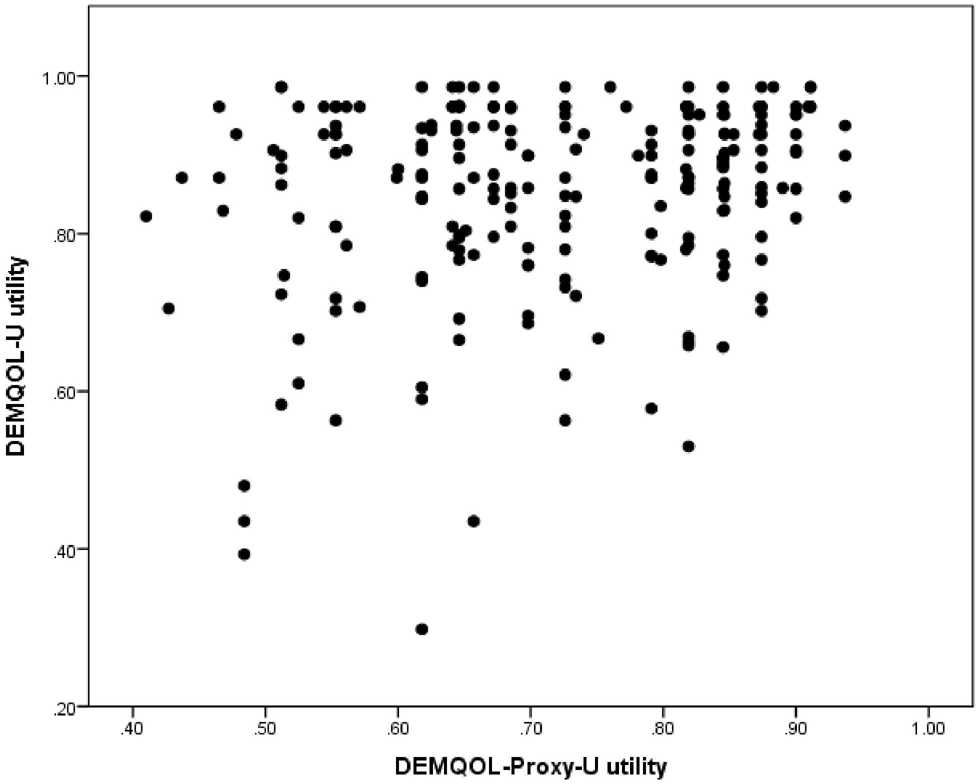
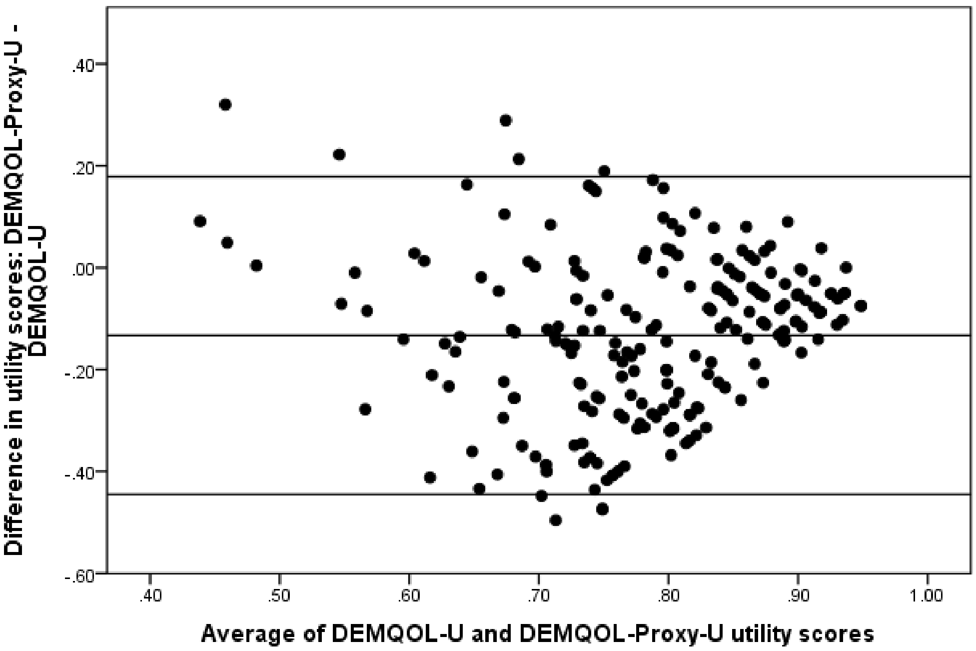


Figure 4-16 Scatterplot of DEMQOL-U and DEMQOL-Proxy-U utility values

In order to assess whether the self and proxy-rated DEMQOL instruments are producing similar utility values for a given participant, the level of agreement between the DEMQOL-U and DEMQOL-Proxy-U was graphically presented using a Bland-Altman plot. Figure 4-17 presents the difference in utility scores (DEMQOL-Proxy-U – DEMQOL-U) on the vertical axis and the average utility score on the horizontal axis for each participant with both a DEMQOL-U and DEMQOL-Proxy-U score. Where DEMQOL-U and DEMQOL-Proxy-U provided similar utility scores, the points on the graph will cluster around the zero line on the vertical axis.

The mean difference for the utility scores was -0.134, with the 95 per cent limits of agreement (LOA) ranging from -0.445 to 0.178. Utility scores for the DEMQOL-U are bounded from 0.243 to 0.986 while utility scores for the DEMQOL-Proxy-U range from 0.363 to 0.937. The convergence and diamond shape on the right side of the Bland-Altman plot is expected given utility estimates are bounded to (approximately) 1. This pattern is not as clear on the left side of the plot. There is evidence of a higher level of agreement between the two instruments at higher levels of utility, with more responses clustering around the zero mean difference. In general, the DEMQOL-U instrument appears to produce higher utility scores than the DEMQOL-Proxy-U. At lower levels of utility, illustrated on the left side of the plot, the DEMQOL-Proxy-U appears to produce higher utility values than the DEMQOL-U.



Mean difference = -0.134
95% L.O.A. = -0.445 to 0.178
N = 222

Figure 4-17 Bland-Altman plot analysing agreement between DEMQOL-U and DEMQOL-Proxy-U utility values

Spearman’s rank order correlations were calculated to assess convergent validity between utility scores and clinical determinants of cognitive function (PAS-Cog; DSS; FAST), physical function (MBI), and neuropsychiatric symptoms (NPI-Q), and are presented in Table 4-16. Generally speaking, the correlation sizes were low to negligible across both instruments, with the DEMQOL-Proxy-U index scores demonstrating significant associations with all clinical determinants at the 0.01 level with the exception of the PAS-Cog which showed no association for this subgroup. The DEMQOL-U index scores showed no significant associations with any of the clinical determinants with the exception of a weak correlation with the NPI-Q which was significant at the 0.05 level.

The DEMQOL-U and DEMQOL-Proxy-U have three dimensions in common: positive emotion, memory, and negative emotion. Figure 4-18 provides a graphical representation of the self and proxy responses for each of these dimensions. If proxies were giving similar responses to the participants for whom they were reporting, the distribution of responses in the self and proxy categories should appear equal. As the charts show, only the memory dimension appears to show consistent responses between self and proxy ratings.

Table 4-16 Spearman correlation coefficients of DEMQOL-U and DEMQOL-Proxy-U dimensions with clinical outcome measures

		Cognition (PAS-Cog)	Dementia severity (DSS)	Dementia severity (FAST)	Physical function (MBI)	Behavioural and psychological symptoms (NPI-Q)
DEMQOL-U	Positive emotion	0.088	0.115	0.109	-0.154*	0.157*
	Negative emotion	-0.068	-0.041	-0.125	0.139*	-0.141*
	Loneliness	-0.099	-0.135*	-0.059	0.016	-0.194**
	Memory	-0.019	0.010	0.108	-0.006	-0.002
	Relationships	-0.107	-0.050	-0.062	0.073	0.051
	DEMQOL-U index	-0.107	-0.091	-0.079	0.114	-0.168*
DEMQOL-Proxy-U	Positive emotion	0.106	0.199*	0.217**	-0.117	0.108
	Negative emotion	0.132	-0.098	-0.052	0.155*	-0.242**
	Memory	-0.194**	-0.181**	-0.169*	0.067	-0.041
	Appearance	-0.024	0.039	0.075	-0.007	-0.016
	DEMQOL-Proxy-U index	-0.092	-0.237**	-0.232**	0.179**	-0.183**

* Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed

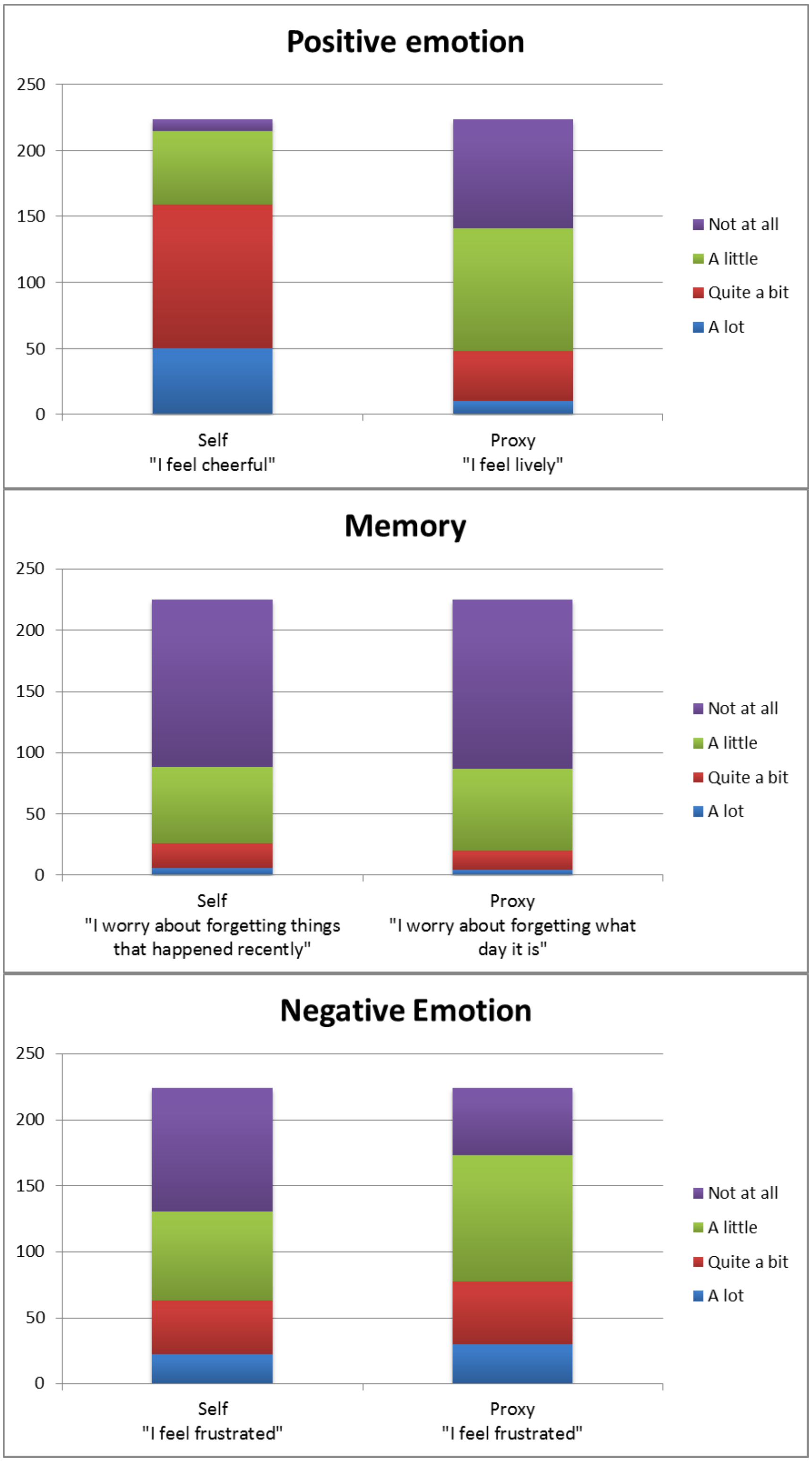


Figure 4-18 Comparison of Self and Proxy responses for the common dimensions of 'positive emotion', 'memory', and 'negative emotion'

Table 4-17 presents the results of the Wilcoxon Signed Ranks Test, which was used to test for statistical differences between the self-rated and proxy-rated dyads for each common dimension. The results indicate that dyad responses for the 'memory' dimension were not significantly different from each other. In contrast, the self and proxy scores were significantly different for the dimensions of 'positive emotion' and 'negative emotion'. Proxy responses indicated higher levels of negative emotion (frustration) and lower levels of positive emotion (cheerfulness/liveliness) than participants themselves reported.

Table 4-17 Test of association between common dimensions of the DEMQOL-U and DEMQOL-Proxy-U instruments and self vs. proxy ratings.

Dimension[1]	**Self-rated**		**Proxy-rated**		**Test of difference**	
	Mean (SD)	95% CI	Mean (SD)	95% CI	z-statistic	p-value
Positive emotion	2.11 (0.79)	2.00, 2.21	3.11 (0.84)	3.00, 3.22	-10.03	>0.001
Memory	1.53 (0.77)	1.43, 1.63	1.49 (0.71)	1.40, 1.58	-0.38	0.706
Negative emotion	1.96 (1.00)	1.82, 2.09	2.25 (0.96)	2.12, 2.38	-3.14	0.002

1 Scores for individual dimensions range from 1 to 4, with higher scores indicating greater disutility.

Responsiveness to change for DEMQOL-U and DEMQOL-Proxy-U measures

The distribution of responses across the dimension levels are presented for the DEMQOL-U in Figure 4-19 and for the DEMQOL-Proxy-U in Figure 4-20. The percentages of respondents who answered the best response (ceiling) and worst response (floor) for each dimension are presented in Table 4-18. Floor effects for the DEMQOL-U ranged from 2.7 per cent for "memory" to 9.8 per cent for "negative emotion". For the DEMQOL-Proxy-U, floor effects ranged from 1.8 per cent for "memory" to 37.1 per cent for "positive emotion". Ceiling effects for the DEMQOL-U ranged from 22.2 per cent for "positive emotion" to 67.1 per cent for "relationships". For the DEMQOL-Proxy-U instrument, ceiling effects ranged from 4.5 per cent for the "positive emotion" dimension to 61.3 per cent for "memory".

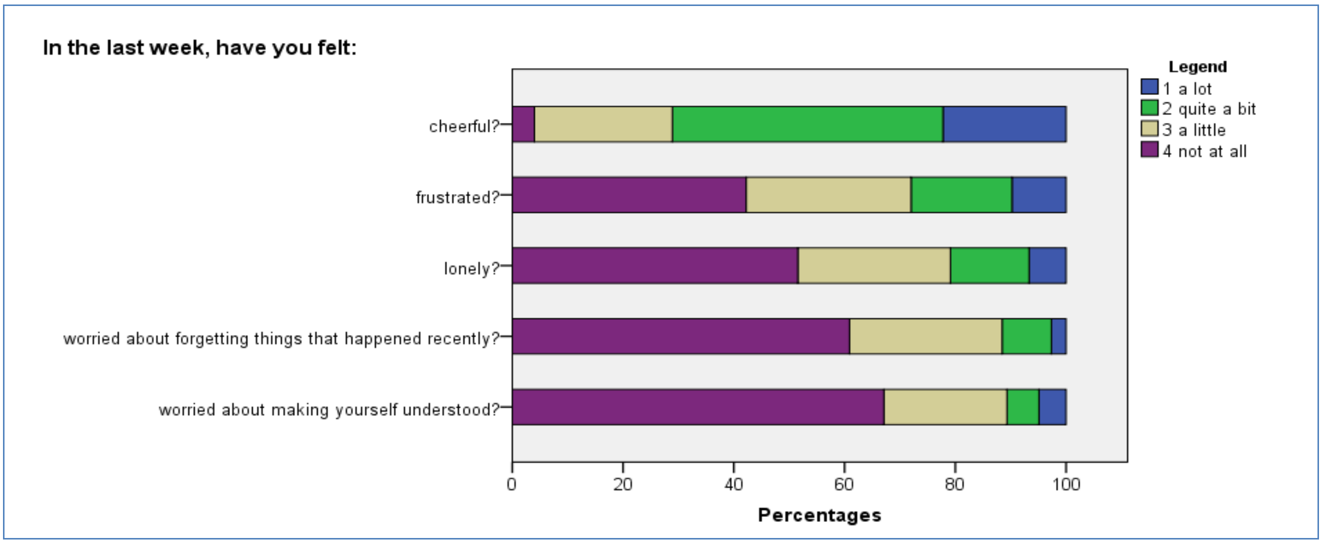


Figure 4-19 Distribution of responses across DEMQOL-U dimensions in the Self vs. Proxy subgroup

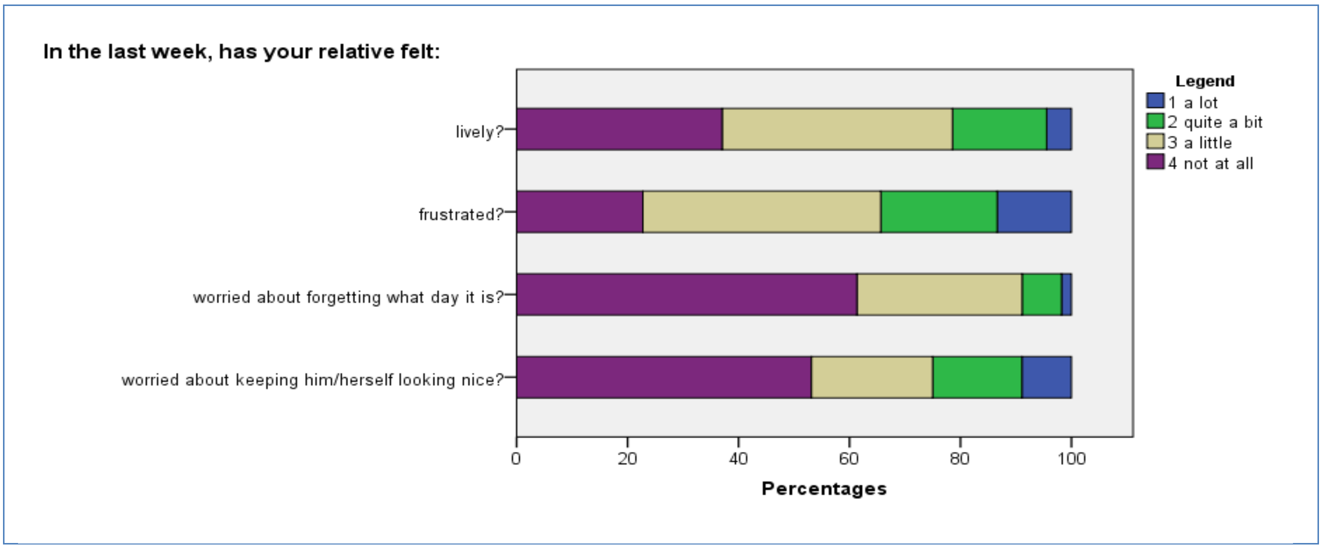


Figure 4-20 Distribution of responses across DEMQOL-Proxy-U dimensions in the Self vs. Proxy subgroup

Table 4-18 Floor and ceiling effects for the EQ-5D-5L-Proxy and DEMQOL-Proxy-U (n = 225)

Measure	Dimension	% floor	% ceiling
DEMQOL-U	Positive emotion	4.0	22.2
	Negative emotion	9.8	42.2
	Loneliness	6.7	51.6
	Memory	2.7	60.9
	Relationships	4.9	67.1
	DEMQOL-U index	0.0	6.7
DEMQOL-Proxy-U	Positive emotion	37.1	4.5
	Negative emotion	13.4	22.8
	Memory	1.8	61.3
	Appearance	8.9	53.1
	DEMQOL-Proxy-U index	0.0	1.3

4.3 Summary of findings

Objective 3 outlined in the literature review was to compare the performance of two preference-based measures of health-related quality of life: one generic and one dementia-specific. This comparison was made in terms of practicality and validity.

Practicality refers to an instrument's acceptability to respondents. To assess the practicality of the EQ-5D-5L, the DEMQOL-U, and their proxy versions, the questionnaire lengths, response rates, and completion rates were compared. The EQ-5D-5L, with six questions, was one-fifth the length of the DEMQOL and DEMQOL-Proxy questionnaires which had 29 and 32 questions respectively.

Compared to the entire study cohort (n=541), the subset of residents who completed both self-rated instruments (n=143) had a lower prevalence of dementia, better cognitive function, better physical function, and reported fewer behavioural and psychological symptoms. This is an important finding in and of itself in relation to instrument practicality in residential aged care settings. By following the existing evidence which suggests the EQ-5D-5L may be appropriate in mild to moderate dementia, or in other words for participants with a PAS-Cog score less than or equal to 11, the collections of both self-reported health-related quality of life measures were limited to 26 per cent of potential participants on the basis of insufficient cognitive ability.

Construct validity assesses the extent to which the dimensions of a utility measure correlate with other indicators of health, or health-related quality of life in the population of interest. With the exception of the moderate correlation found between physical function and the EQ-5D-5L, the typical clinical outcome measures for people with dementia – cognition, physical function, and neuropsychological symptoms – showed little association with the utility scores produced by the EQ-5D-5L and DEMQOL-U instruments. Interestingly, higher levels of cognitive impairment were associated with higher EQ-5D-5L utilities and overall mean utility scores for residents with a diagnosis of dementia were higher than for those without a diagnosis of dementia.

Findings in the proxy-rated subsample showed better association with clinical outcome measures than the self-rated sample. The EQ-5D-5L-Proxy dimensions performed relatively well when compared with clinical measures. Physical dependence showed a moderately strong negative correlation with the EQ-5D-5L index in that higher physical dependence was associated with lower quality of life. Cognitive impairment as measured by the PAS-Cog showed a moderately strong negative correlation with the EQ-5D-5L-Proxy cognition bolt-on and a negative correlation with the EQ-5D-5L-Proxy index overall, indicating higher levels of cognitive impairment were associated with lower proxy-rated quality of life.

In terms of the utility scores generated by the EQ-5D-5L and DEMQOL-U, the mean difference was 0.2 with utility scores generated by the EQ-5D-5L tending to be lower than those generated by the DEMQOL-U. A similar mean difference was found for the EQ-5D-5L-Proxy and DEMQOL-Proxy-U, with utility scores generated by the EQ-5D-5L-Proxy being on average 0.2 points below scores generated by the DEMQOL-Proxy-U.

Finally, responsiveness to change considers the ability of an instrument to measure changes in health status. Ceiling effects were apparent for both the EQ-5D-5L and DEMQOL-U dimensions, as well as for two out of four dimensions on the DEMQOL-Proxy-U. Floor effects were apparent for the EQ-5D-5L-Proxy and the “positive emotion” dimension of the DEMQOL-Proxy-U. Neither of the self-rated measures showed any indication of a floor effect. These findings are consistent with the more severe levels of cognitive impairment and dementia present in the proxy-rated subgroup compared with the self-rated subgroup.

With its strong association with physical functioning, the EQ-5D-5L may be a more suitable instrument for the assessment of health-related quality of life in mixed residential care populations that include people with dementia but also people with co-morbidities, high levels of physical disability and frailty with good cognition. The DEMQOL-U and DEMOL-Proxy-U, on the other hand, may be suitable for dementia-specific interventions that are more psycho-social in nature.

This chapter has highlighted some important differences between the EQ-5D-5L and the DEMQOL-U, and their proxy versions that have the potential to materially impact the results of economic evaluations in terms of their interpretation and comparability with other studies. The findings of this study will be discussed in the context of their implications for economic evaluations in a residential aged care setting in Chapter 8. We now move to a deeper examination of the costs involved in the provision of residential aged care. Chapter 5 will present the results of the project examining the facility-level costs of residential care in Australia, using the full INSPIRED sample of 17 residential aged care facilities.

CHAPTER 5: FACILITY-LEVEL COSTS

As the results of the systematic review have shown, the issue of what it costs to provide residential aged care has been the subject of previous study. In terms of peer-reviewed, published economic evidence, the systematic review presented in Chapter 2 identified only two studies undertaken in Australia. These were conducted by Chenoweth and colleagues (2009, 2014) and focused upon person-centred care and person-centred environments in residential care.

In addition to these studies, the Australian government has commissioned a number of reviews into the costs of providing residential aged care (see, for instance Access Economics, 2009; Deloitte Access Economics, 2011; Grant Thornton Australia, 2008; Hogan, 2004; Productivity Commission, 2011), and the Aged Care Financing Authority, which provides advice to the government on funding and financing issues, has published a number of relevant reports (Aged Care Financing Authority, 2014; 2015). To ensure future research is targeted at areas with the greatest potential for impact, it is critical to understand the key cost drivers and sources of cost variation relating to the provision of Australian residential aged care services.

Further to this, given the additional costs noted in the literature arising from the provision of care in isolated locations with financially disadvantaged populations, and the increased burden of ill health in these populations, it was hypothesized that metropolitan facilities may have higher capital costs and wage expenses (due to newer facilities and more highly skilled workforce) but residents may have lower health system costs due to closer proximity to better quality health care.

This chapter aims to provide a micro-level analysis of residential aged care costs from the perspective of the provider. A subset of South Australian facilities were then selected to feed into the macro-level analysis which explores the costs to the government incurred in the broader health care system in Chapter 7. Specifically, the objectives of this project were to (1) identify the relevant cost categories and their relative proportions in determining the overall running costs of residential care at a facility level; and (2) investigate the key cost drivers and main sources of cost variation.

5.1 Methods

Methodology for the cost analysis was based on the conceptual model published by Ehreth (1992) as well as the 2012 Grant Thornton report on service costs in modern residential aged care facilities (Grant Thornton Australia, 2012). An overview of Ehreth's conceptual model for long-term care cost evaluation is presented in Figure 5-1. The cost analysis covered two levels of costs: facility and health-system levels. Cost relationships within each level and between levels were examined. According to Ehreth, the facility- level analysis (deemed as the micro-level in Ehreth's model) relates inputs such as staffing, supplies, and overheads to the output which is the provision of care supplied by the residential care facility. The facility- level analysis enables comparisons of input factors between programs, or facilities, such as the use of registered nurses versus personal care workers.

The purpose of the facility-level cost analysis was to describe the individual variables that contributed to the running cost for each facility in order to partially address Objective 4 of this thesis, which aimed to explore the relevant costs of residential aged care at the facility level. Therefore, the outcome variable (dependent variable) for this analysis was the running cost for each facility. Due to the relatively small numbers of facilities involved (n=17), results of a regression model would have been weak and would have needed to be interpreted with extreme caution. Accordingly no modelling was done at this stage. Statistical analysis was undertaken using Microsoft Excel and IBM SPSS Statistics Version 22 (IBM Corp, Released 2013).

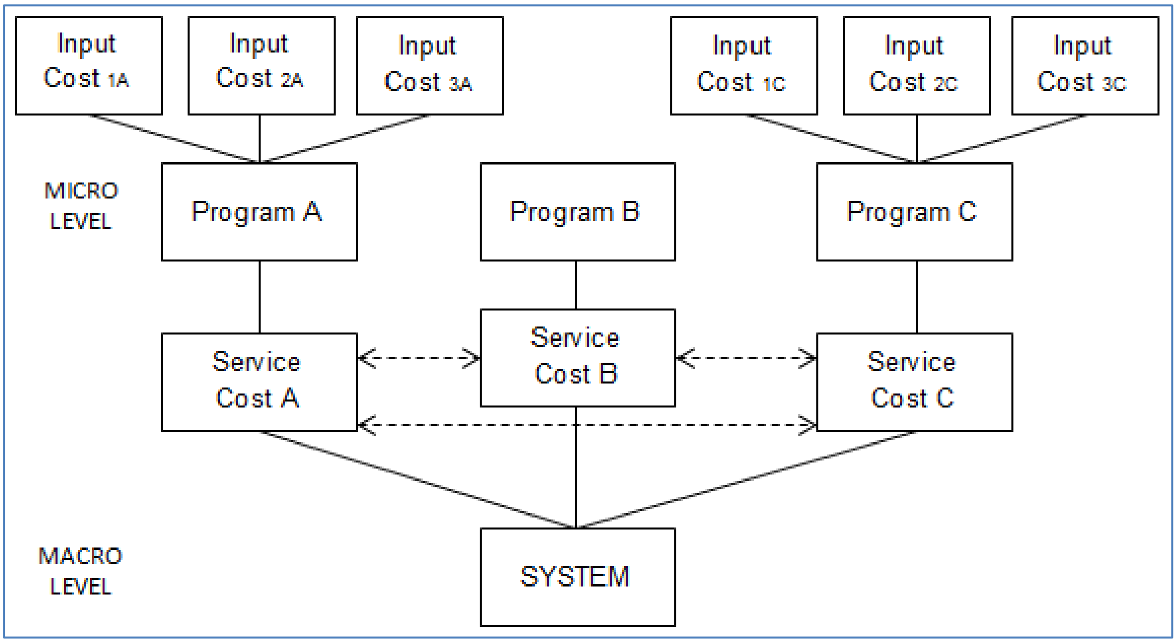


Figure 5-1 Ehreth's conceptual model for long-term care cost evaluation (Ehreth, 1992)

5.1.1 Determining the representativeness of participating facilities

The StewartBrown Aged Care Financial Performance Survey divides participating facilities into bands, for benchmarking purposes, based on their operating income as aggregated by resident care fees, care subsidies, and extra service fees. The income band distribution of participating facilities for the INSPIRED study was compared to the distribution of participating facilities in the StewartBrown Aged Care Financial Performance Survey, as a means of determining the representativeness of the INSPIRED sample.

5.1.2 Overview of general financial results

The first series of facility-level analyses examined the unadjusted financial data to provide an overview of the general financial results and facility profile of participating residential aged care facilities. This overview included labour costs, workforce, earnings before interest, taxation, depreciation and amortisation (EBITDA), age of buildings, capital costs, internal rates of return, and dementia-specific units.

Financial data pertaining to revenue and expenses were collected in two formats, either as an annual figure for the facility, or as the dollar amount per resident per day. Annual figures were then converted to a dollar amount per resident per day using the following formula:

$$Cost\ per\ resident\ per\ day\ = \frac{Annual\ facility\ cost}{Total\ no.of\ beds\ \times\ Average\ occupancy\ rate} \div 365\ days$$

This allowed for direct comparisons between facilities regardless of facility size.

Labour costs

Labour costs were defined as wages plus associated on-costs. On-costs are the additional costs that are incurred above employee salary and include items such as payroll tax, superannuation, workers' compensation and WorkCover costs as well as staff recruitment costs and education costs. To determine total labour costs for each facility, the following expenses from the Facility Cost Survey, question 20 (Summary of expenses – Year ended 30 June 2014) were summed. Labour costs were then converted to a percentage of total expenses.

$$\begin{aligned} Labour\ costs\ =\ & Care\ wages\ + Cleaning\ wages + Laundry\ wages + Catering\ wages \\ & + Property\ \&\ maintenance\ wages + Administration\ wages + Wage\ oncosts \end{aligned}$$

To explore further with regard to labour, staff training costs for direct care workers were examined. Staff training costs included both wage-related and non-wage costs associated with the training and development provided to direct care workers. Annual amounts were reported for the 2013/14 financial year in question 14 of the Facility Cost Survey. To facilitate direct comparisons between facilities, training and development costs were divided by the number of full-time equivalent (FTE) direct care workers at each facility in order to determine the average training and development cost per FTE unit. In Australia, one FTE unit is equivalent to one or more employees who work a total of 38 hours per week (7.6 hours per day over 5 days). FTE data for direct care workers were collected in question 6 of the Facility Cost Survey and included nurses, personal care attendants, allied health professionals and other employees with direct involvement in the care of residents. The number of rostered workers was collected for morning (AM), evening (PM), and night shifts (Night) on weekdays, as well as Saturdays and Sundays. The FTE number was then calculated by determining the total hours worked in a standard 7-day week, and dividing this by the standard-hour workload for one FTE which is 38 hours.

$$Total\ FTEs = [5 \times (AM + PM + Night) + Saturday + Sunday] \times \frac{7.6}{38}$$

Workforce

The Australian Government Department of Health and Ageing separates the residential aged care workforce into three categories: direct care workers, non-direct care workers, and non-PAYG workers (King et al., 2012). Direct care workers are primarily the nurses and personal care attendants that provide care to residents on a daily basis. Other direct care workers include allied health professionals such as physiotherapists and occupational therapists, as well as activities staff who organise various social activities for the residents. Non-direct care workers provide necessary support to the direct care workers to ensure the successful functioning of the facility. Non-direct care workers include administration and management roles as well as the cleaning, catering, laundry, and maintenance staff. Non-PAYG workers include agency or brokered staff, whose services are contracted out to the facility, as well as volunteers.

Direct care hours and non-direct care hours were calculated on a ‘per resident per day’ basis using the following formulas.

$$Direct\ care\ hours\ per\ resident\ per\ day\ = \frac{Direct\ care\ FTEs\ per\ day \times 7.6}{Total\ no.of\ beds\ \times\ Average\ occupancy\ rate}$$

$$\begin{aligned} &Non - direct\ care\ hours\ per\ resident\ per\ day \\ &\qquad = \frac{Indirect\ care\ FTEs\ per\ day \times 7.6}{Total\ no.of\ beds\ \times\ Average\ occupancy\ rate} \end{aligned}$$

Non-PAYG care hours were not analysed in this way, rather the agency rate (agency workers as a percentage of total workers) was collected. The average number of volunteer hours at each facility was also collected.

Average care hours per resident per day were then calculated for each facility by determining the average care hours received over one week and dividing this weekly total by 7. This was done by adding the average direct care hours received per resident on a weekday (Weekday) and the average direct care hours received per resident on a weekend (Weekend) and dividing by 7. Average non-direct care hours per resident per day were calculated in the same way. No adjustments were made for the differing care needs of residents across facilities.

$$Average\ care\ hours\ per\ resident\ per\ day\ = \frac{(5 \times Weekday) + Weekend}{7}$$

Direct care is primarily provided to residents by either nursing staff or personal care attendants. Nursing staff are more highly qualified than personal care attendants and receive higher wages accordingly. It was therefore worthwhile to examine whether variation existed in direct care staffing arrangements in terms of an organisation’s choice to employ personal care attendants versus nurses. For the purpose of this comparison, total care hours were equal to the sum of total hours of care per resident per day provided by nursing staff plus the total hours of care per resident per day provided by non-nursing care workers (e.g. personal care attendants). Nursing hours were then calculated as a percentage of total care hours.

The other type of direct care worker is the allied health professional. The final workforce comparison explored the number of allied health professionals employed per facility. FTE units were calculated as per the equation laid out in the *Labour cost* section above. An increased use of allied health professionals in residential aged care has been linked to better outcomes in areas such as functional status (Przybylski et al., 1996) and reduced hospital admissions (Schneider et al., 2007), and thus variations in the number of allied health professionals employed at facilities could have implications for costs of care as well as residents’ quality of life.

Profitability

There are a number of measures which can be used to evaluate the profitability of an organisation (Aged Care Financing Authority, 2014). The net income (or net profit) of an organisation is calculated by subtracting the total costs incurred during a period from the revenues earned in that period. These costs include the day-to-day expenses as well as interest payments, taxes, depreciation and amortisation. The interest expense incurred by an organisation is subject to the financing decisions and the capital structure of the organisation. For instance, a company financed wholly with equity would not incur any interest costs while a company financed with debt may have substantial interest expenses. This can complicate direct comparisons of net income between organisations, as two organisations could have identical revenues and day-to-day expenses, yet the organisation financed by debt will appear less profitable in terms of net income once the interest payments are subtracted. Taxes, depreciation, and amortisation are subject to accounting decisions which can have similar confounding effects on the interpretation of net income figures. For instance, the cost incurred from an asset purchase may be spread out over the course of its useful life, which is known as depreciation.

Earnings before interest, taxes, depreciation and amortisation (EBITDA) is a useful measure for profitability comparisons between organisations because it eliminates the effects of financing and accounting decisions (W. P. Hogan, 2005). EBITDA is calculated by adding back interest expenses, tax, depreciation and amortisation to the net income. It is essentially a measure of an organisation's ability to produce income from its operations in a given year. Due to the difficulties interpreting net income comparisons, as highlighted above, EBITDA was chosen to compare profitability between participating residential aged care facilities. The summary of expenses collected in question 20 of the Facility Cost Survey excluded interest, taxes, depreciation, and amortisation. Thus, EBITDA was calculated by subtracting the *total expenses* in question 20 from the *total operating revenue* in question 19.

Age of buildings and capital costs

The construction year of participating facilities was collected in question 12 of the Facility Cost Survey. Facility age was then calculated by subtracting the year constructed from the year the data were collected (2015). Capital costs are fixed, one-off expenses which include construction, fit-out, and land costs for an aged care facility. Participating facilities were asked to provide historical data for their capital expenditures at either the initial time of building, or the most recent refurbishment (Facility Cost Survey question 13). These data were reported on a cost per bed basis. Total capital costs were divided by the number of beds at the facility in order to facilitate comparisons between different sized facilities.

Internal rate of return

The internal rate of return (IRR) is a metric used in capital budgeting to measure the profitability of potential investments, such as whether to build a new aged care facility or refurbish an existing one. Using a method of financial analysis called the discounted cash flow method, the IRR is the interest rate that will bring a series of cash flows to a net present value of zero (Gilbert, 2012). Cash outflows are input as negative values and cash inflows are input as positive. In terms of the construction of a new aged care facility, the IRR is the interest rate at which the expected future cash inflows from accommodation revenues (accommodation charges and daily accommodation payments, interest from accommodation bonds and refundable accommodation deposits, and accommodation supplements from the government) less the expected future cash outflows (property and maintenance costs and interest paid on bonds) will equal the initial outlay of capital required to construct the facility.

IRR Formula:

$$0 = \sum_{t=0}^{n} \frac{(Inflows - Outflows)_t}{(1 + IRR)^n}$$

Where

t = time period, time = 0 to n

n = analytic horizon (in years)

In order to estimate the internal rate of return (IRR) relating to accommodation for the participating facilities, accommodation-related income and expenses were extracted for each facility for the 2013 and 2014 financial years. An initial capital outlay was estimated from the depreciation expense assuming a depreciation rate of 4 per cent for all facilities.

Dementia-specific units

With regard to dementia-specific care, the Facility Cost Survey collected information as to whether the facility provided a dementia-specific area which could be a separate unit or wing, or an entire dementia-specific facility (Question 1). The survey also collected information concerning the provision of dementia training to care staff (Question 14). Average operating revenues and expenses were compared for facilities with and without dementia units, both graphically and using the Wilcoxon Signed Ranks test.

5.1.3 Identification of cost drivers

The second series of analyses aimed to explore the primary cost drivers of residential aged care facilities in Australia. Cost drivers are characteristics of service delivery that cause a facility to incur costs. By analysing cost drivers, we can better understand the correlation between the cost of providing care and the activities or characteristics that contribute to this overall cost.

The first step of analysis was to identify the primary expense categories pertaining to facility running costs. Determining a cost driver among potential options depends on how well each cost driver may correlate with one of the expense categories, or ‘cost objects’. Table 5-1 provides a list of potential cost drivers that were analysed for relationships with each of the expense categories identified. Potential cost drivers were selected based on commonly examined factors in the existing literature.

Table 5-1 Potential cost drivers for facility costs

Potential cost drivers
ASGC Remoteness Area (locality)
Total number of physical beds (size)
Number of secure dementia beds
Number of extra services beds
Average annual resident turnover
Resident case-mix
Agency rate
Proportion of staff on casual contracts
Annual staff turnover
Average number of volunteers
Proportion of multi-bed rooms
Average room size
Number of floors in facility
Age of facility
RN Level 1 wage rate (as proxy for cost of living difference between states)

The distributions of each variable were assessed for normality using the Kolmogorov-Smirnov test with Lilliefors significance correction and the Shapiro-Wilks test. Non-parametric correlations were calculated between each potential cost driver and each cost category using the Spearman’s Rank Order Correlation (rho).

In order to further examine the relationships between assessed level of care required for residents, government subsidies and care costs, the correlations between each category of the ACFI – activities of daily living (ADL), behaviour (BEH), and complex health care (CHC) were examined in relation to the identified cost categories.

It was also hypothesized that there may be a relationship between the ACFI subsidy categories and the number of care staff rostered at each facility. To examine this relationship, Spearman Rank Order Correlations were calculated between the ADL, BEH, and CHC subsidies received and the number of FTE direct care staff at each facility.

5.2 Results

In 2015, Facility Cost Survey was collected by the candidate (TE) from 13 facilities managed by the three Cognitive Decline Partnership Centre industry partner organisations, Helping Hand, HammondCare and Brightwater Care Group. In addition, two facilities each from two external organisations, RSL Care SA (SA) and Southern Cross Care (QLD) Inc. were recruited. The total number of facilities was 17, across 5 not-for-profit organisations and 4 Australian states (SA, NSW, WA and QLD). Data collection commenced in February 2015, in parallel with recruitment of sites and was completed in November 2015 for two years of cost data: the financial year ended 30 June 2013 and the financial year ended 30 June 2014.

Due to the small number of facilities in this investigation, caution should be exercised as to what conclusions may be drawn from comparisons between facilities. Insights gained from exploring the data may help determine influential independent variables, which affect the overall running costs of aged care facilities. The financial information collected related primarily to the 2012-13 and 2013-14 financial years, prior to the introduction of Refundable Accommodation Deposits (RADs) and Daily Accommodation Payments (DAPs).Table 5-2 provides a stratification of the data by state, sector, and locality. Locality was determined according to the Australian Standard Geographical Classification (ASGC) Remoteness Areas.

Table 5-2 Stratification of participating facilities by state, sector, and locality

	Number of participating facilities
State stratification	
NSW	5
QLD	2
SA	7
WA	3
TOTAL	17
Sector stratification	
Not-for-profit	17
TOTAL	17
Locality stratification	
Major Cities (RA1)	13
Inner Regional (RA2)	1
Outer Regional (RA3)	3
TOTAL	17

Participating facilities ranged in size from 40-bed single-story facilities up to 155-bed multi-story facilities. The average facility size was 83 beds.

5.2.1 StewartBrown Income Bands

The revenue and expense portion of the financial cost survey was collected via facility reports for the StewartBrown Aged Care Financial Performance Survey. StewartBrown divides participating facilities into bands, for benchmarking purposes, based on their operating income as aggregated by resident care fees, care subsidies, and extra service fees. The income bands for 2013 and 2014 are shown in Table 5-3, along with the distribution of the 17 participating facilities, the majority of which fall into Band 1.

Table 5-3 Distribution of participating facilities according to StewartBrown Income Bands

StewartBrown Income Bands	2013		2014	
	Operating income	Number of participating facilities	Operating income	Number of participating facilities
Band 1	Over $195	16	Over $210	13
Band 2	$175 to $195	1	$190 to $210	4
Band 3	$155 to $175	0	$170 to $190	0
Band 4	$135 to $155	0	$150 to $170	0
Band 5	Under $135	0	Under $150	0

According to the summary of survey outcomes released by StewartBrown for the year ended 30 June 2014, 22 per cent of the 755 participants in 2014 fell into Band 1 whereas 76 per cent of the INSPIRED sample facilities were categorised as Band 1. As a facility's operating income is predominantly determined by the ACFI subsidies of its residents, this would suggest that the INSPIRED sample had higher assessed care needs relative to the overall residential aged care sector represented by StewartBrown. There are two key elements to note from this analysis and the main findings: first, the participating facilities in the INSPIRED study are clustered around the same income band and thus their results are broadly comparable; and second, the INSPIRED study is not necessarily representative of the aged care sector as a whole, but more likely represents those caring for the most vulnerable, high needs portion.

5.2.2 General results (unadjusted)

The results presented in this section provide a summary of the key financial elements of aged care facilities from an operational perspective. Day-to-day operations include the labour costs (which make up the largest component of operating costs), the workforce configurations, and the facility earnings measured before interest, taxes, depreciation and amortisation (EBITDA) for each participating facility.

Capital costs include a summary of the age of the physical buildings and the historical costs of constructing aged care facilities and a simple model to estimate the internal rate of return (IRR) on capital investments. Finally facilities with secure dementia units are compared with facilities without dementia units.

Labour costs

Labour costs consist of wages and associated on-costs. Wage on-costs include expenditures such as superannuation guarantee contributions, workers compensation expenses and payroll tax. In our sample of 17 aged care facilities, labour costs accounted for an average of 72 per cent of total expenses. Labour costs varied between facilities, ranging from a low of 64 per cent to a high of 77 per cent. Figure 5-2 provides a graphical summary of labour costs as a percentage of total expenses for each of the 17 participating facilities.

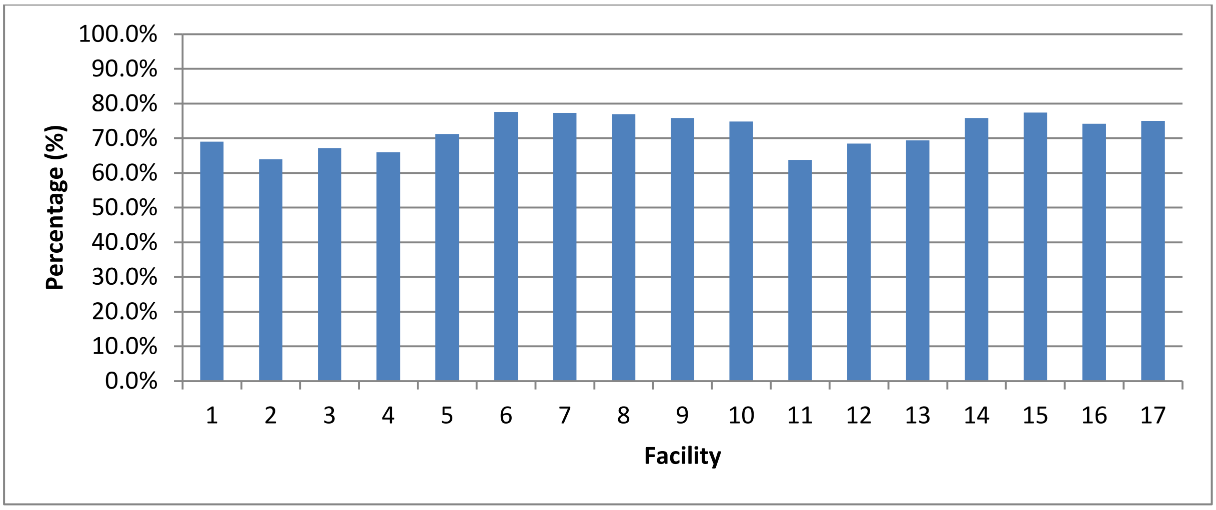


Figure 5-2 Labour costs as a percentage of total expenses

While total labour costs appear relatively consistent across facilities, staff training costs for direct care workers varied widely (See Figure 5-3). Fifteen facilities provided data on this area. Training and development costs included both wage-related and non-wage costs associated with training provided to direct care workers. After adjusting for facility size by dividing the total training and development costs for direct care workers by the number direct care FTEs at each facility, training and development costs for direct care workers ranged from $487 per full-time direct care employee to $4,511 per full-time direct care employee.

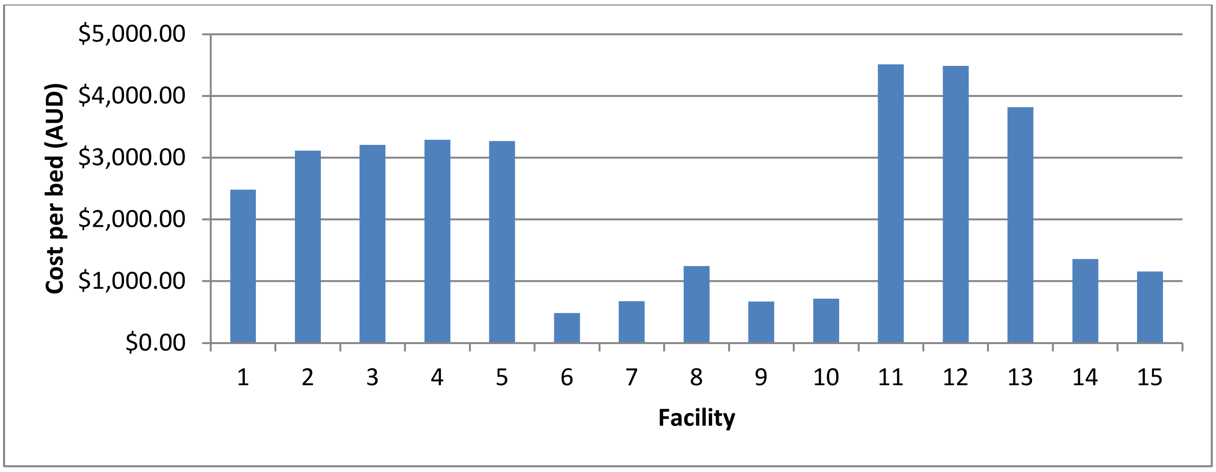


Figure 5-3 Training and development costs per direct care FTE

Workforce

The residential aged care workforce can be broken down into direct care workers and non-direct care workers. Direct care workers are primarily the nurses and personal care attendants that provide care to residents on a daily basis. Other direct care workers include allied health professionals such as physiotherapists and occupational therapists, as well as activities staff who organise various social activities for the residents.

Non-direct care workers provide necessary support to the direct care workers to ensure the successful functioning of the facility. Non-direct care workers include administration and management roles as well as the cleaning, catering, laundry, and maintenance staff.

Table 5-4 presents a summary of the mean and range of direct and non-direct care hours across all 17 facilities. Total average care hours for our sample was 3.7 hours per resident per day, and ranged from a minimum of 2.6 hours per resident to a maximum of 5.3 hours per resident.

Table 5-4 Summary of care hours per resident per day across 17 residential care facilities

	Mean	Range
Direct care hours per resident per day	2.7	1.9 to 3.8
Non-direct care hours per resident per day	1.0	0.4 to 1.6
TOTAL	**3.7**	**2.6 to 5.3**

Figure 5-4 shows the average care hours per resident per day for each of the 17 facilities, broken down into direct and Non-direct care hours. Average direct care hours were 2.7 hours per resident per day, and ranged from a minimum of 1.9 hours per resident to a maximum of 3.8 hours per resident. No adjustments were made for the differing care needs of residents across facilities.

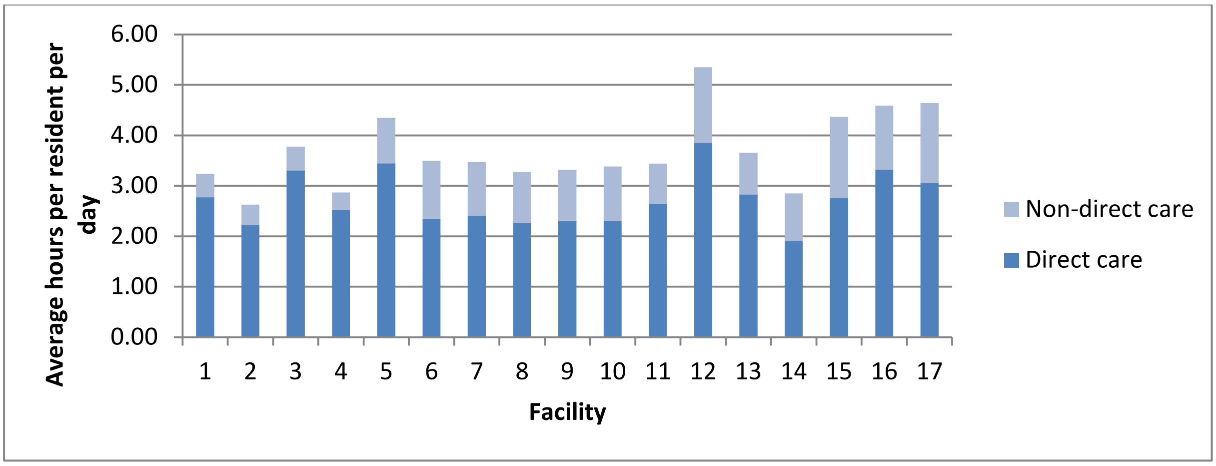


Figure 5-4 Average care hours per resident per day

As stated previously, direct care is primarily provided to residents by either nursing staff or personal care attendants. As shown in Figure 5-5, there is a significant amount of variation between aged care facilities in terms of the proportion of direct care that is provided by nursing staff. Nursing hours as a percentage of total care hours ranged from 2.3 per cent to 55.9 per cent. For the purpose of this comparison, total care hours are equal to the sum of total hours of care per resident per day provided by nursing staff plus the total hours of care per resident per day provided by non-nursing care workers (e.g. personal care attendants). Allied health and activities staff are not included in this comparison.

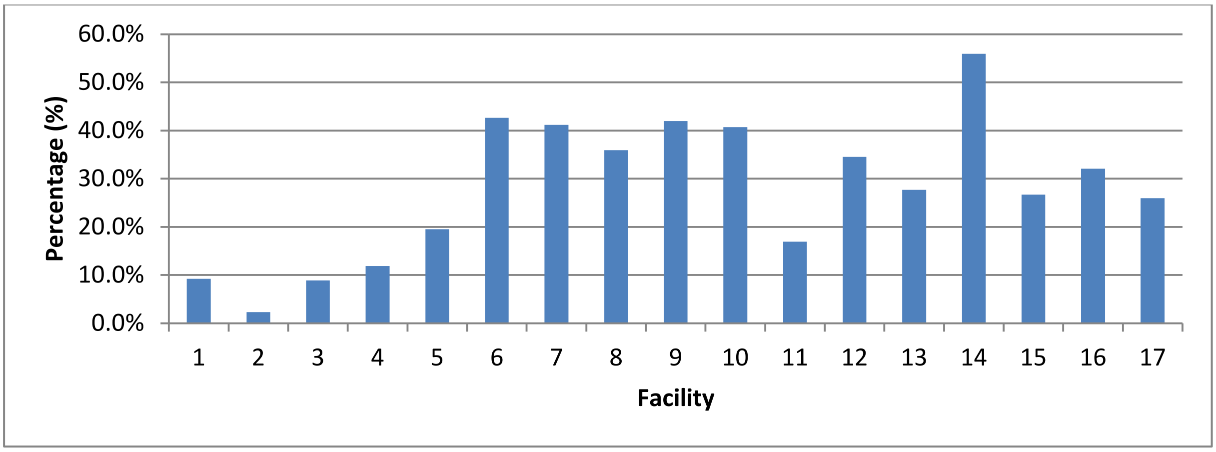


Figure 5-5 Nursing hours as a percentage of total care hours

Allied health services are not provided by all residential care facilities. While most facilities (11/17) directly employ some level allied health professionals, the number of full-time equivalent allied health professionals ranged widely from 0.1 FTE to 5.1 FTE per facility. Six facilities did not employ any allied health professionals. Figure 5-6 illustrates the number of allied health professionals directly employed by each facility.

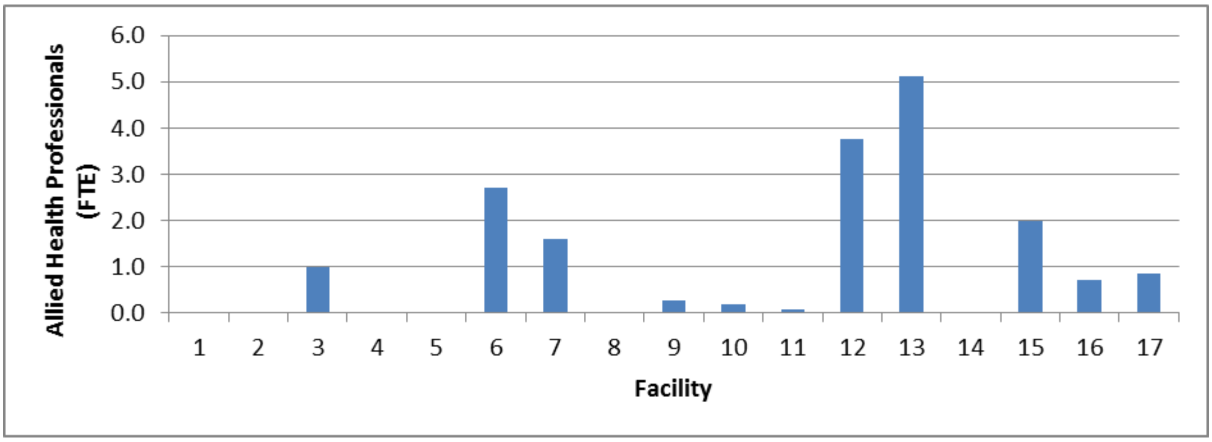


Figure 5-6 Number of allied health professionals employed per facility (FTE)

EBITDA

Earnings before interest, taxes, depreciation and amortisation (EBITDA) is a useful measure for profitability comparisons between organisations because it eliminates the effects of financing and accounting decisions. EBITDA is calculated by adding back interest expenses, tax, depreciation and amortisation to the net income. It is essentially a measure of an organisation's ability to produce income from its operations in a given year.

For the financial year ended 30 June 2014, 6 out of 17 facilities (35 per cent) reported a loss in EBITDA terms. For the previous year ended 30 June 2013, 3 out of 17 facilities (18 per cent) reported a loss. When looking across both the 2012-13 and 2013-14 financial years, 7 out of 17 facilities (41 per cent) reported a loss in EBITDA terms in at least one of the two years.

Figure 5-7 provides a summary of the reported EBITDAs across both financial years for each participating facility. EBITDA per bed per day is used to enable comparisons across different sized facilities. EBITDAs across both years ranged from a loss of $18.71 to a profit of $42.73 per bed per day. The average EBITDA across all facilities and both financial years was a profit of $14.46 per bed day.

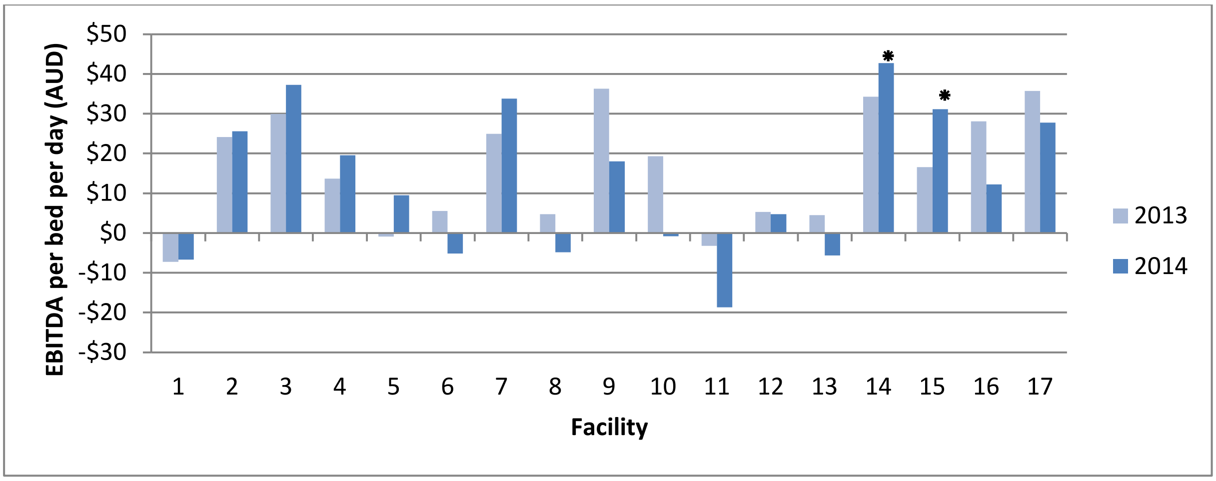


Figure 5-7 Facility EBITDAs for the financial years ended 30 June 2013 and 30 June 2014

*It should be noted that Facility 14 and 15 in Figure 5-7 above provided interim results as at 31 Dec 2013 for the 2013-14 financial year. Accordingly these results do not reflect the full financial year, and should be interpreted with caution.

Age of buildings

The building age of participating facilities ranged from 2 to 98 years, with initial facility construction reportedly taking place between 1917 and 2013. Figure 5-8 provides a summary of initial facility construction dates. Two facilities reported undergoing significant refurbishments since April 2012, which makes them eligible to receive a higher accommodation supplement under the government's Significant Refurbishment Guidelines. A significant refurbishment is defined as providing benefit to at least 40 per cent of residents, or involving an increase of at least 25 per cent of the number of rooms at the facility.

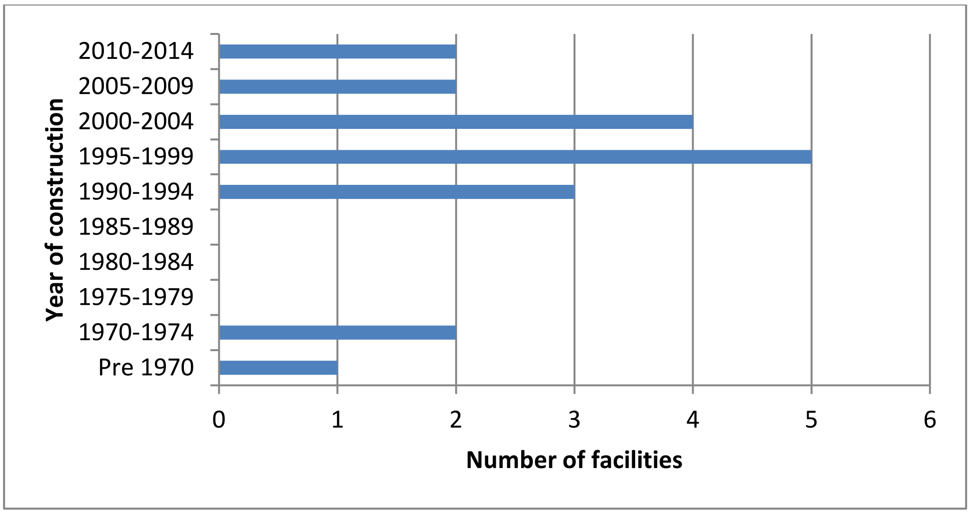


Figure 5-8 Year of initial facility construction

Capital costs

Capital costs are fixed, one-off expenses which include construction, fit-out, and land costs for an aged care facility. Participating facilities were asked to provide historical data for their capital expenditures at either the initial time of building, or the most recent refurbishment. Ten facilities provided data on their capital costs; eight facilities provided historical build costs, while two facilities reported capital costs from recent significant refurbishments. Figure 5-9 illustrates the historical construction and fit-out costs per bed for ten aged care facilities.

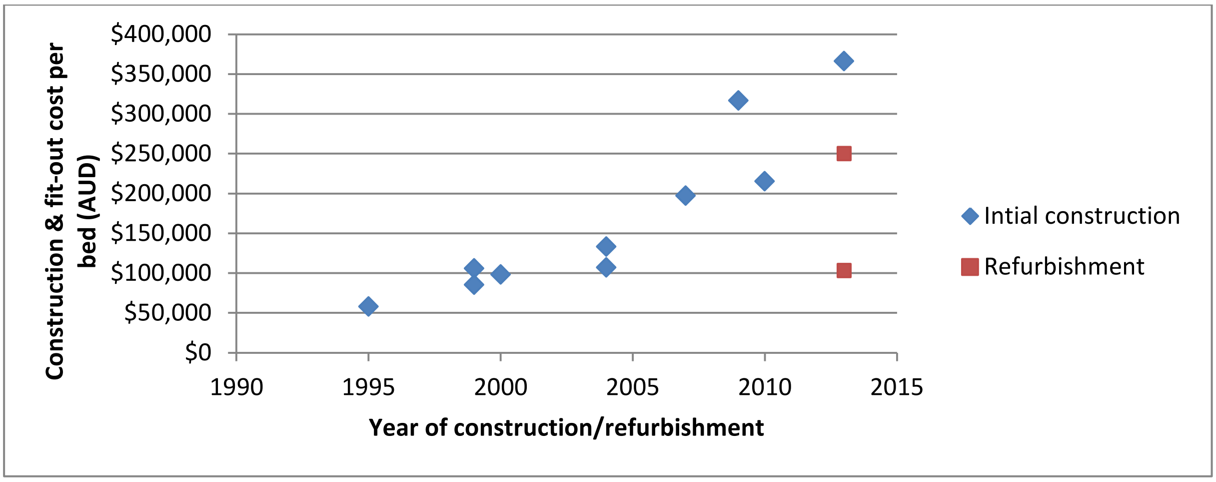


Figure 5-9 Historical construction and fit out costs per bed

IRR

Figure 5-10 provides a summary of the estimated IRRs across both financial years for each participating facility. Where both the initial outlay and annual cash flow were negative, it was not possible to calculate an IRR.

Estimated facility IRRs for accommodation ranged from -4.66 per cent to +9.43 per cent. The average IRR across both 2013 and 2014 financial years was 1.87 per cent. In other words, the average facility generates a return of only 1.87 per cent from their investment in the building itself. Ten facilities had negative IRRs in 2014, suggesting the majority of facilities do not generate sufficient revenues from accommodation to offset the initial capital outlay required to construct the facility.

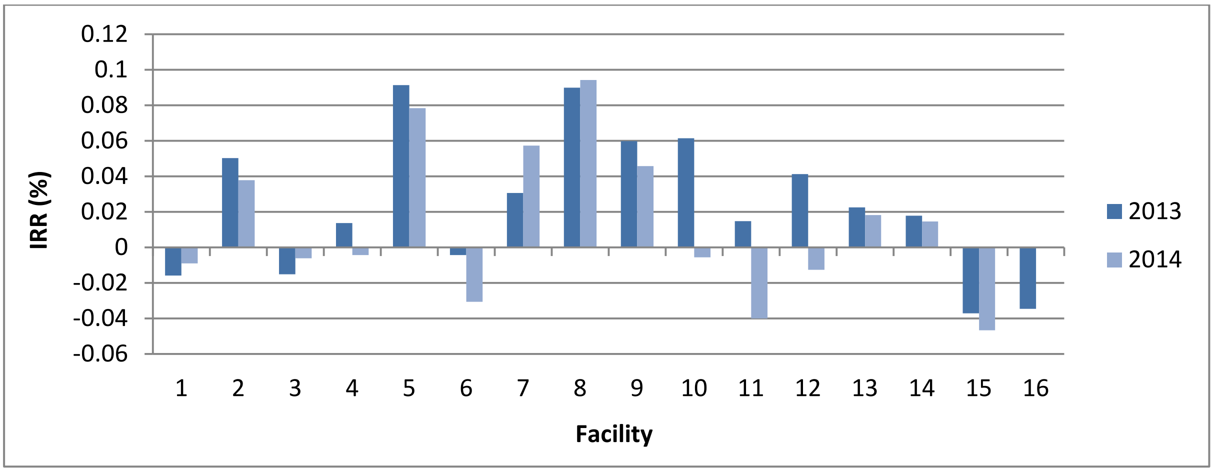


Figure 5-10 Estimated facility IRRs for the financial years ended 30 June 2013 and 30 June 2014

Dementia-specific units

Of the 17 participating facilities, 14 facilities reported having a dementia-specific unit, wing, or facility. Dementia-specific environments can range from securing a particular unit within an existing facility to building purpose-built dementia facilities to cater specifically to the care needs of residents with dementia.

In addition to specialised environments, aged care providers are also providing dementia training to care staff. All 17 facilities provide dementia training to their direct care staff. Eight out of 17 facilities (47 per cent) have indicated they provide mandatory dementia training to direct care staff, while 9 facilities offer non-mandatory dementia training (Figure 5-11).

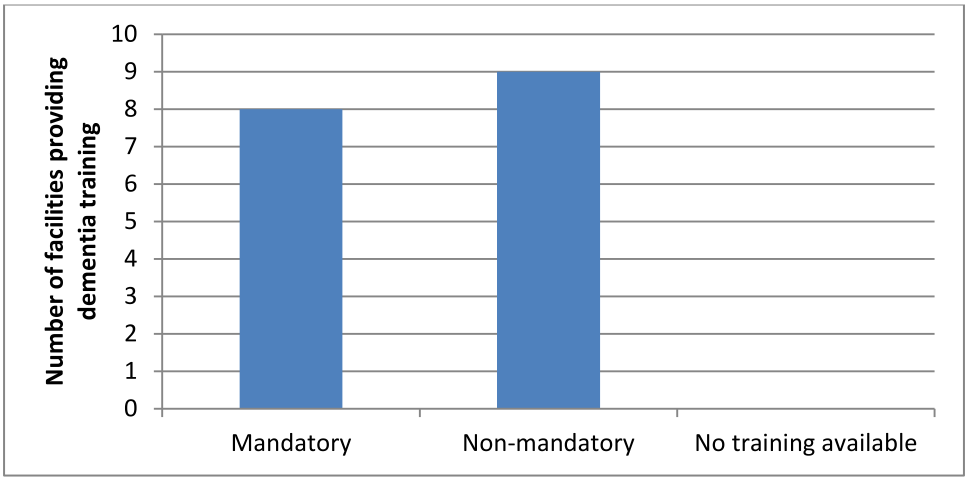


Figure 5-11 Dementia training provided to direct care staff

When comparing average operating income for facilities with and without dementia units, as shown in Figure 5-12, facilities with dementia units tend to generate slightly more income on average. This trend is similar for average operating expenses, which are shown in Figure 5-13. In our sample of 17 facilities, average operating expenses were marginally higher for facilities with dementia units compared to facilities without.

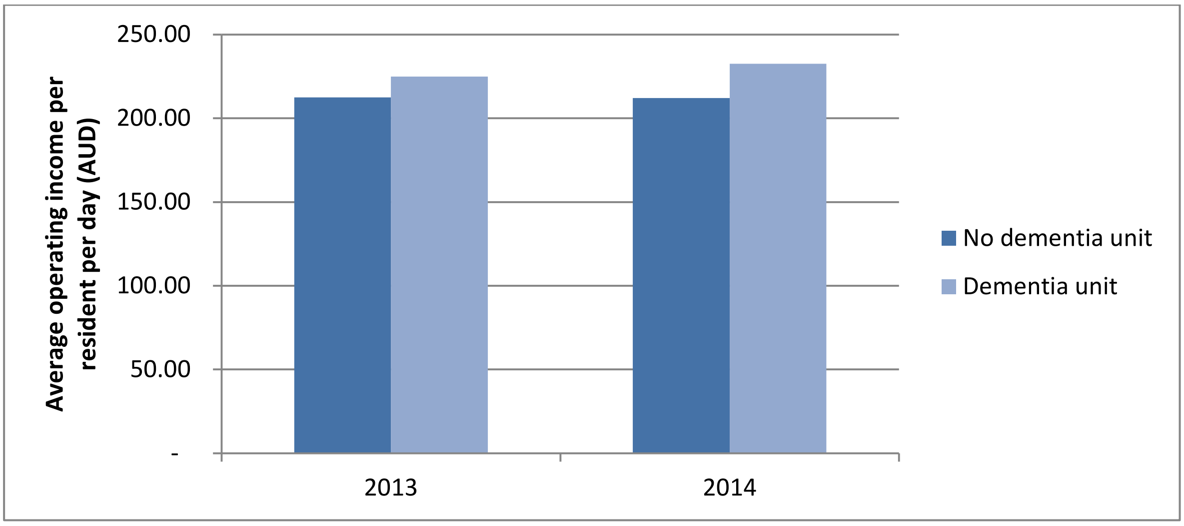


Figure 5-12 Average operating income for facilities with and without dementia units

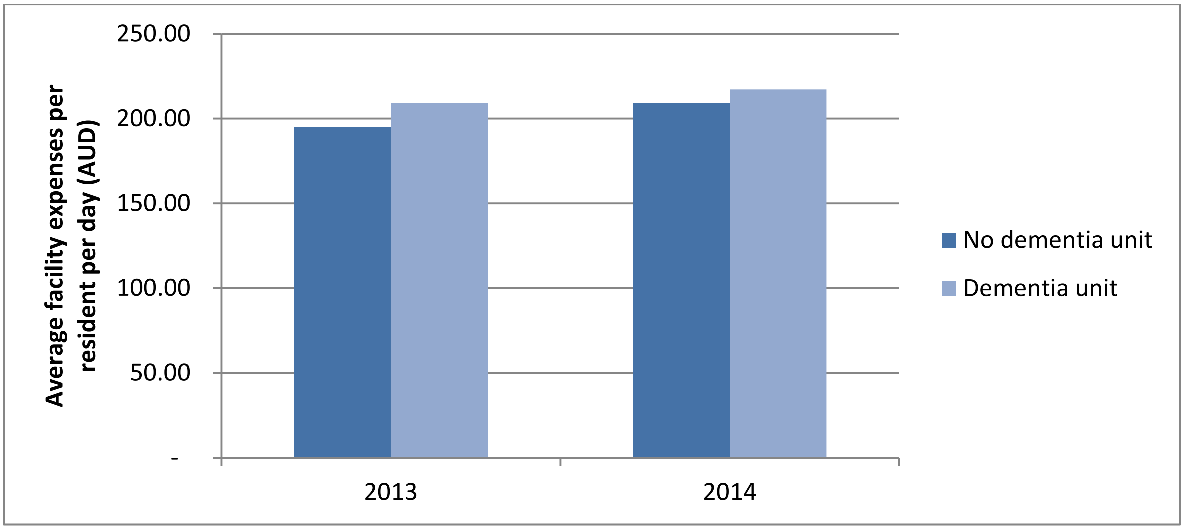


Figure 5-13 Average facility expenses for facilities with and without dementia units

5.2.3 Statistical analyses and identification of cost drivers

Overview of facility costs

Facility costs were broken down into seven expense categories, as outlined in Table 5-5. The sum of these expenses (total facility cost) can be interpreted as the unadjusted cost per resident per day from the perspective of the aged care facility.

Table 5-5 Expense categories for facility running costs

Expense categories
Care
Cleaning
Laundry
Catering
Property and maintenance
Administration
Wage on-costs
Total facility cost

Out of these seven expense categories, care costs make up the biggest proportion of total costs (61 per cent), followed by administration (14 per cent), catering (8 per cent), property and maintenance (7 per cent) and wage on-costs (5 per cent). The smallest expense categories on average are laundry (1 per cent) and cleaning (3 per cent). Figure 5-14 illustrates the average distribution of costs amongst the seven expense categories for the 17 participating facilities.

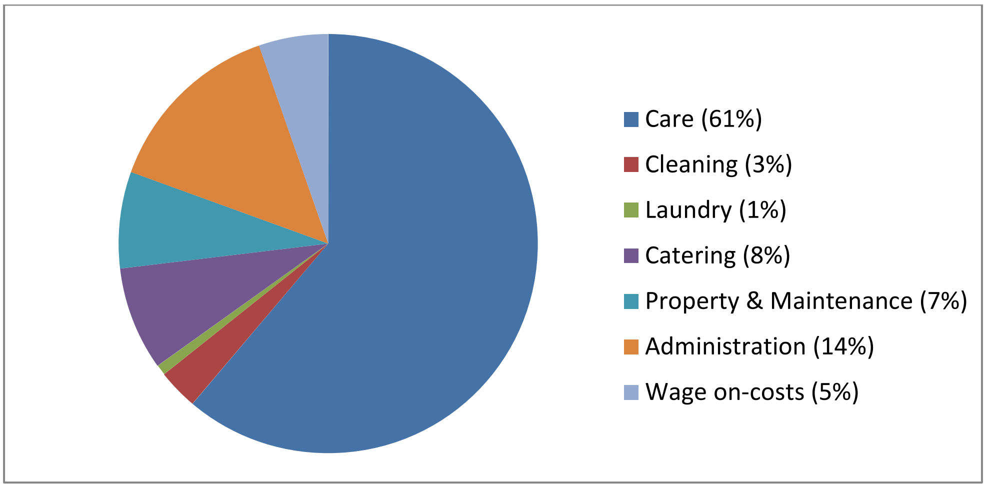


Figure 5-14 Average cost for each expense category as a proportion of total costs

The analyses presented in this section examine the potential cost drivers associated with the running costs of a residential aged care facility and explore potential associations between caring for residents with dementia and a facility's resource use.

Correlation analysis

Preliminary analyses results indicated the variables of interest were non-parametric. Accordingly, non-parametric correlations were calculated between each potential cost driver and each cost category using the Spearman's Rank Order Correlation (rho). Results are shown in Table 5-6.

The correlation analysis revealed several relationships of interest.

1. There was a moderate positive correlation between resident turnover and care costs, $\rho=0.468$, $n=28$, $p<0.05$, with higher resident turnover associated with higher costs of care. (Figure 5-15)

2. There was a strong positive correlation between government care subsidies received and care costs, $\rho=0.524$, $n=34$, $p<0.01$, with higher government subsidies associated with higher costs of care. (Figure 5-16)

3. There was a strong positive correlation between government care subsidies received and total facility costs, $\rho=0.673$, $n=34$, $p<0.01$, with higher government subsidies associated with higher total facility costs. (Figure 5-17)

4. There was a strong positive correlation between Registered Nurse Level 1 wage rates and care costs, $\rho=0.546$, $n=17$, $p<0.05$, with higher RN wage rates associated with higher costs of care. (Figure 5-18)
5. There was also a strong positive correlation between Registered Nurse Level 1 wage rates and administration costs, $\rho=0.618$, $n=17$, $p<0.01$, with higher RN wage rates associated with higher administration costs. (Figure 5-19)
6. There was a moderate positive correlation between Registered Nurse Level 1 wage rates and total facility costs, $\rho=0.399$, $n=17$, $p=0.113$, but this was not found to be statistically significant. (Figure 5-20)

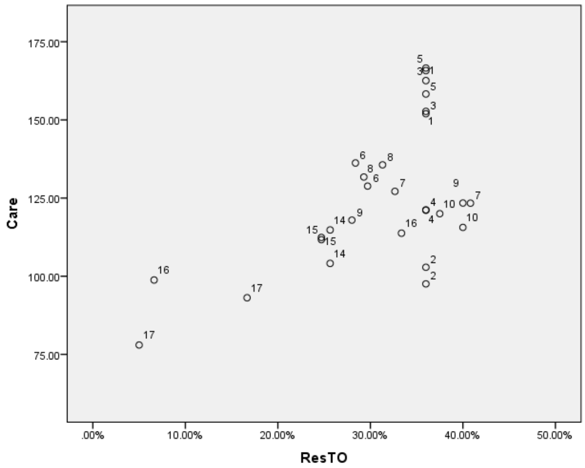
A deeper consideration of the materiality of the relationships noted above is discussed in Chapter 8 (Section 8.6.2). With care and administration costs making up the majority of total facility costs, the discussion of cost drivers focuses predominantly on these categories. The correlation analysis found a number of other statistically significant relationships, but the clinical significance of these findings is less clear. The correlation analysis did not control for organisation-level factors, which may have impacted some of the smaller cost categories. For instance, moderate to strong negative correlations were found between the proportion of secure dementia beds and the costs for laundry, catering, property and maintenance, and wage on-costs. The clinical significance of this is unclear; one of the participating organisations ran predominantly dementia-specific facilities and their model of care had personal care attendants undertaking the majority of cooking and laundry tasks. As a result, these facilities tended to have lower expenses in cost categories such as catering and laundry. Thus these correlations may have more to do with the individual organisation than with the proportion of secure dementia beds.

Table 5-6 Spearman Rank Order Correlations of potential cost drivers with expense categories

Costs **Drivers**	Care	Cleaning	Laundry	Catering	Property and maintenance	Administration	Wage on-costs	**Total facility cost**
ASGC Remoteness Area	-0.072	-0.496**	-0.239	0.288	-0.123	-0.159	0.217	-0.245
Total number of physical beds	0.036	0.093	0.184	0.266	-0.329	-0.034	0.224	0.102
Number of secure dementia beds	0.315	-0.322	-0.516**	-0.670**	-0.496**	0.579**	-0.593**	0.187
Number of extra services beds	0.115	-0.102	-0.071	0.159	-0.401*	0.061	0.184	0.235
Average annual resident turnover	0.468*	-0.612**	-0.536**	-0.135	-0.273	0.554**	-0.472*	0.235
Resident case-mix (Gov. subsidies used as proxy)	0.524**	0.508**	0.047	-0.142	-0.111	0.332	0.029	0.673**
Agency rate	0.090	0.138	0.441*	0.349	0.154	-0.210	0.063	0.062
Proportion of staff on casual contracts	-0.322	0.319	0.435*	0.653**	0.414	-0.664**	0.630**	-0.188
Annual staff turnover	-0.086	-0.071	0.173	-0.413*	-0.014	-0.425*	0.355*	-0.206
Average number of volunteers	-0.017	-0.390	0.000	0.120	-0.218	0.096	-0.105	-0.150
Proportion of multi-bed rooms	0.383	0.082	0.158	0.041	-0.355	0.152	0.309	0.412
Average room size	-0.405	0.128	0.256	0.256	0.420	-0.469	0.391	-0.231
Number of floors in facility	-0.199	0.188	0.454	0.520*	-0.061	-0.354	0.565*	-0.066
Age of facility	0.422	0.118	0.243	-0.268	0.223	0.222	-0.227	0.253
RN Level 1 wage rate (as proxy for cost of living)	0.546*	0.139	0.032	-0.592*	0.048	0.618**	-0.696**	0.399

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).



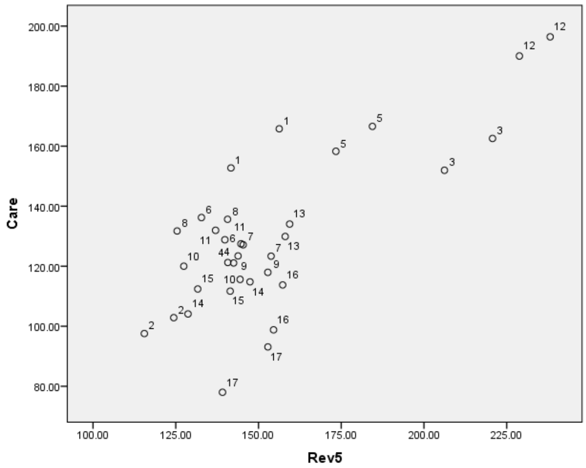
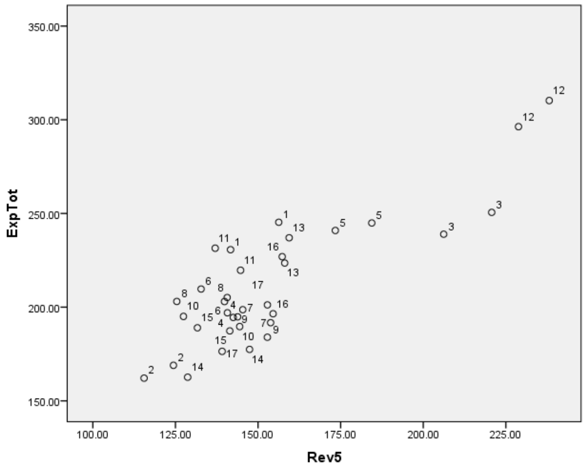


Figure 5-15 Relationship between resident turnover and care costs

Figure 5-16 Relationship between government care subsidies and care costs



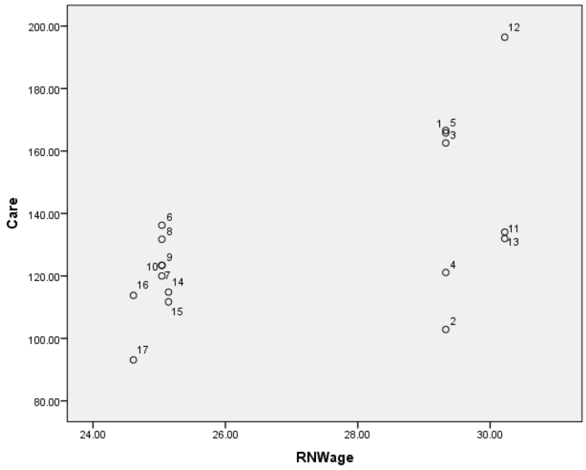


Figure 5-17 Relationship between government care subsidies and total facility costs

Figure 5-18 Relationship between RN Level 1 wages and care costs

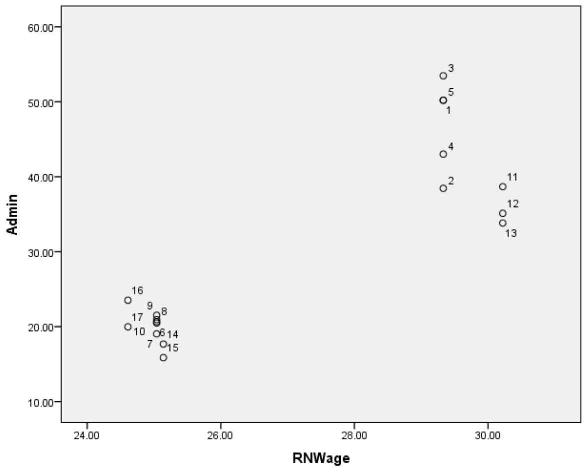


Figure 5-19 Relationship between RN Level 1 wages and administration costs

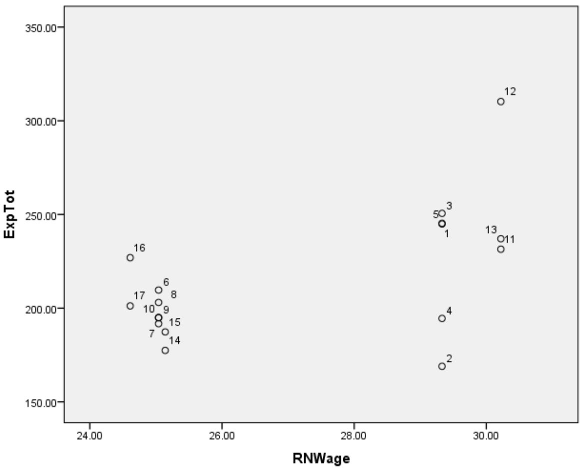


Figure 5-20 Relationship between RN Level 1 wages and total facility costs

5.2.4 Resident case mix

There are three main categories of the ACFI – activities of daily living (ADL), behaviour (BEH), and complex health care (CHC). Results of the correlation analysis between ACFI categories and cost categories are shown in Table 5-7. There was a strong positive correlation between average ADL subsidies and care costs, ρ=0.569, n=17, p<0.05, and also between average ADL subsidy and total facility costs, ρ=0.559, n=17, p<0.05. This is to be expected, as logically higher needs in the Activities of Daily Living category, which includes areas such as mobility and toileting, would be associated with higher costs of care.

Table 5-7 Spearman Rank Order Correlations of ACFI categories with expense categories

Costs Drivers	Care	Cleaning	Laundry	Catering	Property and maintenance	Administration	Wage on-costs	Total facility cost
Average ADL subsidy per resident (2014)	0.569*	0.444	0.142	-0.267	-0.279	0.311	-0.142	0.559*
Average BEH subsidy per resident (2014)	0.368	0.120	-0.382	-0.640**	-0.324	0.799**	-0.402	0.520*
Average CHC subsidy per resident (2014)	0.331	0.081	0.159	0.132	0.186	-0.159	-0.047	0.051

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Average BEH subsidies showed a strong negative correlation to catering, ρ=-0.640, n=17, p<0.01, a strong positive correlation with administration costs, ρ=0.799, n=17, p<0.01, and a strong positive correlation with total facility costs, ρ=0.520, n=17, p<0.05. Higher behaviour subsidies are associated with higher facility costs, higher administration costs, and lower catering costs. Scatterplots of these relationships are shown in Figure 5-21.

Average CHC subsidies did not show any significant correlations with costs.

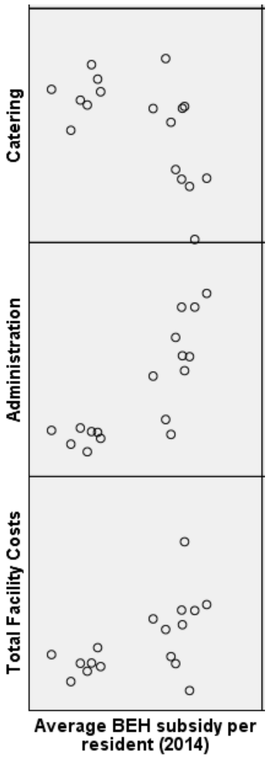


Figure 5-21 Scatterplots of BEH subsidy with catering costs, administration costs, and total facility costs

We also hypothesized that there may be a relationship between the ACFI subsidy categories and the number of care staff rostered at each facility. To examine this relationship, Spearman Rank Order Correlations were calculated between the ADL, BEH, and CHC subsidies received and the number of FTE direct care staff at each facility. Correlation results are shown in Table 5-8.

Table 5-8 Spearman Rank Order Correlations between ADL, BEH, and CHC subsidy categories and number of care staff

	Direct care staff FTEs [1]	Carer FTEs [2]	Allied Health Professional FTEs
Total ADL subsidy (2014)	0.922**	0.752**	0.525*
Total BEH subsidy (2014)	0.853**	0.914**	0.398
Total CHC subsidy (2014)	0.767**	0.471	0.480

1 Includes nurses and care workers, but excludes allied health)

2 Includes personal care attendants and specialised dementia carers, excludes nurses and allied health)

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Figure 5-22 displays scatterplots of the care staff FTEs with the ACFI subsidy categories. All three subsidy categories showed strong positive correlations with direct care staff FTEs. The ADL and BEH subsidy categories also showed very strong positive correlations with care worker FTEs.

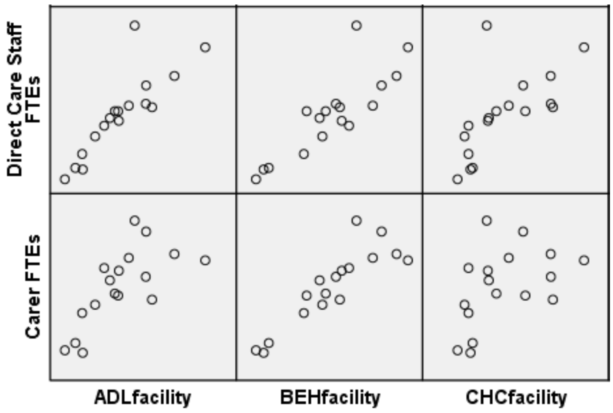


Figure 5-22 Scatterplots of care staff FTEs with ACFI subsidy categories

5.3 Summary of findings

This facility-level analysis provides an overview of the variation in funding and costs across 5 aged care organisations and 17 participating facilities and confirmed that organisations choose to allocate funds received differently. Significant variation was noted in the amount of direct care hours provided, the proportion of care provided by registered nurses, and the amount of money spent on training and development.

In our sample of 17 aged care facilities, labour costs were the greatest expense, accounting for an average of 72 per cent of total expenses, ranging from a low of 64 per cent to a high of 77 per cent. Out of the seven expense categories defined (care, cleaning, laundry, catering, property and maintenance, administration, and wage on-costs), care was the predominant expense accounting for an average of 61 per cent of total facility costs.

In terms of profitability measures, internal rates of return on accommodation were generally low. Ten facilities had negative IRRs in 2014, suggesting the majority of facilities did not generate sufficient revenues from accommodation to offset the initial capital outlay required to construct the facility. Earnings before interest, taxes, depreciation and amortisation – a measure of a facility's ability to generate income from its operations – ranged from a loss of $18.71 to a profit of $42.73 per bed per day. The average EBITDA across all facilities for both financial years was a profit of $14.46 per bed day, or roughly $5,000 per bed per annum.

Not surprisingly higher ACFI levels were associated with higher government subsidies and facility costs. For example, higher behavioural subsidies were associated with higher overall costs. There was no significant association between rural and remote location and costs. When dementia was focused on there was evidence that caring for those with dementia incurred higher costs but providing dementia specific units was no more or less expensive than providing care in mixed units. While higher behaviour subsidies were associated with higher facility costs and higher administration costs, no significant differences were noted in the costs of care provided in dementia specific units when compared with care provided in mixed accommodation.

Importantly, this analysis does not tell us the effectiveness of alternative allocations, such as implementing additional care hours or providing a dementia specific unit for example. These data therefore need to be considered in connection to outcome measures such as quality of life, use of medication, use of hospitals, and consumer preferences. The final two results chapters will link individual-level data from residents to a subset of the participating facilities. The addition of resident-level data will provide the opportunity to apply more complex statistical models to investigate the factors associated with costs and quality of life.

CHAPTER 6: HEALTH SYSTEM COSTS

The costs involved in caring for residents of aged care facilities are not limited to those incurred at the facility itself. This chapter aims to develop a deeper understanding of the broader health care costs associated with the provision of residential aged care services such as hospital admissions, general practitioner consultations, or prescription medications for example. Using a sample of residents from residential aged care facilities in South Australia, health system costs were compared in facilities located across regional areas relative to those located in metropolitan areas, and the relationship between government costs and potential cost drivers are examined. Characteristics of the South Australian subsample used for this study are presented at a facility and individual level. The mean annual government expenditure is presented for aged care subsidies, Medicare and pharmaceutical (PBS) claims, and hospitalisations.

6.1 Methods

According to the conceptual framework by Ehreth (1992), the system-level analyses explore the effects of program outputs on other costs in the healthcare system. Individuals residing in residential aged care facilities, for instance, may incur costs outside of the aged care facility from services such as hospital admissions, consultations with general practitioners or specialists, and prescription medications.

In order to explore costs incurred in the broader healthcare system, system-level costs were collected for a subset of individuals residing in residential aged care facilities across regional and metropolitan areas of South Australia. This South Australian subsample of the INSPIRED study consisted of a sample of five residential aged care facilities belonging to a single aged care organisation. System-level costs collected for this subsample included ACFI subsidies, MBS claims, PBS claims, and hospitalisation costs. Hospitalisation costs consisted of costs for emergency department visits as well as hospital admissions. The analyses outlined in this section were designed to address Objectives 4 and 5 of this thesis: exploring the relevant costs of residential aged care at a system-level and determining the main factors which contribute to system-level costs. These factors were selected to represent the full spectrum of data that was collected, including facility-level variables (locality, size) as well as individual-level variables (resident demographics, dementia diagnosis, cognitive impairment, physical functioning, and neuropsychiatric symptoms). Measures of dementia severity, including the DSS and FAST scales were not included in the models, as they were applicable to only a subset of the population (for instance, the FAST scale is used to stage Alzheimer's disease). All econometric analyses were conducted in Stata/SE version 13 (StataCorp, 2013).

6.1.1 Outcome variable: Government cost

Calculation of ACFI subsidies

A daily ACFI subsidy amount was calculated for each participating resident based on their assigned needs rating in each of the three categories. The daily subsidy paid for a resident comprises the sum of the amounts payable for each of the three care categories: activities of daily living (ADL), behaviour (BEH), and complex health care (CHC).

$$Daily\ ACFI\ subsidy = ADL + BEH + CHC$$

The basic subsidy rates applicable from 1 July 2014 to 30 June 2015 are shown in Table 6-1 (Department of Social Services). The daily subsidy for each participant was then converted to an annual figure by multiplying the daily subsidy by 365 days.

Table 6-1 Daily ACFI subsidy rates applicable from 1 July 2014 to 30 June 2015

Level	Activities of daily living (ADL)	Behaviour (BEH)	Complex health care (CHC)
Nil	$0.00	$0.00	$0.00
Low	$35.65	$8.14	$16.04
Medium	$77.61	$16.88	$45.68
High	$107.52	$35.20	$65.96

Calculation of MBS and PBS claims costs

For each participant a total MBS cost was calculated by summing all Medicare items’ schedule fees for that participant. Similarly, the total PBS cost was the total of the item costs (patient contribution + net benefit) for each prescription. The time period of the Medicare and PBS cost data was the retrospective 12-month period from the start date of data collection at each facility.

Calculation of hospitalisation costs

Hospitalisation costs for each participant were calculated from inpatient and emergency department separations data. Each hospital visit was categorised according to the Australian Refined Diagnostic Related Group (AR-DRG). The average cost pertaining to the AR-DRG was then applied to each inpatient admission. Average cost per AR-DRG for public hospital inpatient admissions were sourced from the National Hospital Cost Data Collection cost weights for AR-DRG version 7.0, round 18 (2013-14) (Independent Hospital Pricing Authority (IHPA), 2016). Average cost per AR-DRG for private hospital inpatient admissions were sourced from the Hospital Casemix Protocol: Annual Report 2014-15 for national averages for DRG version 8.0 (Department of Health, 2016b). Emergency department separations which did not lead to an inpatient admission were applied a standard cost of $584.44, based on the national average cost per presentation (Independent Hospital Pricing Authority (IHPA), 2016). Emergency department separations which did lead to an inpatient admission were not applied a separate cost, as this cost is included in the average AR-DRG cost applied to the inpatient admission. Costs were then summed for each participant. No hospitalisation data was assumed to mean the participant did not visit hospital. The time period of the hospitalisation cost data was the retrospective 12-month period from the start date of data collection at each facility.

Total cost to government

A government cost variable was calculated to represent the system-level costs incurred by the health system.

$$Government\ costs = Annualised\ ACFI\ subsidy + MBS\ cost + PBS\ cost + Hospitalisation\ cost$$

6.1.2 Missing data

Univariate analysis was conducted to examine factors that may affect the inclusion of each of the variables in a regression model. Distribution, skew, and missing data were inspected. The variables used in analysis along with their level of completeness are set out in Table 6-2.

Table 6-2 Variables used in macro-level cost analysis with level of completeness

Variable	Description	Missing n (%)	Total n
Locality	Dummy variable (1 = Regional, 0 = Metropolitan)	0 (0.0)	180
Age	Age in years, continuous variable	0 (0.0)	180
Sex	Dummy variable (1 = Female, 0 = Male)	0 (0.0)	180
Dementia Diagnosis	Dummy variable (1 = Yes, 0 = No/Unknown	1 (0.6)	180
PAS-Cog score	Measure of cognitive impairment, continuous variable	4 (2.2)	180
MBI score	Measure of physical function, continuous variable	1 (0.6)	180
NPI-Q score	Measure of neuropsychiatric symptoms, continuous variable	1 (0.6)	180
Number of beds	Number of beds as a measure of facility size	0 (0.0)	180
ACFI subsidy	Aged care subsidy in dollars based on ACAT assessment, continuous variable	1 (0.6)	180
MBS cost	Cost to the Medicare Benefits Scheme, continuous variable	29 (16.1)	180
PBS cost	Cost to the Pharmaceutical Benefits Scheme, continuous variable	53 (29.4)	180
Hospitalisation cost	Cost of hospital admissions, continuous variable	113 (62.8)	180

MBI: Modified Barthel Index; ACFI: Aged Care Funding Instrument; NPI-Q: Neuropsychiatric Inventory (short).

For variables with less than 5 per cent missing data, missing values were replaced with the mean value of the complete data for that variable. This mean replacement method was used for dementia diagnosis, PAS-Cog score, MBI score, NPI-Q score, and ACFI subsidy. A multiple imputation technique was used for variables with more than 5 per cent missing data. Multiple imputation is a simulation-based statistical technique for dealing with missing data which involves using other variables of interest to impute or predict missing values (Schafer, 1997). To account for the uncertainty around imputed values, this process was repeated for 50 imputations, creating 50 plausible values for each missing value. The resulting 50 complete data sets were then pooled and an average of the 50 imputed values was taken for each missing value. Multiple imputation was used to estimate missing values for MBS and PBS costs.

Missing hospitalisation data were assumed to signify that the participant had not been admitted to hospital during the study period. As such, a value of zero was applied to all missing hospitalisation costs.

6.1.3 Descriptive statistics

The first phase of the descriptive analysis presented information on the five facilities included in the study. Mean facility characteristics were presented for the regional and metropolitan subgroups and included number of beds, proportion of beds which were secure dementia beds, facility age, occupancy rate, resident turnover, staff turnover, nursing hours per resident per day, carer hours per resident per day, and operating expenses. Standard deviations and p-value calculations were not undertaken due to the small sample size of five facilities.

For individual-level participants, summary statistics were generated for the total sample as well as stratified by locality. Variables included (1) participant characteristics including age, sex, education level, marital status, and the existence of a dementia diagnosis; (2) clinical outcome measures for cognitive function (PAS-Cog), physical function (MBI), and neuropsychiatric symptoms (NPI-Q); and (3) individual cost measures including daily ACFI subsidy, annualised ACFI subsidy, Medicare costs, PBS costs, and hospitalisation costs. Summary statistics included sample size, mean, standard deviation, and range. The distributions of each variable were assessed for normality using the Kolmogorov-Smirnov test with Lilliefors significance correction and the Shapiro-Wilks test. To generate p-values the chi-square test for independence (with Yates' correction for continuity for 2 by 2 tables) was used for categorical variables and the independent samples Mann-Whitney U test was used for continuous variables. A resulting significance level below 0.05 indicated a statistically significant difference. A cost distribution was plotted for the annual cost to government per resident, which included ACFI subsidies, Medicare, PBS, and hospitalisations.

6.1.4 Factors associated with government costs

In order to explore the factors associated with government costs, a generalized linear model (GLM) with an identity link function and Poisson variance was used. GLM is a multivariable technique that models both the mean and variance functions and requires the selection of a link function and family based on the observed data (Glick, Doshi, Sonnad, & Polsky, 2015). The modified Parks test was used to select an appropriate family for the model (Manning & Mullahy, 2001).

Using the identity function and Poisson distribution, we have the following regression equation:

$$E(y) = x\beta, \qquad y \sim Poisson$$

Age, sex, locality, facility size, diagnosis of dementia, cognitive impairment (PASCog), physical function (MBI) and neuropsychiatric symptoms (NPI-Q) were included in the model as covariates (x) with Government Costs as the dependent variable (y). The standard error was adjusted for clustering at the facility level. The recorded outputs for each variable in the model included the coefficient, the robust standard error, and the p-value. Statistical significance was assumed for p-values below the 0.05 level. The constant, which is the value of the dependent variable when all independent variables are set to zero, was deemed to be of no intrinsic value and thus ignored as it would not be logical for variables such as age or facility size to be set to zero.

6.2 Results

The South Australian subsample of the INSPIRED study consisted of a sample of five aged care facilities belonging to a single aged care organisation. A total of 404 residents lived across the five facilities, of which 285 (71 per cent) met all eligibility criteria. Of those eligible residents, 97 were eligible to self-consent and 188 required a family member to consent on their behalf. In total, 180 residents participated in the study: 74 residents provided self-consent and 106 residents were consented via a proxy. Figure 6-1 provides an overview of the recruitment process.

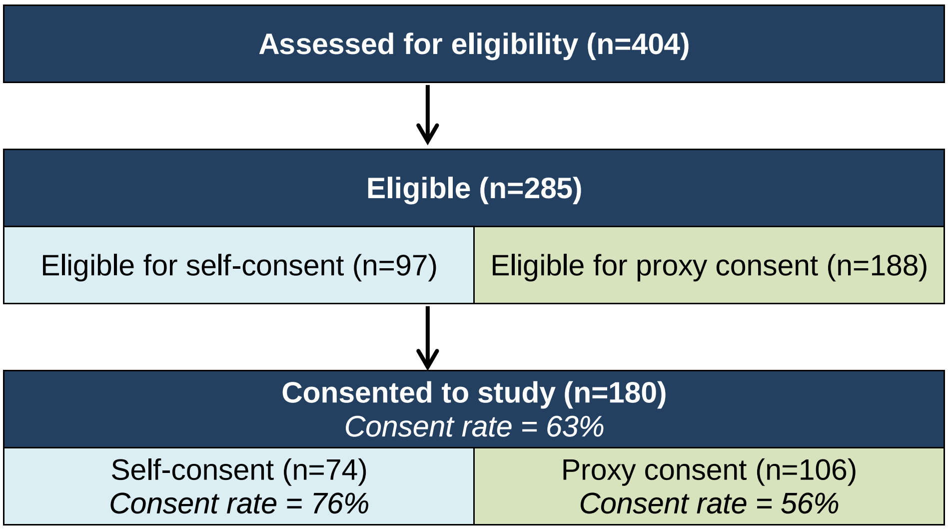


Figure 6-1 Flow diagram of the recruitment process for the SA subsample of the INSPIRED study

Of the five aged care facilities in the subsample, two were located in a metropolitan area and three were located in regional areas. Table 6-3 provides an overview of residential aged care facility characteristics by locality. All values displayed are means. Standard deviations and p-value calculations were not undertaken due to the small sample size. On average facilities located in the city were larger, more recently built, had a higher proportion of secure dementia beds, higher occupancy, and lower resident and staff turnover.

Table 6-3 Residential Aged Care Facility characteristics by locality (Mean)

Characteristic	Metropolitan (n=2)	Regional (n=3)
Number of beds	129	63
Proportion of beds that are secure dementia	23%	15%
Facility age (years)	7	11
Occupancy	98.4%	95.2%
Resident turnover	32.9%	34.3%
Staff turnover	25.8%	29.0%
Nursing hours per resident per day	0.81	0.79
Carer hours per resident per day	2.02	1.98

On average, facility running expenses were lower in regional facilities. Independent samples Mann-Whitney U test did not show significance between total costs in regional and metropolitan facilities (p=0.476), though this may be a result of the small sample size (n=5). At the cost category level, no real differences were evident apart from laundry costs which were lower in regional facilities (p=0.010). This difference was insignificant overall as laundry costs were only a very small component of total expenses (roughly 1 per cent). Figure 6-2 and Table 6-4 present the mean facility expenditure per resident per day by locality and financial year in both graphical and tabular form. As discussed in Chapter 3: Overview to the INSPIRED study, the facility cost survey collected data at a facility, rather than individual level, and thus the results presented are based on the aggregate running costs for the entire facility for a full year, divided by the number of residents in that facility and reduced to an average cost per day.

Table 6-4 Mean costs (AUD) by cost category for regional and metropolitan facilities

	2013		**2014**	
Cost category	**Metropolitan**	**Regional**	**Metropolitan**	**Regional**
Care	127.98	123.07	129.79	125.05
Laundry	2.11	1.37	2.06	1.52
Catering	20.51	20.16	22.37	22.47
Property & Maintenance	12.57	12.50	13.57	14.89
Administration	20.74	19.39	19.76	21.04
Oncosts	13.56	13.95	9.76	10.17
Total Expenses	**200.84**	**192.92**	**200.70**	**197.65**

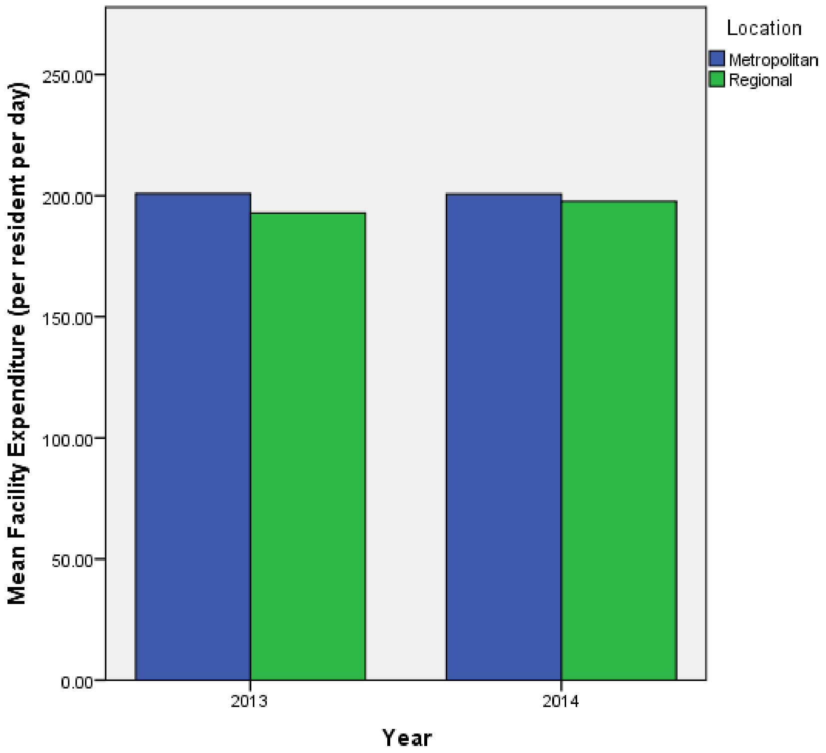


Figure 6-2 Mean facility expenditure per resident per day by financial year and locality

Key demographic characteristics of participants for the total SA subsample and by locality are presented in Table 6-5. The mean age of participants was 86.3 years. The sample consisted of 76 per cent female participants, and 47 per cent of participants had a diagnosis of dementia. Residents in regional (n=82) and metropolitan (n=98) facilities were not significantly different in age, gender, level of cognitive impairment or physical function. However, residents in regional facilities had less education on average, and fewer behavioural and psychological symptoms of dementia compared with those living in metropolitan facilities.

Table 6-5 Key demographic characteristics of participants for total sample and by locality

Characteristic	Metropolitan (n=98)	Regional (n=82)	Total (n=180)	p-value
Age				
Mean (SD)	87.1 (6.5)	85.3 (9.5)	86.3 (8.0)	0.255
Range	66-98	48-104	48-104	
Age category				
< 80 years, n (%)	15 (15%)	17 (21%)	32 (18%)	0.452
≥ 80 years, n (%)	83 (85%)	65 (79%)	148 (82%)	
Sex				
Male, n (%)	23 (23%)	20 (24%)	43 (24%)	1.000
Female, n (%)	75 (77%)	62 (76%)	62 (76%)	
Education level				
Did not complete high school, n (%)	26 (27%)	33 (40%)	59 (33%)	0.002
Completed high school, n (%)	46 (47%)	17 (21%)	63 (35%)	
Post-secondary, n (%)	15 (15%)	16 (20%)	31 (17%)	
Unknown, n (%)	10 (10%)	16 (20%)	26 (14%)	
Marital status				
Married, n (%)	16 (16%)	20 (24%)	36 (20%)	0.091
Widowed, n (%)	69 (70%)	50 (61%)	119 (66%)	
Other, n (%)	12 (12%)	12 (15%)	24 (13%)	
Dementia diagnosis				
Yes, n (%)	46 (47%)	39 (48%)	85 (47%)	1.000
No, n (%)	48 (49%)	41 (50%)	89 (49%)	
Unknown, n (%)	3 (3%)	2 (2%)	5 (3%)	
Cognitive Impairment				
No or minimal (PAS-Cog 0-3), n (%)	25 (26%)	14 (17%)	39 (22%)	0.165
Mild (PAS-Cog 4-9), n (%)	25 (26%)	20 (24%)	45 (25%)	
Moderate (PAS-Cog 10-15), n (%)	16 (16%)	15 (18%)	31 (17%)	
Severe (PAS-Cog 16-21), n (%)	31 (32%)	32 (39%)	63 (35%)	
Health and physical functioning				
MBI score (max 100), mean (SD)	46.4 (32.1)	55.3 (33.2)	50.5 (32.8)	0.092
NPI-Q score (max 30), mean (SD)	8.3 (6.1)	6.3 (4.6)	7.4 (5.5)	0.031

MBI: Modified Barthel Index (0: total dependence; 100: independence);

NPI-Q: Neuropsychiatric Inventory (short) (0: no behavioural disturbances; 30: severe behavioural disturbances).

To generate p-values the chi-square test for independence (with Yates' correction for continuity for 2 by 2 tables) was used for categorical variables and the independent samples Mann-Whitney U test was used for continuous variables.

6.2.1 System-level costs

System-level costs collected for this subsample included ACFI subsidies, MBS costs, PBS costs, and hospitalisation costs. Hospitalisation costs consisted of costs for emergency department visits as well as hospital admissions. All of these categories represented costs to the Australian government. An overview of mean government costs for participants, stratified by locality, is presented in Table 6-6. On average, residents living in metropolitan facilities received higher ACFI subsidies, had lower PBS costs, and had higher MBS and hospitalisation costs compared with residents living in regional facilities. However, these differences were not statistically significant.

Annual costs to government ranged from $19,112 up to $174,280 (see Figure 6-3). Standard deviation provides a measure of the level of variation from the mean. A large standard deviation indicates that data points are far from the mean, while a small standard deviation indicates that data points are clustered around the mean. In absolute terms, ACFI subsidies had the highest standard deviation (SD=13,895), followed by hospitalisation costs (SD=12,948), PBS costs (SD=4,646), and MBS costs (SD=1,384). Relative to the size of the mean, hospitalisation costs were found to have the highest level of variation, with a standard deviation equal to 2.7 times the mean hospitalisation cost compared to 1.9 times for PBS costs, 0.8 times for MBS costs, and 0.3 times for ACFI subsidies.

Table 6-6 Mean (SD) government costs (AUD) for regional and metropolitan facilities

Government Costs	Total (n=180)	Metropolitan (n=98)	Regional (n=82)	p-value*
Daily ACFI subsidy (max 184)	139.03 (38.07)	142.54 (38.79)	134.88 (37.00)	0.122
Annualised ACFI subsidy	50,747 (13,895)	52,027 (14,160)	49,232 (13,506)	0.122
MBS costs	1,639 (1,384)	1,877 (1,588)	1,316 (965)	0.061
PBS costs	2,492 (4,646)	2,107 (1,627)	2,950 (6,646)	0.552
Hospitalisation costs	4,716 (12,948)	4,792 (13,595)	4,625 (12,212)	0.412

ACFI: Aged Care Funding Instrument; MBS: Medicare Benefits Scheme; PBS: Pharmaceutical Benefits Scheme
** P values generated using Independent-Samples Mann-Whitney U test.*

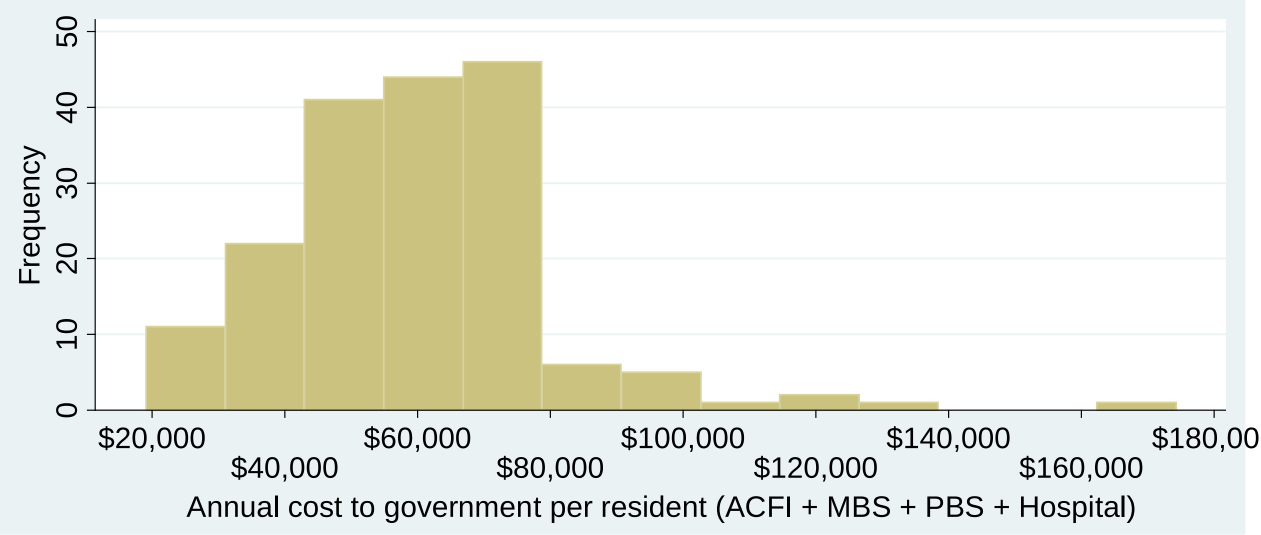


Figure 6-3 Average cost to government per resident, including ACFI subsidies, MBS, PBS, and hospitalisations

6.2.2 Factors associated with government costs

A generalized linear model was developed to examine the factors that predict government expenditure. Age, sex, locality, facility size, diagnosis of dementia, cognitive impairment (PAS-Cog), physical function (MBI) and neuropsychiatric symptoms (NPI-Q) were tested. Regression results are presented in Table 6-7. Lower government costs were found to be associated with better physical function (p<0.001), and females (p=0.039). The presence of more behavioural symptoms (as measured by the NPI-Q) was associated with higher costs, though not at a statistically significant level (p=0.053). Age, diagnosis of dementia, level of cognitive impairment, facility location, and facility size, were not significantly associated with government costs.

Table 6-7 Factors associated with government expenditure on health and aged care: results of a generalized linear model.

Variable	**Coefficient**	**Robust Standard Error** $^{\#}$	**p-value**
Locality	-3386.1	4448.879	0.447
Age	-139.027	139.9388	0.320
Sex	-5050.94	2440.886	0.039*
Dementia Diagnosis	-3104.98	1967.462	0.115
PAS-Cog	186.3417	286.7686	0.516
MBI	-304.52	21.49473	0.000*
NPI-Q	443.5755	229.0057	0.053
Number of beds	-74.8974	52.59039	0.154
Constant	96465.16	18801.6	0.000
Number of observations	180		
Residual degrees of freedom	176		

** Statistically significant value*
 # Standard Error adjusted for 5 clusters in FacilityID

6.3 Summary of findings

Using a sample of residential care facilities located across regional and metropolitan areas of South Australia, this chapter analysed the health system costs that individuals residing in residential aged care facilities may incur outside of the residential aged care facility itself. From the perspective of the government, the mean annual expenditure was presented for aged care subsidies, Medicare claims, pharmaceutical (PBS) claims, and hospital visits. On average, the government spends $60,000 per year for older people living in residential aged care facilities. Hospitalisation costs were found to be the biggest contributor to variability in government spending. No significant cost differences were found between metropolitan and regional facilities. When the relationship between government costs and potential cost drivers was examined, physical function was found to be significantly associated with costs, with increased physical impairments linked to higher government expenditure. Female residents were associated with lower government costs than male residents. Increased behavioural symptoms may be associated with higher government costs as well; however a larger sample is needed to confirm this relationship.

The next chapter presents the results of the final analysis undertaken in this thesis, linking individual characteristics, government costs, and resident quality of life in a regression model to investigate factors which may influence resident quality of life.

CHAPTER 7: SYNTHESIS OF COSTS AND OUTCOMES

The final study presented below brings together facility-level costs, costs to the health system, and individual resident outcomes, specifically health-related quality of life. The analyses undertaken aimed to address first of all whether quality of life differed in regional and metropolitan facilities, and secondly, which factors contributed to better overall quality of life.

In terms of geographical distribution, approximately 60 per cent of residential aged care facilities are located in major cities, while roughly 40 per cent are located in regional, rural and remote areas of Australia (Alston et al., 2017; Bagheri et al., 2017; Youl et al., 2016). Notwithstanding the poorer health of Aboriginal and Torres Strait Island people, who comprise a greater proportion of the population in remote areas, rural and remote Australians overall have shorter life expectancy and higher rates of disability and some chronic conditions than those residing in metropolitan areas (Dixon & Welch, 2000; National Rural Health Alliance, 2011).

While little is known about differing outcomes between localities in Australian residential aged care facilities, a number of recent studies pertaining to geographical inequalities in health care more broadly have reported a higher burden of ill health outside of major cities (Alston, Allender, Peterson, Jacobs, & Nichols, 2017; Bagheri, Furuya-Kanamori, Doi, Clements, & Sedrakyan, 2017; Youl et al., 2016).

The Rural Doctors Association of Australia has expressed the need for person-centred, innovative models of aged care to be developed in rural and remote communities (Rural Doctors Association of Australia, 2017). Key issues identified include improving patient health outcomes and better addressing the needs of vulnerable populations. As part of this, the Rural Doctor’s Association of Australia has requested that the Australian Government work with rural and remote doctors and their teams to firstly identify best practice models of aged care, and then tailor these models for local circumstances.

The INSPIRED study contained facilities located in areas classified as ‘inner regional’ and ‘outer regional’ but did not include facilities in rural or remote regions. However, this work is an important step towards identifying best practice models of care, and whether the outcomes for these models differ between metropolitan facilities and their regional counterparts. If outcomes are equally strong in regional facilities, then perhaps a similar model of care could be adapted for remote communities as well.

Regardless of where they reside, all Australians should have access to high quality health services and the opportunity for equivalent health and quality of life outcomes (National Rural Health Alliance, 2011).

7.1 Methods

The aim of the final analysis was to explore the factors associated with resident quality of life in an Australian residential aged care setting, and whether quality of life differs in regional and metropolitan facilities. This aim is in line with Objectives 6 and 7 of this thesis.

With the additional challenges present in more regional areas, and an increased burden of ill-health in these populations, it was hypothesized that care in metropolitan areas would be superior, possibly translating to residents reporting higher quality of life, due to newer facilities, more highly skilled staff, closer proximity to medical facilities, and a lower burden of ill health. It was also hypothesized that metropolitan facilities may have lower health care utilisation and expenditure resulting from a lower burden of ill health.

The first step of analysis explored the distributions of participant responses across the various dimensions of health-related quality of life in regional versus metropolitan facilities. The next step of analysis developed generalized linear models to explore factors relating to resident quality of life. This analysis used the same South Australian subsample of the INSPIRED study as the system-level cost analysis, consisting of a sample of five residential aged care facilities belonging to a single aged care organisation. All econometric analyses were conducted in Stata/SE version 13 (StataCorp, 2013).

7.1.1 Quality of life in regional and metropolitan facilities

To analyse quality of life scores in regional and metropolitan facilities, the Mann-Whitney U test was used to test quality of life scores for the total sample, differentiated by locality. The null hypothesis tested was that the distribution of utility values was the same across categories of locality. The distribution of responses across the dimensions of the EQ-5D-5L, EQ-5D-5L-Proxy, DEMQOL-U, and DEMQOL-Proxy-U were then compared for residents living in regional and metropolitan facilities. Chi-square tests for independence were conducted between quality of life dimensions and locality. Where the minimum expected count was less than five, response levels were grouped together and re-analysed. DEMQOL-U and DEMQOL-Proxy-U responses were changed from four levels to two. The EQ-5D-5L and EQ-5D-5L-proxy were converted from five levels to three. These changes are illustrated in Table 7-1 below.

Table 7-1 Combined response levels for chi-square tests for independence

Instrument(s)	Original response levels	Combined response levels
DEMQOL-U; DEMQOL-Proxy-U	1 = a lot; 2 = quite a bit; 3 = a little; 4 = not at all	1 = a lot, quite a bit; 2 = a little, not at all
EQ-5D-5L; EQ-5D-5L-Proxy	1= no problems; 2 = slight problems; 3 = moderate problems; 4 = severe problems; 5 = extreme problems / unable	1 = no problems, slight problems; 2 = moderate problems; 3 = Severe problems, extreme problems / unable

7.1.2 Outcome variable: Disutility scores

As in the system-level cost analysis, univariate analysis was conducted to examine factors that may affect the inclusion of each of the variables in a regression model. Distribution, skew, and missing data were inspected. Health state values, or utility scores, fall on a scale that is anchored at zero and one, with zero representing a health state equivalent to death and one representing full health. However, values less than zero, representing health states worse than death, are possible on the EQ-5D-5L and EQ-5D-5L-Proxy instruments. This possibility for negatively valued health states presented additional problems when developing models. As a workaround, disutility scores were input into the model instead. The disutility score is the amount by which full health has been reduced. In other words, it is the utility decrement. Disutility is calculated by subtracting a participant’s utility score from the maximum utility score produced by that instrument. For instance, for the EQ-5D-5L and EQ-5D-5L-Proxy which have a possible range of -0.281 to 1, a utility score of 0.8 would be equivalent to a disutility, or utility decrement, of 0.2. Similarly, a utility score of -0.281 would be equivalent to a disutility of 1.281. By using disutility scores, the outcome variable ranged from 0 to 1.281 for the EQ-5D-5L and EQ-5D-5L-Proxy with higher values representing higher disutility and lower quality of life. A positive range facilitated more options in the development of generalised linear models. For consistency, the DEMQOL-U and DEMQOL-Proxy-U scores were also converted to disutility scores.

Disutility calculations:

$$EQ\text{-}5D\text{-}5L\ disutility = 1 - utility$$

$$EQ\text{-}5D\text{-}5L\text{-}Proxy\ disutility = 1 - utility$$

$$DEMQOL\text{-}U\ disutility = 0.986 - utility$$

$$DEMQOL\text{-}Proxy\text{-}U\ disutility = 0.937 - utility$$

7.1.3 Missing data

The variables from the system-level cost analysis previously outlined (see Table 6-2) were carried through to the synthesis of costs and quality of life. In addition, four quality of life variables were included. These additional variables and their level of completeness are set out in Table 7-2. It should be noted that while the total participants in this subgroup was 180, not all participants were asked to complete all of the health-related quality of life questionnaires. Self-reporting of the EQ-5D-5L was encouraged for all participants with a PAS-Cog score less than or equal to 11. For participants who declined or were unable to complete the EQ-5D-5L and for those with a PAS-Cog score greater than 11, a proxy-assessment via a family member was sought. In accordance with the developers' guidelines, both a DEMQOL and DEMQOL-Proxy were sought for all participants with a PAS-Cog score below 18, while only the DEMQOL-Proxy was completed for residents with a PAS-Cog score greater than or equal to 18. Accordingly, the 'total n' in Table 7-2 below reflects the number of individuals eligible to complete each questionnaire rather than the total number of participants in the subgroup.

Table 7-2 Health-related quality of life variables used in analysis with level of completeness

Variable	Description	Complete n	Missing n (%)	Total n*
EQ-5D-5L	Self-rated measure of generic health-related quality of life, continuous variable	78	17 (17.9)	95
EQ-5D-5L-Proxy	Proxy-rated measure of generic health-related quality of life, continuous variable	103	2 (1.9)	105
DEMQOL-U	Self-rated measure of dementia-specific health-related quality of life, continuous variable	98	33 (25.2)	131
DEMQOL-Proxy-U	Proxy-rated measure of dementia-specific health-related quality of life, continuous variable	177	3 (1.7)	180

*reflects the number of individuals eligible to complete each questionnaire rather than the total number of participants in the South Australian subgroup

The EQ-5D-5L and EQ-5D-5L-Proxy use the same descriptive system (Figure 3-1), with proxy respondents asked to respond as they thought their relative would if their relative were able to complete it themselves. The same is true of the three-level version. As such, numerous studies have combined EQ-5D self and proxy responses into a single variable for analyses (Lung et al., 2017; Parsons, Griffin, Achten, & Costa, 2014; Said et al., 2015).

At the same time, other studies have found proxy responses to contain bias, and recommend that proxy responses be treated separately from self-rated responses (Hounsome et al., 2011; Parker, Petrou, Underwood, & Madan, 2017). In order to accommodate for this uncertainty, two different methods were used to construct the EQ-5D-5L outcome variable used in the generalized linear models. In each case all utility scores were converted to disutility scores. The first method used EQ-5D-5L self-rated responses only. For participants who did not complete their own EQ-5D-5L questionnaire (n=102), a multiple imputation was used to predict their self-rated disutility score. To account for the uncertainty around imputed values, this process was repeated for 50 imputations, creating 50 plausible values for each missing value. The resulting 50 complete data sets were then pooled and an average of the 50 imputed values was taken for each missing value. The second method used proxy responses where self-rated responses were missing or unavailable.

The DEMQOL-U and DEMQOL-Proxy-U consist of different descriptive systems (Figure 3-2). As such, it was not possible to combine self and proxy responses into a single variable. DEMQOL-U and DEMQOL-Proxy-U disutility scores were therefore treated as separate outcome variables when constructing generalized linear models. For the DEMQOL-U, a multiple imputation technique using 50 imputations was used to predict missing DEMQOL-U disutility scores. As the DEMQOL-Proxy-U had less than 5 per cent missing data, mean replacement was used to estimate the missing disutility scores.

The four outcome variables used in the GLM regressions are summarised below:

(1) EQ-5D-5L disutility: Self-rated (n=78) + Imputed Self-rated (n=102)
(2) EQ-5D-5L disutility: Self-rated (n=78) + Proxy-rated (n=102)
(3) DEMQOL-U disutility: Self-rated (n=98) + Imputed Self-rated (n=82)
(4) DEMQOL-Proxy-U disutility: Proxy-rated (n=177) with mean replacement (n=3)

7.1.4 Descriptive statistics

Summary statistics were generated to examine the distribution of disutility scores after imputations. Summary statistics included sample size, mean, standard deviation, and range. The distributions of each variable were assessed for normality using the Kolmogorov-Smirnov test with Lilliefors significance correction and the Shapiro-Wilks test. A disutility distribution was plotted for each of the four outcome variables described above.

7.1.5 Factors associated with quality of life

In order to explore the factors associated with quality of life, generalized linear models (GLM) with an identity link function were developed. The first step was to conduct the modified parks test to determine the appropriate family for each GLM regression (Manning & Mullahy, 2001). Facility characteristics input in the model as covariates included locality, facility size, and facility cost variables. Resident characteristics input in the model as covariates included age, sex, dementia diagnosis, cognitive impairment (PAS-Cog), physical function (MBI), behavioural symptoms (NPI-Q), MBS costs, PBS costs, and hospitalisation costs. Four separate regression models were developed, one for each of the quality of life outcome variables described in the missing data section (p.151). In each model, the standard error was adjusted for clustering at the facility level. The recorded outputs for each variable in the model included the coefficient, the robust standard error, and the p-value. Statistical significance was assumed for p-values below the 0.05 level. The constant, which is the value of the dependent variable when all independent variables are set to zero, was deemed to be of no intrinsic value and thus ignored.

7.2 Results

7.2.1 Complete data

The first analysis addressed whether quality of life differed in regional and metropolitan facilities, using unadjusted, complete data only. Table 7-3 presents the mean quality of life scores for the total sample and the mean quality of life scores differentiated by locality. Mean utility scores generated by the EQ-5D-5L and EQ-5D-5L-Proxy were an average of 0.08 and 0.09 higher respectively in regional facilities compared with metropolitan facilities. Utility differences were less apparent in the DEMQOL instruments with utility scores generated by the DEMQOL-U found to be 0.02 higher on average in regional facilities than metropolitan facilities and scores generated by the DEMQOL-Proxy-U an average of 0.01 lower in regional facilities compared with metropolitan. The Mann-Whitney U test was used to test the null hypothesis that the distribution of utility values was the same across regional and metropolitan facilities. No statistically significant difference in utility scores based on locality was found for any of the instruments.

Table 7-3 Quality of life scores for total sample and differentiated by locality

Instrument	Total sample (n=180)		Metropolitan (n=98)		Regional (n=82)		p-value
	Mean (SD)	Valid n	Mean (SD)	Valid n	Mean (SD)	Valid n	
EQ-5D-5L	0.66 (0.28)	78	0.63 (0.29)	50	0.71 (0.23)	28	0.252
EQ-5D-5L-Proxy	0.49 (0.29)	103	0.44 (0.30)	49	0.53 (0.28)	54	0.141
DEMQOL-U	0.86 (0.11)	98	0.85 (0.13)	58	0.87 (0.09)	40	0.712
DEMQOL-Proxy-U	0.69 (0.13)	177	0.69 (0.14)	96	0.68 (0.12)	81	0.289

Chi-square tests for independence between quality of life dimensions and locality found no significant differences for the EQ-5D-5L, EQ-5D-5L-Proxy, DEMQOL-U or DEMQOL-Proxy-U. The distribution frequencies of responses across quality of life dimensions in regional and metropolitan facilities are represented graphically below for each of the quality of life measures (Figure 7-1; Figure 7-2; Figure 7-3; Figure 7-4).

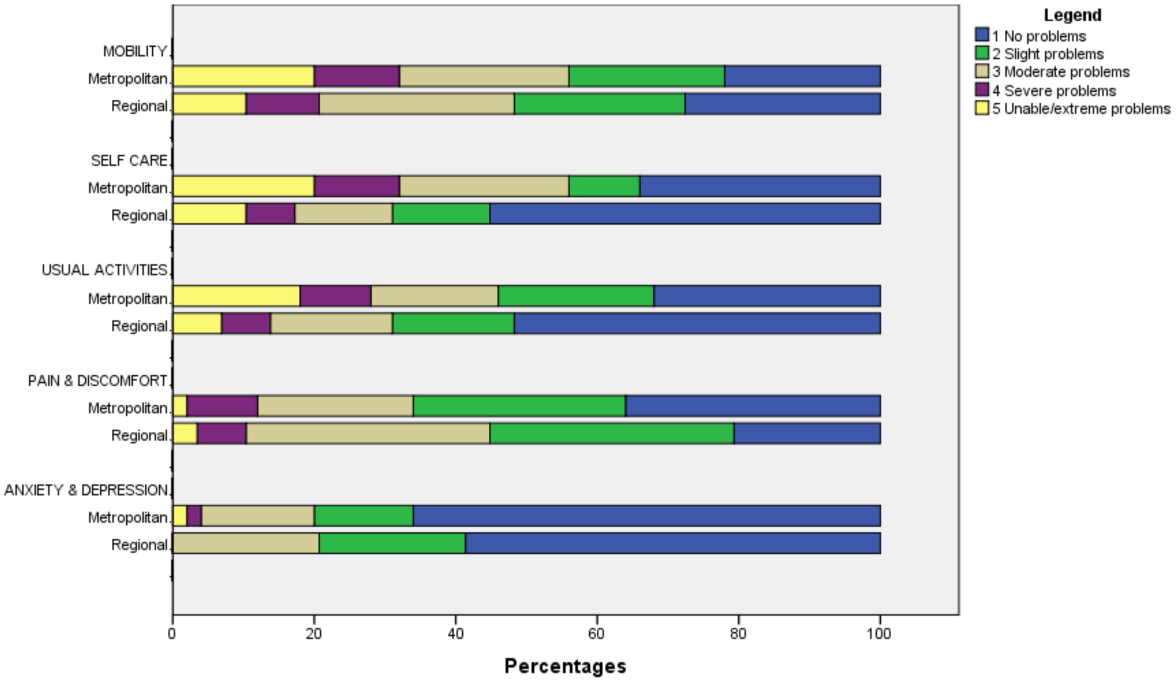


Figure 7-1 Distribution frequency (percentage) of EQ-5D-5L responses across dimensions by locality (n=78)

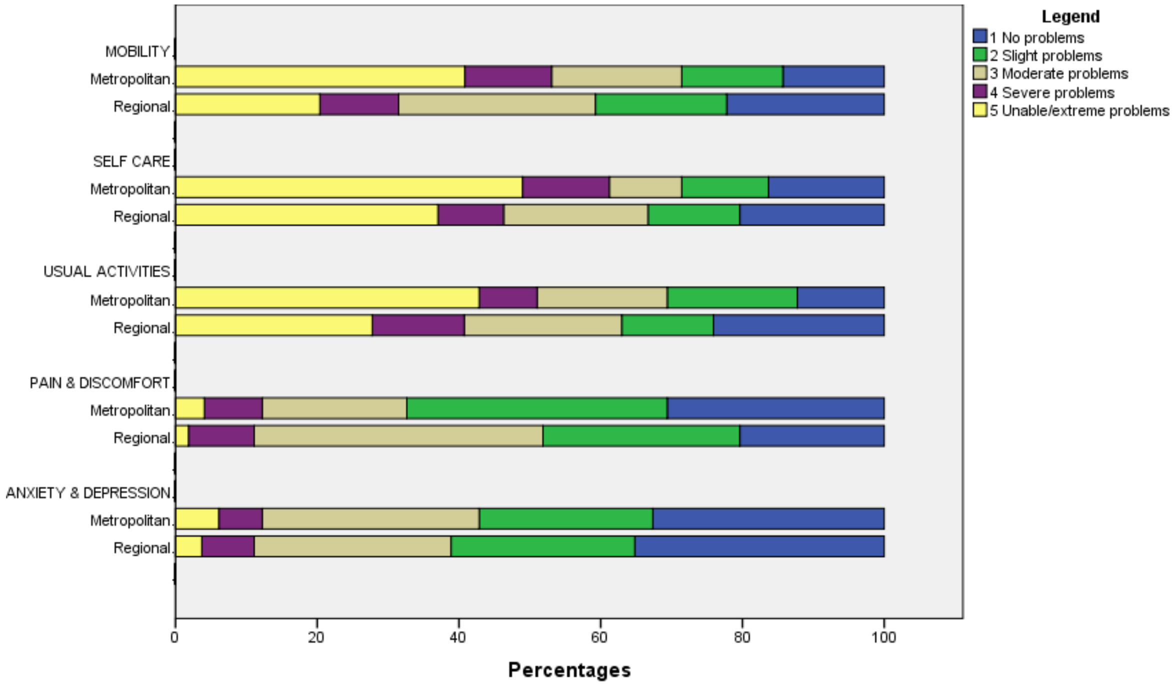


Figure 7-2 Distribution frequency (percentage) of EQ-5D-5L-Proxy responses across dimensions by locality (n=103)

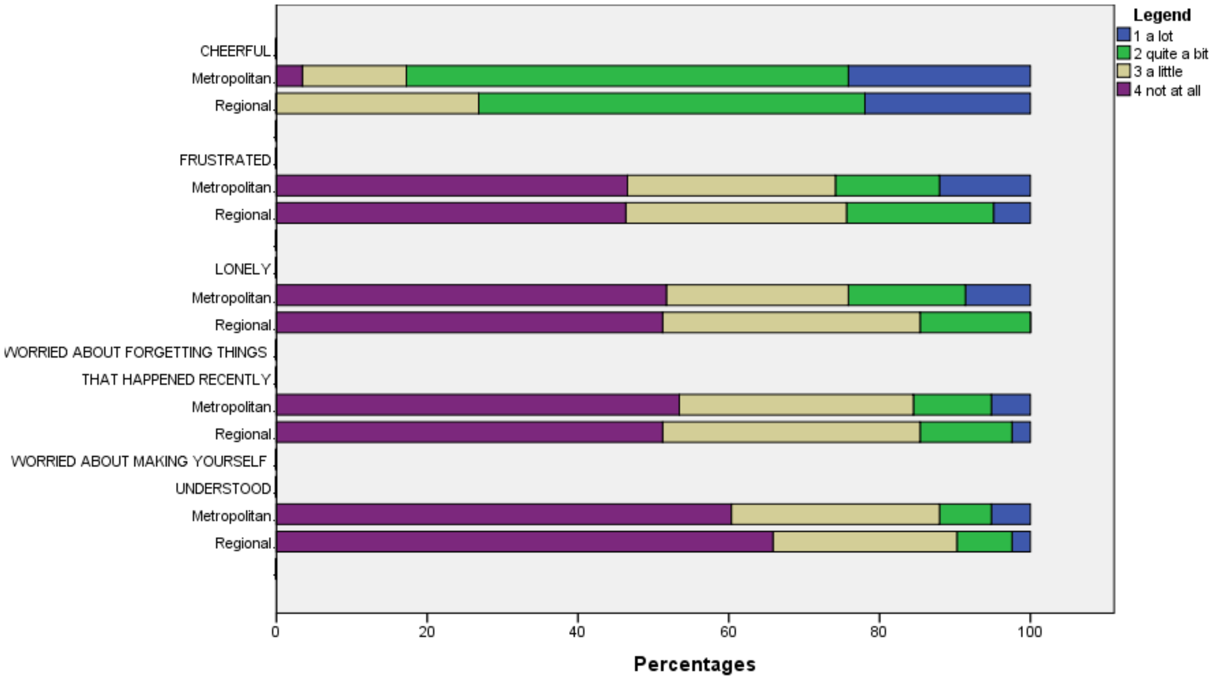


Figure 7-3 Distribution frequency (percentage) of DEMQOL-U responses across dimensions by locality (n=98)

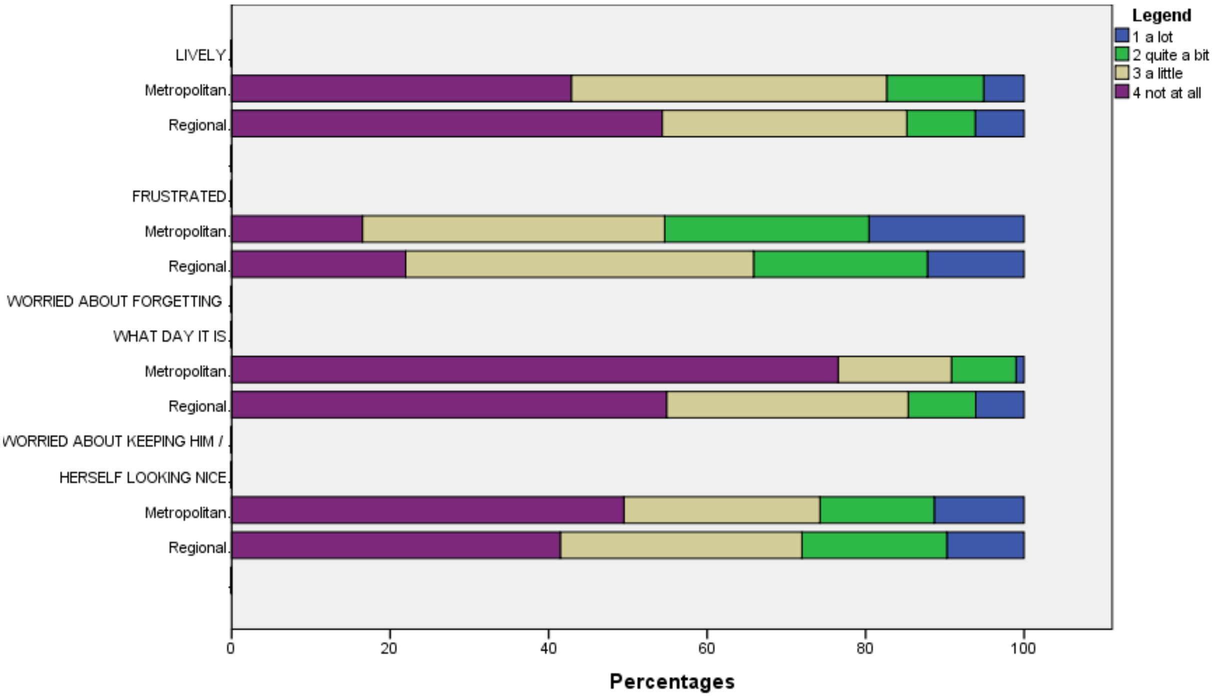


Figure 7-4 Distribution frequency (percentage) of DEMQOL-Proxy-U responses across dimensions by locality (n=177)

7.2.2 Imputed data

The second analysis investigated which factors were associated with health-related quality of life using generalized linear models. Facility characteristics tested included locality, facility size, and facility cost variables. Resident characteristics tested included age, sex, dementia diagnosis, cognitive impairment (PAS-Cog), physical function (MBI), behavioural symptoms (NPI-Q), Medicare costs, PBS costs, and hospitalisation costs.

EQ-5D-5L disutility: Self-rated (n=78) + Imputed Self-rated (n=102)

The first outcome variable modelled was EQ-5D-5L disutility, constructed from self-rated EQ-5D-5L scores and imputed self-rated EQ-5D-5L scores. Regression results are presented in Table 7-4. Higher quality of life (in other words, less disutility) was found to be associated with better physical function (p<0.001), increased behavioural symptoms (p<0.001), higher facility costs (p<0.001), higher pharmaceutical costs (p=0.002), lower Medicare costs (p<0.001), lower hospitalisation costs (p<0.001), and males (p<0.001). Age, level of cognitive impairment, facility location, and facility size were not significantly associated with quality of life.

Table 7-4 Factors associated with EQ-5D-5L disutility (Self-rated + Imputed Self-rated): results of a generalized linear model.

Variable	**Coefficient**	**Robust Standard Error #**	**p-value**
Locality	0.0060	0.0403	0.882
Number of beds	0.0012	0.0008	0.135
Age	-0.0021	0.0013	0.102
Sex	0.0790	0.0113	0.000*
PAS-Cog	-0.0009	0.0020	0.652
MBI	-0.0046	0.0004	0.000*
NPI-Q	-0.0051	0.0007	0.000*
Facility running cost	-0.0140	0.0031	0.000*
Medicare cost	3E-05	4.80E-06	0.000*
PBS cost	-3.58E-06	1.14E-06	0.002*
Hospitalisation cost	2.93E-06	7.98E-07	0.000*
Constant	3.4242	0.4930	0.000
Number of observations	180		
Residual degrees of freedom	176		

** Statistically significant value*
 # Standard Error adjusted for 5 clusters in FacilityID

EQ-5D-5L disutility: Self-rated (n=78) + Proxy-rated (n=102)

The second outcome variable modelled was EQ-5D-5L disutility constructed from self-rated EQ-5D-5L scores and proxy-rated EQ-5D-5L scores. Regression results are presented in Table 7-5. Higher quality of life (less disutility) was found to be associated with metropolitan facilities (p=0.005), fewer beds (p<0.001), better physical function (p<0.001), higher facility costs (p<0.001), higher pharmaceutical costs (p<0.001), lower Medicare costs (p<0.001), and lower hospitalisation costs (p=0.020). Age, sex, level of cognitive impairment, and behavioural symptoms were not significantly associated with quality of life.

Table 7-5 Factors associated with EQ-5D-5L disutility (Self-rated + Proxy-rated): results of a generalized linear model.

Variable	Coefficient	Robust Standard Error #	p-value
Locality	0.1287	0.0461	0.005*
Number of beds	0.0030	0.0008	0.000*
Age	0.0009	0.0029	0.766
Sex	0.0509	0.0275	0.064
PAS-Cog	0.0012	0.0032	0.707
MBI	-0.0044	0.0005	0.000*
NPI-Q	0.0043	0.0031	0.170
Facility running cost	-0.0190	0.0031	0.000*
Medicare cost	4.06E-05	1.13E-05	0.000*
PBS cost	-6.39E-06	1.77E-06	0.000*
Hospitalisation cost	2.42E-06	1.04E-06	0.020*
Constant	3.8838	0.4602	0.000
Number of observations	180		
Residual degrees of freedom	176		

** Statistically significant value*
 # Standard Error adjusted for 5 clusters in FacilityID

DEMQOL-U disutility: Self-rated (n=98) + Imputed Self-rated (n=82)

The third outcome variable modelled was DEMQOL-U disutility constructed from self-rated DEMQOL-U scores and imputed self-rated DEMQOL-U scores. Regression results are presented in Table 7-6. Higher quality of life (less disutility) was found to be associated with no diagnosis of dementia (p=0.031), fewer behavioural symptoms (p<0.001), higher pharmaceutical costs (p=0.001), and lower hospitalisation costs (p<0.001). Age, sex, facility location, facility size, physical function, facility running costs, and Medicare costs were not significantly associated with quality of life.

Table 7-6 Factors associated with DEMQOL-U disutility (Self-rated + Imputed Self-rated): results of a generalized linear model.

Variable	Coefficient	Robust Standard Error #	p-value
Locality	0.0082	0.0095	0.390
Number of beds	0.0003	0.0002	0.127
Age	-0.0006	0.0011	0.572
Sex	0.0082	0.0094	0.378
Dementia Diagnosis	0.0213	0.0099	0.031*
MBI	-0.0002	0.0003	0.508
NPI-Q	0.0112	0.0017	0.000*
Facility running cost	0.0005	0.0008	0.522
Medicare cost	1.04E-05	7.86E-06	0.184
PBS cost	-1.94E-06	5.93E-07	0.001*
Hospitalisation cost	2.28E-06	3.63E-07	0.000*
Constant	-0.0165	0.0670	0.805
Number of observations	180		
Residual degrees of freedom	176		

** Statistically significant value*

 # Standard Error adjusted for 5 clusters in FacilityID

DEMQOL-Proxy-U disutility: Proxy-rated (n=177) with mean replacement (n=3)

The final outcome variable modelled was DEMQOL-Proxy-U disutility constructed from proxy-rated DEMQOL-Proxy-U scores. Regression results are presented in Table 7-7. Higher quality of life (less disutility) was found to be associated with metropolitan facilities (p=0.021), younger residents (p=0.002), better physical function (p=0.014), fewer behavioural symptoms (p<0.045), lower Medicare costs (p=0.031), and lower hospitalisation costs (p=0.018). Sex, facility size, level of cognitive impairment, facility running costs, and pharmaceutical costs were not significantly associated with quality of life.

Table 7-7 Factors associated with DEMQOL-Proxy-U disutility (Proxy-rated): results of a generalized linear model.

Variable	**Coefficient**	**Robust Standard Error #**	**p-value**
Locality	0.1369	0.0591	0.021*
Number of beds	0.0019	0.0011	0.083
Age	0.0025	0.0008	0.002*
Sex	0.0047	0.0233	0.839
PAS-Cog	-0.0023	0.0026	0.362
MBI	-0.0004	0.0002	0.014*
NPI-Q	0.0079	0.0040	0.045*
Facility running cost	-0.0082	0.0043	0.058
Medicare cost	7.64E-06	3.54E-06	0.031*
PBS cost	-9.19E-07	8.09E-07	0.256
Hospitalisation cost	1.63E-06	6.87E-07	0.018*
Constant	1.3895	0.6886	0.044
Number of observations	180		
Residual degrees of freedom	176		

** Statistically significant value*
 # Standard Error adjusted for 5 clusters in FacilityID

7.3 Summary of findings

Utilising a sample of residential care facilities located across regional and metropolitan areas of South Australia, this chapter examined individual characteristics, government costs, and resident quality of life in order to investigate factors which may influence quality of life in Australian residential aged care facilities. In examining the complete, unadjusted quality of life data for the EQ-5D-5L, DEMQOL-U, and their proxy versions, there were no statistically significant differences between residents living in regional residential aged care facilities compared with those living in metropolitan facilities.

When the relationship between quality of life, individual characteristics, and government costs was examined, lower hospitalisation costs were associated with better quality of life. This relationship held for each of the instruments used to measure quality of life. Other factors which appeared to improve quality of life included better physical function and fewer behavioural symptoms. Better physical function was found to be significantly associated with higher quality of life for both of the EQ-5D-5L models, as well as for the DEMQOL-Proxy-U model. No relationship was found between physical function and quality of life as measured by the DEMQOL-U. Fewer behavioural symptoms were associated with better quality of life when measured using the DEMQOL-U and DEMQOL-Proxy-U instruments. The EQ-5D-5L models did not capture this relationship.

In terms of costs, higher pharmaceutical costs were associated with better quality of life in both of the EQ-5D-5L models as well as the DEMQOL-U model. No association was found between pharmaceutical costs and quality of life as measured by the DEMQOL-Proxy-U. Lower Medicare costs were associated with better quality of life in both of the EQ-5D-5L models as well as the DEMQOL-Proxy-U model. No association was found between Medicare costs and quality of life as measured by the DEMQOL- U. Both of the EQ-5D-5L models associated higher facility running costs with better quality of life, whereas no relationship was found in either of the DEMQOL models.

Facility size and locality had no clear association with quality of life, although metropolitan facilities were associated with better quality of life in the EQ-5D-5L model constructed from self-rated and proxy-rated responses, as well as for the DEMQOL-Proxy-U model. There was no consistent association between age or sex and quality of life. Finally, no association was found between cognitive impairment and quality of life.

The next chapter moves on to a discussion of the findings that have been presented in the previous four chapters. It also discusses the research process, addresses the research objectives outlined at the start of this thesis, considers the implications for economic evaluation methodology in this area, and highlights areas for further research.

CHAPTER 8: DISCUSSION AND CONCLUSIONS

8.1 Discussing the research process

Prior to discussing the findings of this thesis, it is important to acknowledge and discuss the research process itself as well as the strengths and limitations of this thesis. The INSPIRED study was a collaborative project involving researchers and stakeholders around Australia. This study provided the data used to address the objectives of this thesis.

8.1.1 Limitations

The first limitation to discuss is the issue of representativeness and sample size. There are more than 190,000 Australians living in over 2,600 residential aged care facilities around the country. Approximately one-third of Australian residential aged care providers are for-profit organisations. The total INSPIRED study sample size was 541 residents from 17 residential aged care facilities across 5 not-for-profit aged care organisations. The South Australian subset used in macro-level cost analysis and synthesis of costs and outcomes consisted of 180 residents from 5 residential aged care facilities belonging to one aged care organisation. The INSPIRED study sample may be considered small relative to the residential aged care industry as a whole, and thus it is not known whether the results presented in this thesis are representative of the Australian residential care industry as a whole, or even the not-for-profit portion of aged care providers. Furthermore, the sample obtained was not a random sample, and thus the results cannot be generalised to the population of older people living in residential aged care facilities in Australia.

There are studies which have been conducted in residential aged care settings which have included large numbers of participants (for instance, over 6000 in a study conducted by Mehr and Fries (1995)), but these have all been based on large administrative data sets such as those maintained by the Centers for Medicare & Medicaid Services in the United States (Arling et al., 1987; Davis, 1993; Holmes, 1996; Mehr & Fries, 1995; Sulvetta & Holahan, 1986). The largest such data set in Australia is the general purpose financial data collected annually by the Department of Health which includes de-identified data from the income statements and balance sheets of residential aged care providers, or the data on care needs collected during ACFI assessment which is held by the Australian Institute of Health and Welfare. Financial benchmarking surveys such as Stewart Brown and Bentley’s are also able to produce data based on large numbers of organisations due to the high participation rates of residential care providers (Bentleys Chartered Accountants, 2017; StewartBrown, 2014). The key difference is that these large datasets do not collect data directly from facility residents. A core component of the INSPIRED study was the direct involvement of residents and family members. A sample size of 541 is on the larger scale of studies evaluating health-related quality of life in residential aged care. There is extra time and complexity involved in the data collection process when residents are included, and in addition when considering the depth and breadth of data the project collected, and the use of intensive data collection methods (face-to-face interviews with experienced trained data collectors) the sample size achieved is appropriate. In addition, the sample size is larger than several other studies conducted in this setting previously (Chenoweth et al., 2009; Lalic et al., 2016; Theou et al., 2016) and similar in size with the PerCEN study which looked at person-centred residential care and environment for people with dementia (Chenoweth et al., 2014).

Facilities included in this study were not selected randomly from all facilities in Australia and therefore there are limitations to the generalizability of the findings. Facilities consented to participate voluntarily and any participation in the study first required the support and approval of the aged care organisation's Chief Executive Officer (CEO). Consequently, it is possible the participating facilities in the INSPIRED study are biased toward those with higher care standards or more advanced care practices, which may have affected the level of variation found in analysis. It is also important to emphasise that no for-profit facilities participated in the INSPIRED study; therefore, we cannot be sure how the findings in this thesis apply to that sector. Ideally future studies would include both for profit and not-for-profit organisations to ensure a more representative sample.

There are also limitations to generalizability arising from INSPIRED's study population. Eligible participants had to have been residing at the aged care facility for at least 12 months. This was to ensure 12 months of retrospective data could be collected for MBS and PBS costs, given the cross-sectional study design. Australian statistics estimate that over one-third of aged care residents (38 per cent) are in care for less than one year, and the primary reason for leaving is death (Australian Institute of Health and Welfare, 2012b). Moreover, these deaths are predominantly male residents (Australian Institute of Health and Welfare, 2012b). The INSPIRED study, therefore, was a study of survivors and there are limits to how generalizable some of the data are. For instance, it is possible that residents dying more quickly could have higher health care costs. So while the INSPIRED study has collected accurate data on a subset of people in aged care, it may not have captured the whole picture. A prospective longitudinal study which aimed to include all aged care residents with linked data sets could address this gap in the future.

A prospective longitudinal study would also facilitate the collection of aged and health care utilisation data, plus quality of life data, prospectively over a defined time period. This would allow for a complete economic evaluation to be conducted, including the calculation of cost-effectiveness ratios comparing different models of care. While the studies contained in this thesis include comprehensive cost and quality of life data, an economic evaluation was not conducted as data were collected at only a single time point. The findings in this thesis could, however, be used to inform the design of an economic evaluation study, and this would be the ideal way to move forward.

As scoring algorithms are not yet available based on Australian general population members, the scoring algorithms for both the EQ-5D-5L and DEMQOL-U were from a UK general population sample despite the study having taken place in Australia. Further empirical analyses are warranted when Australian scoring algorithms become available, as country-specific tariffs have been shown to be sensitive to the preference weights used (Brennan & Teusner, 2015; Oremus et al., 2014). That being said, other studies undertaken in Australia have used UK general population algorithms (Hoon, Gill, Pham, Gray, & Beilby, 2017; Jamieson et al., 2017; McCaffrey, Kaambwa, Currow, & Ratcliffe, 2016), and there is precedent for doing so. A study which compared EQ-5D-3L population norms in Queensland, Australia using scoring algorithms from Australia, the UK, and the United States found the UK value set to provide comparable utility scores to the Australian value set (Clemens, Begum, Harper, Whitty, & Scuffham, 2014).

In terms of the Facility Cost Survey, this work included only those people who had lived in residential aged care for at least one year and therefore the financial information collected related to the 2012-13 and 2013-14 financial years. This time period was prior to the regulatory reforms which introduced Refundable Accommodation Deposits (RADs) and Daily Accommodation Payments (DAPs). Accordingly the impact of these regulatory reforms is not considered. Ideally one would always include prospective data collection, and include resource use and cost data at the level of the individual resident (rather than at a facility level), but due to the highly resource intensive nature of data collection required to accurately assess resource use and costs of providing residential care at an individualised level and the cross-sectional design of the INSPIRED study, only retrospective data could be collected.

Due to the nature of routinely collected cost data in residential aged care organisations, the Facility Cost Survey collected aggregate facility-level expenditures rather than individual-level costs of care. This has implications when combined with the individual-level cost data on hospitalisations, Medicare, and pharmaceuticals. The facility-level data were converted to a cost per resident per day, which was an average cost rather than an individual cost. Therefore it is possible that one or two people with very large care costs may have influenced the average value for a particular facility. A more detailed, bottom-up study on individual residential aged care costs would provide a more comprehensive understanding of the variations within facilities.

Finally on costs, data on hospital outpatient visits were not captured in the Medicare or hospitalisation datasets. Consequently, it is possible that this thesis has underestimated the total health-system costs.

8.1.2 Strengths

The greatest strength of the research presented in this thesis is the inclusion of participants with dementia. Wherever possible, the INSPIRED study aimed to collect information on quality of life and outcomes of care directly from the residents themselves. This approach had the support of our partner organisations and consumer representative members of the Cognitive Decline Partnership Centre. People living with dementia and their family members also contributed to the INSPIRED study's planning and development during the early stages.

People living with dementia are a vulnerable population, and the additional challenges involved in conducting research with this population means they are often excluded from studies conducted in a residential aged care setting. Through the inclusion of both residents and proxies for outcome assessment, the INSPIRED study enabled a view of outcomes for all residents in the facility. This is important to ensure that study results represent the entire residential aged care population, and not just those who have full cognitive ability.

The breadth of data collection, both in terms of the outcomes measured and the study's participants, was extensive. Multiple states across Australia were involved, and within states, both regional and metropolitan facilities were represented. Such large-scale, geographically diverse studies of residential aged care are uncommon in Australia. The PerCEN study, for example, which included 38 facilities and 601 participants, included facilities only within the state of New South Wales (within 500 kilometres of Sydney) (Chenoweth et al., 2014).

Studies which link health system costs, residential care costs, health status, and health-related quality of life are uncommon in the Australian residential aged care setting. The breadth of data collected in the INSPIRED study provided an opportunity to investigate these links through generalized linear models, the findings of which can be used to inform the design of future economic evaluations in Australia. This research also contained detailed evaluation of resident quality of life, using multiple instruments and both self and proxy-reporting. Detailed cost data were collected as well, at an individual level where possible, and for a full 12-month period. At the facility level, costs were collected for two financial years to ensure infrequent expenses (such as refurbishments, for example) would not distort the results.

8.2 Introduction to the discussion

The following sections address the lines of inquiry and gaps in knowledge identified in the systematic review of literature presented in Chapter 2. Namely, the measurement of quality of life effects and the inclusion of residents with dementia in economic evaluations conducted in a residential aged care setting, and the transferability and generalizability to an Australian setting. Before moving on to a detailed discussion of the findings, the remainder of this section will revisit the stated aims of this thesis and address each one in turn.

AIM 1: Identify the extent to which economic evaluations have been conducted in a residential aged care setting and their impact on our knowledge of aged care

A systematic, narrative review of the literature was undertaken as a means of framing this research in the current literature and identifying gaps in knowledge that this thesis could then address. The broad, scoping nature of this review resulted in two publications; the first was published in Cost Effectiveness and Resource Allocation (2016) focussing on the workforce structure and care processes, and the second was published in BMC Health Services Research (2017) focussing on residential aged care infrastructure.

AIM 2: Determine how residents with dementia have been included in existing economic evaluations

The systematic review of the literature identified only six studies, out of 30 identified, containing an economic component, which investigated dementia-specific service configurations. Twenty-one studies identified by this review did not disclose whether residents with dementia had participated. While it is uncertain whether these studies included participants with dementia, the omission suggests that no particular consideration was given to this subgroup during study design. The remaining three studies appeared to have included residents with a range of cognitive abilities, as indicated by the average cognitive assessment scores reported in two of the studies (Molloy et al., 2000; Schneider et al., 2007)and the dementia-specific training incorporated into the third (Teresi et al., 2013).

AIM 3: Compare the performance of generic versus condition-specific preference-based measures of health-related quality of life in a population of older adults living in residential aged care

A comparison of the dementia-specific preference-based DEMQOL instruments with the generic preference-based EQ-5D-5L instruments in a sample of 541 participants across Australia found that the DEMQOL instruments and EQ-5D-5L capture distinct aspects of health-related quality of life. EQ-5D-5L appeared to more closely reflect the typical clinical outcome measures for older people with cognitive impairment, dementia and disability while the DEMQOL instruments appeared more reflective of the psychological and emotional well-being impacts associated with cognitive impairment and dementia. On average utility scores generated by DEMQOL instruments were higher than those generated by EQ-5D-5L (mean difference 0.20). Although these instruments were designed to measure the same concept of utility on an equivalent quality adjusted life years (QALY) scale, it is apparent that QALYs produced by the condition-specific DEMQOL instruments are not directly comparable with QALYs produced by the EQ-5D-5L. With its strong association with physical functioning, the EQ-5D-5L instruments may be more suitable for the assessment of health-related quality of life in mixed residential care populations that include people with dementia but also people with co-morbidities, high levels of physical disability and frailty with good cognition. The DEMQOL-U and DEMOL-Proxy-U, on the other hand, may be suitable for dementia-specific interventions that are more psycho-social in nature.

AIM 4: Explore the relevant costs of residential aged care in Australia at both a facility and system-level, specifically whether differences exist between regional and metropolitan facilities

Residential aged care costs collected at a facility and system level for 17 residential aged care facilities across five aged care organisations and four Australian states did not reveal any statistically significant differences between regional and metropolitan facilities. On average facilities located in the city were larger, more recently built, had a higher proportion of secure dementia beds, higher occupancy, and lower resident and staff turnover, though these differences were not found to be statistically significant. No statistically significant cost differences were found based on a facility's size or location. Care costs, in particular labour costs, were the largest contributor to the operating costs of residential aged care facilities. The major cost driver at a facility level was the assessed level of care needs of the residents as determined by the aged care funding instrument.

The implication of this is that if aged care residents in rural and remote areas have higher care needs due to the higher rates of disability and chronic conditions in these populations (Dixon & Welch, 2000; National Rural Health Alliance, 2011), it would follow that these facilities could have higher operating costs. Thus equivalent quality of life outcomes may be more costly to achieve in regional, rural and remote communities. A larger costing study would be required to further investigate this possibility. The INSPIRED study sample was limited to 17 participating facilities, none of which were located in rural or remote locations.

In terms of costs to the broader health-care system, data from five residential aged care facilities in South Australia were analysed more extensively to examine costs for an individual resident in terms of medical services, medication use, and hospitalisations. Annual costs to government ranged from approximately \$19,000 up to \$174,000 with an average aged care resident utilising government funds of approximately \$60,000 per annum. The largest contributor to cost variability was found to be hospitalisation costs. These findings highlight the potential for programs implemented at residential aged care facilities to produce cost savings at a health-system level, for instance by introducing interventions designed to reduce hospitalisations.

AIM 5: Determine the main factors which contribute to system-level costs in an Australian residential aged care setting

A generalized linear model was built to determine factors associated with government costs. Findings indicated that lower costs were associated with better physical function ($p>0.001$), and females ($p=0.040$). Results of the model also suggested that the presence of more behavioural symptoms was associated with higher costs, though this was not found to be statistically significant ($p=0.053$). Age, locality, diagnosis of dementia, and level of cognitive impairment were not found to be associated with system-level costs. These findings are not unsurprising given that ACFI subsidies comprise the highest proportion of government costs, and reported function and behaviour are two major components of the ACFI assessment.

AIM 6: Examine whether quality of life differs in regional and metropolitan aged care facilities

Using resident-level data from five residential aged care facilities in South Australia, quality of life responses collected in regional facilities were compared with those collected in metropolitan facilities. Dimensions of the EQ-5D-5L, EQ-5D-5L-Proxy, DEMQOL-U and DEMQOL-Proxy-U were analysed. No statistically significant differences were found between regional and metropolitan facilities, though both EQ-5D-5L and EQ-5D-5L-Proxy scores were higher on average in regional facilities when left unadjusted.

AIM 7: Explore the factors which contribute to resident quality of life in an Australian residential aged care setting

Generalized linear models were built to determine factors associated with resident quality of life as measured by EQ-5D and DEMQOL instruments. Regardless of the instrument used to measure quality of life, fewer hospitalisations were associated with better quality of life. Other factors which were found to be associated with improved quality of life included better physical function and fewer behavioural symptoms. In terms of costs, higher pharmaceutical costs and lower Medicare costs were associated with better quality of life. Results indicated that facility size and locality had no clear association with quality of life. No association was found between cognitive impairment and quality of life.

8.3 The extent of economic evaluations conducted in a residential aged care setting

The issue of what it costs to provide residential aged care has been the subject of previous academic research; however, a systematic review of the literature revealed that substantial gaps exist. The systematic review undertaken and presented in Chapter 2 of this thesis had a broad scope in order to provide a comprehensive summary of the evidence, including whether and how economic studies had included health or quality of life outcomes. The search criteria limited studies to those conducted in a residential aged care setting with at least one alternative intervention or control, and included studies had to report the cost of the service configuration or intervention measured as monetary units or resources. In the Australian context, it should be noted that the Australian government has commissioned a number of reviews into the costs of providing residential aged care (see, for instance Access Economics, 2009; Deloitte Access Economics, 2011; Grant Thornton Australia, 2008; Hogan, 2004; Productivity Commission, 2011), and the Aged Care Financing Authority has published a number of relevant reports (Aged Care Financing Authority, 2014; 2015). However these reports did not meet the inclusion criteria for this systematic review, as they were generally descriptive in nature, and did not contain specific interventions or comparators.

The findings of this systematic review, and the subsequent gaps identified, helped to shape the research questions and overall direction of this thesis. Governmental agencies in healthcare, such as the Medical Services Advisory Committee (MSAC) and Pharmaceutical Benefits Advisory Committee (PBAC) in Australia, and the National Institute for Health and Care Excellence (NICE) in the UK, require cost-effectiveness evidence in order to appraise new medical services and new pharmaceuticals, where possible, in the form of incremental cost per QALY. As a result, systematic reviews of economic evaluations of health and medical technologies tend to include much higher numbers of papers. An example of this is a recent systematic review of cost-effectiveness research in cancer therapy, which identified 574 studies containing a full economic evaluation (Al-Badriyeh, Alameri, & Al-Okka, 2017).

While economic evaluation is well established for the evaluation of health technologies and interventions, this is not yet the case in the aged care sector. Out of 30 studies identified in the systematic review for this thesis, only seven of these studies contained a full economic evaluation. The remaining 23 contained an analysis of the costs, but did not link these costs to outcomes within an economic evaluation framework. Further scrutiny of the existing economic evidence highlighted methodological inconsistencies that will need to be improved in order to enhance the usability of future economic evaluations conducted in a residential aged care setting.

For instance, out of 30 studies identified by the systematic review, only four studies directly measured quality of life using six different measurement instruments. Only one of these undertook a cost-utility analysis using quality-adjusted life-years. This contrasts sharply to the health care sector, in which cost-utility analyses are the standard fare. Other direct outcomes found in included studies comprised agitation, improved social interactions, behaviour, function, depressive symptoms, quality of care, rates of decubitus ulcers, catheterisation, physical restraints, and chemical restraints. In Australia, where the stated objective of the government for residential aged care is the quality of life of the residents, there is a clear disconnect between the outcomes that have been collected in existing economic evaluations, and the objective of residential aged care. This hinders the transferability of findings to the Australian residential aged care setting.

The primary methodological limitations that this thesis has helped to address include the inclusion of health and quality of life effects, the generalizability and transferability to an Australian setting, and the inclusion of residents with dementia. The following section addresses the specific issues identified with the inclusion of residents with dementia in existing research.

8.4 The inclusion of residents of residents with dementia in existing research

The systematic review of the literature conducted for this thesis identified only six studies, out of 30 containing an economic component, which investigated dementia-specific service configurations.

In addition to whether or not residents with dementia were included in a study, it is also prudent to look at how residents with dementia were included with regard to the consent process and study participation. In terms of informed consent, in each of the dementia-specific studies, with the exception of one study which used a pre-existing dataset (Mehr & Fries, 1995), proxy consents from family members or legal guardians were sought for participants with dementia who were unable to consent themselves. In addition, two studies required physician consent on top of the consent provided by the resident and/or family member (Rovner et al., 1996; van de Ven et al., 2014). One study required physician consent, family consent, and resident assent before allowing the resident to participate in the study (Rovner et al., 1996). Recommendations from Alzheimer Europe on informed consent for dementia research recommend that consent from a carer or relative be sought when the person with dementia lacks the capacity to do so, and that studies should strive to involve people in all stages and with all forms of dementia (Alzheimer Europe, 2011).

With regard to how residents with dementia participated in studies, the majority of data were extracted from resident files and facility records (Maas et al., 1998; Mehr & Fries, 1995; van de Ven et al., 2014) or through resident observation (Chenoweth et al., 2009; Rovner et al., 1996; van de Ven et al., 2014). Only one study elicited outcome data from the residents themselves; Chenoweth and colleagues (Chenoweth et al., 2014) collected quality of life data via interviews using the DEMQOL and DEMQOL-proxy questionnaires.

In the endeavour to improve the quality of life of older people living in residential aged care facilities, it seems prudent to collect information directly from residents themselves where possible, rather than rely on observation or second-hand information, and in fact this is the recommended practice by research governance organisations in the sector (National Health and Medical Research Council, Australian Research Council, & Australian Vice-Chancellors' Committee, 2015; Taylor, DeMers, Vig, & Borson, 2012). This may require researchers to adopt different approaches specific to the needs of each individual (Alzheimer Europe, 2011). These systematic review findings provided the basis for the empirical comparison of three preference-based quality of life measures for the measurement of health-related quality of life in a residential aged care setting. The results of this comparison are presented in Chapter 4 and discussed in the following section.

8.5 The choice of instrument for the measurement of health-related quality of life

The results presented in Chapter 4 represent one of the first empirical comparisons in Australia and internationally of the measurement properties of the EQ-5D-5L, EQ-5D-5L-Proxy, DEMQOL-U and DEMQOL-Proxy-U instruments. This analysis involved self-rated and proxy-rated responses for the EQ-5D-5L, EQ-5D-5L-Proxy, DEMQOL-U and DEMQOL-Proxy-U in a subset of older adults living in residential aged care in Australia. This study aimed to contribute to the gap in knowledge surrounding the measurement of quality of life in a residential aged care setting. More specifically, the issues highlighted in the introduction and literature review chapters of this thesis relate to whether dementia-specific or generic instruments would be more suited to this setting, and whether questionnaire responses are more reliable from self or proxy reports. This section provides an overview of the study findings before delving into a more specific discussion of the practicality and validity of the instruments.

Broadly speaking, the results suggest that the DEMQOL and EQ-5D-5L instruments capture distinct aspects of quality of life. The EQ-5D-5L and its proxy version appeared to more closely reflect the typical clinical outcome measures for older people with cognitive impairment, dementia and disability whereas the DEMQOL instruments appeared more reflective of the psychological and emotional well-being impacts associated with cognitive impairment and dementia. On average utility scores generated by DEMQOL instruments were higher than those generated by EQ-5D-5L by a mean difference of 0.20. Although these instruments were designed to measure the same concept of utility on an equivalent quality adjusted life years (QALY) scale, it is apparent that QALYs produced by the condition-specific DEMQOL instruments are not directly comparable with QALYs produced by the EQ-5D-5L.

Using the DEMQOL and DEMQOL-Proxy questionnaires, it was possible to compare self-rated and proxy-rated responses. Results suggested that on average proxy-assessment reported lower quality of life scores than did self-assessment with a mean difference of 0.13. Proxies tended to report higher levels of negative emotion (frustration) and lower levels of positive emotion (liveliness/cheerfulness) than the resident reported themselves.

Importantly, the results support a growing body of evidence which emphasizes firstly that people with dementia are able to participate in the assessment of their own quality of life, and secondly that their input provides a unique and valuable contribution to the evaluation of services or interventions for people with dementia (Hoe et al., 2009; Hounsome et al., 2011; Naglie, Hogan, Krahn, Beattie, et al., 2011; Orgeta et al., 2015; R. Trigg, Jones, Lacey, & Niecko, 2012)

A discussion of the practicality and validity of the EQ-5D-5L, DEMQOL-U, and their proxy versions follows in the context of existing literature in this area. As the DEMQOL-U and DEMQOL-Proxy-U are very newly developed (B. Mulhern et al., 2013), the vast majority of existing research into dementia-specific quality of life involves non-preference-based measures such as the DEMQOL and DEMQOL-Proxy. The discussion which follows incorporates the existing literature on the non-preference-based DEMQOL and DEMQOL-Proxy alongside three published studies which incorporated the preference-based DEMQOL-U and DEMQOL-Proxy-U (B. Mulhern et al., 2013; J. Ratcliffe et al., 2016; Rowen et al., 2015). Similarly, the existing body of literature utilising the EQ-5D in study populations with dementia predominantly use the three-level version of the EQ-5D rather than the more recently developed five-level version. In the discussion below the particular instrument used in each study will be explicitly labelled as EQ-5D-3L for the three-level version and EQ-5D-5L for the five-level version.

8.5.1 Practicality

Practicality refers to an instrument's acceptability to respondents. To assess the practicality of the EQ-5D-5L, the DEMQOL-U, and their proxy versions, the questionnaire lengths, response rates, and completion rates were compared. The EQ-5D-5L, with six questions, is one-fifth the length of the DEMQOL and DEMQOL-Proxy questionnaires which have 29 and 32 questions respectively. In terms of questionnaire length alone, the EQ-5D-5L, would appear to be better suited to the residential aged care population as it would presumably be less of a burden to complete.

When looking at response rates, the EQ-5D-5L had a lower response rate (67.5 per cent) compared with the DEMQOL (76.5 per cent). At first glance, this would seem to suggest that the DEMQOL was preferred by respondents despite its longer length; however, more residents were approached to complete the DEMQOL compared with the EQ-5D-5L. The INSPIRED study protocol followed existing evidence related to the EQ-5D-5L and DEMQOL for use in populations with dementia. For the EQ-5D-5L, the existing evidence suggests that the EQ-5D-5L may be appropriate in mild to moderate dementia, or in other words for participants with a PAS-Cog score less than or equal to 11. In contrast, the developers of the DEMQOL recommend its use with people with a PAS-Cog score up to 18, which is considered severe cognitive impairment. We can compare like with like by only looking at response rates for those with a PAS-Cog score less than or equal to 11. There were 215 participants in total who fell into this category and were thus eligible to complete both the EQ-5D-5L and DEMQOL instruments in accordance with INSPIRED study protocol. Of this group, 90.7 per cent completed the DEMQOL while only 67.5 per cent completed the EQ-5D-5L. Despite the longer length, the DEMQOL questionnaire would appear to be more acceptable to self-reporting participants.

Of the study participants with a PAS-Cog score between 11 and 18, the DEMQOL response rate fell to 41.4 per cent, whereas proxy response rates for both the EQ-5D-5L-Proxy and DEMQOL-Proxy were near perfect across all participant categories. In terms of practicality, both the EQ-5D-5L-Proxy and DEMQOL-Proxy seem appropriate for use in a residential aged care setting across all levels of cognitive impairment. In terms of completeness, the level of missing data was low across all four questionnaires. The DEMQOL-Proxy had the highest level of missing data coming in at 2 per cent. Typically missing data below 5 per cent is considered inconsequential (Schafer, 1999).

8.5.2 Validity

Validity was assessed in terms of construct validity and responsiveness to change. In the self-rated subgroup – with the exception of a moderate correlation found between physical function and the

EQ-5D-5L – cognition, physical function, and neuropsychological symptoms showed little association with the utility scores produced by the EQ-5D-5L and DEMQOL-U instruments. This lack of association between self-rated measures and clinical outcome measures for dementia has also been found in studies undertaken in community settings using the EQ-5D-3L (B. Mulhern et al., 2013; Naglie, Hogan, Krahn, Beattie, et al., 2011) and DEMQOL-U (B. Mulhern et al., 2013).

When comparing the EQ-5D-5L with the DEMQOL-U (and their proxy versions) more directly, the EQ-5D-5L and EQ-5D-5L-Proxy showed generally stronger association with clinical outcome measures than the DEMQOL-U and DEMQOL-Proxy-U. The strongest association was found with physical functioning, or level of dependence, as measured by the MBI. This was true for both the self-rated and proxy-rated subgroups, though correlations were stronger in the proxy-rated subgroup. This finding is consistent with a cross-sectional, observational study conducted in the United Kingdom involving 249 people with probable Alzheimer's disease, which found that associations between dependence and the EQ-5D-3L were consistently more significant than those for the DEMQOL and DEMQOL-Proxy (R. Trigg et al., 2012).

Thus, in terms of the association of health-related quality of life measures with clinical outcome measures, the EQ-5D-5L measures appear to be more strongly correlated than the DEMQOL measures, and the proxy-rated measures show stronger correlations than the self-rated measures. Although, aside from physical functioning and the EQ-5D instruments, none of the correlations were particularly strong. Proxies, however, tend to give lower quality of life rating than residents themselves. In comparing the self versus proxy subgroup, proxies reported utility scores that were 0.13 lower on average than reported by residents. While there are other studies which support this finding (Jönsson et al., 2006; Sheehan et al., 2012), the underlying reason for this difference is not clear. The differences found between the DEMQOL-U and DEMQOL-Proxy-U were primarily in the dimensions of positive emotion and negative emotion. One explanation for this may be that self-rated responses are more reflective of subjective attributes such as mood (Beerens et al., 2013). Alternatively, perhaps proxies are projecting part of their own quality of life onto the individual with dementia for whom they are answering (Arons et al., 2013). A further possibility may be that the proxy is unable to fully appreciate the lived experience of the individual being assessed (Moyle, Fetherstonhaugh, Greben, & Beattie, 2015).

One unusual finding in the self-rated subgroup was that higher levels of cognitive impairment were associated with higher EQ-5D-5L utilities; Overall mean utility scores for residents with a diagnosis of dementia were higher than for those without a diagnosis of dementia. One possible explanation may be that people admitted to residential care without dementia have more severe physical disabilities than those with dementia and this would account for such differences. However, previous research conducted in Australia has found people living in residential aged care facilities with a diagnosis of dementia tend to have higher care needs on average than those without in relation to activities of daily living and behaviour (Australian Institute of Health and Welfare, 2012a). In our sample, the subgroup without dementia had a lower MBI score on average indicating a higher level of dependence, while the subgroup with dementia had a higher average NPI-Q sum score and higher average PAS-Cog score suggesting more cognitive impairment and more behavioural and psychological symptoms than residents without a dementia diagnosis. This finding was not repeated in the proxy-rated subgroup and these results should be interpreted with caution as the effects sizes were small.

Shifting now to the potential responsiveness to change, ceiling effects were apparent for both the EQ-5D-5L and DEMQOL-U dimensions. This is a commonly reported occurrence in self-rated measures for people with dementia (Hounsome et al., 2011; B. Mulhern et al., 2013; Orgeta et al., 2015). Ceiling effects were much less pronounced for the proxy-rated measures, suggesting that the EQ-5D-5L-Proxy and DEMQOL-Proxy-U may be more responsive to health state improvements than their self-rated counterparts. One factor which may have contributed to this finding is that the proxy-rated subgroup consisted of residents that were more symptomatically severe. As the proxy-rated subgroup consisted of residents with more severe levels of cognitive impairment and dementia, and higher physical dependency than the self-rated subgroup, it was expected that ceiling effects would be less prominent in this subgroup compared with the self-rated subgroup.

It is worthwhile noting that the literature surrounding self-rated quality of life for people with dementia has predominantly been conducted in a community setting. Recent studies investigating quality of life in a residential care setting have used proxy-rated instruments (Castro-Monteiro et al., 2014; Diaz-Redondo et al., 2014) and mapping techniques (Keith S. Goldfeld, Hamel, & Mitchell, 2012) to elicit health state values for people with dementia. Similarly, a study measuring quality of life among hospital in-patients with dementia concluded that proxy-ratings were the only feasible option (Sheehan et al., 2012). The research in this thesis has demonstrated that self-assessment health-related quality of life is feasible for at least a proportion of people living in residential care. Self-assessment of health-related quality of life by residents themselves is preferable where possible (John Brazier et al., 2016). Given the results of the analyses in Chapter 4, I am inclined to conclude that proxy-rated measures of health-related quality of life may be a practical option for the elicitation of health state values for use in cost-utility analyses in a residential aged care setting in order to ensure a consistently representative study sample and to facilitate longitudinal assessment which is inclusive of all residents. Above and beyond practicality, however, there are important ethical considerations in deciding whether to use self or proxy measures. This study did not directly compare self and proxy versions of the same instrument, rather it compared generic with dementia-specific instruments for distinct self and proxy subgroups. The results of studies which directly compare self and proxy responses for the same participants should also be considered, along with factors such as proxy bias.

More broadly, in terms of the utility scores generated by the EQ-5D-5L and DEMQOL-U, those generated by the EQ-5D-5L tended to be lower than those generated by the DEMQOL-U by 0.2 points on average. This was equally true for the EQ-5D-5L-Proxy and DEMQOL-Proxy-U. Despite both instruments providing a score on the theoretical 0-1 utility scale, the degree of agreement between the two measures suggests that the DEMQOL-U (and its proxy) may not be an appropriate substitute for the EQ-5D-5L and vice-versa. The poor agreement and low to negligible correlations across all dimensions of the EQ-5D-5L and DEMQOL-U, suggest that the DEMQOL-U and EQ-5D-5L capture distinct and unique aspects of health-related quality of life. This can also be said for the EQ-5D-5L-Proxy and DEMQOL-Proxy in the proxy-rated subgroup. The EQ-5D-5L was found to be more strongly related to physical functioning as assessed by the MBI. The EQ-5D-5L may therefore be a more suitable instrument for the assessment of health-related quality of life in mixed residential care populations that include people with dementia but also people with co-morbidities, high levels of physical disability and frailty with good cognition.

8.6 Facility-level costs of residential aged care in Australia

8.6.1 General Financials

In our sample of 17 aged care facilities, labour costs were the greatest expense, accounting for an average of 72 per cent of total expenses, ranging from a low of 64 per cent to a high of 77 per cent. This is slightly higher than the findings of the 2004 Hogan review of pricing arrangements in 785 Australian residential aged care facilities which found labour costs to be on average 66 per cent of total expenses in mixed care facilities (W. Hogan, 2004). It is more in line with the average labour costs for high care facilities, which was found to be 72 per cent (W. Hogan, 2004). Out of the seven expense categories defined (care, cleaning, laundry, catering, property and maintenance, administration, and wage on-costs), care was the predominant expense accounting for an average of 61 per cent of total facility costs.

The amount of money spent on staff training varied across organisations as did staffing configurations. Average direct care hours per resident ranged from 1.9 hours per day to 3.8 hours per day and there were significant differences in staffing models reflected in the proportion of care provided by nursing staff versus care workers as well as the number of allied health professionals directly employed by a facility. These sources of variability would be worthwhile to investigate in terms of any potential quality of life or outcome differences for residents. This is a line of enquiry that has been pursued in the past. A study by Anderson and colleagues (1998) in the United States suggested that average resident outcomes were better in residential care facilities which had a higher proportion of registered nurses on staff, noting that this also resulted in increased costs. A later study by Hendrix and Foreman (2001) analysed the optimisation of nursing staff mix, finding that 60 per cent of American residential care homes were employing suboptimal levels of nursing staff. An Australian review of residential care found the facility design to play a role in staff optimisation, purporting that single-story facilities designed in modules of 30 to 40 beds with strategically placed nursing stations and living areas led to more economical staffing arrangements (Grant Thornton Australia, 2012). While outside the scope of this thesis, the effect of staff configurations is being investigated by the broader INSPIRED research team.

In terms of profitability measures, internal rates of return (IRR) on accommodation were generally low. Ten facilities had negative IRRs in 2014, suggesting the majority of facilities do not generate sufficient revenues from accommodation to offset the initial capital outlay required to construct the facility. Earnings before interest, taxes, depreciation and amortisation (EBITDA) – a measure of a facility’s ability to generate income from its operations – ranged from a loss of $18.71 to a profit of $42.73 per bed per day. The average EBITDA across all facilities for both financial years was a profit of $14.46 per bed day, or roughly $5,000 per bed per annum. This is markedly less than the ideal EBITDA target estimated by Grant Thornton in their 2012 review of Australian residential aged care facilities, which suggested facilities should ideally generate earnings between $25,000 and $32,000 per bed per annum (Grant Thornton Australia, 2012). That being said, it is consistent with the actual earnings of residential care facilities included in both the 2012 Grant Thornton review, and the 2004 Hogan review (Grant Thornton Australia, 2012; W. Hogan, 2004).

Although the sample size for the INSPIRED study was small, the cost figures are broadly in line with more comprehensive cost studies conducted in the Australian residential aged care sector. While generalizations should be interpreted with caution, these findings suggest that the reforms implemented since 2004 have had little material impact on the viability of the Australian residential aged care industry. It should be noted that the financial data collected for this thesis were prior to the most recent regulatory reforms which introduced Refundable Accommodation Deposits (RADs) and Daily Accommodation Payments (DAPs). Broadly speaking, the RADs and DAPs are a reconfiguration of the method in which accommodation payments are made, and give residents the choice to pay for their accommodation either in the form of a bond or a daily payment, or a combination of the two. It is unclear how these most recent reforms will impact the financial viability of the sector. At the time of data collection for this thesis, financial results post these reforms were not yet available.

8.6.2 Cost-drivers

A Spearman Rank Order correlation analysis revealed a number of statistically significant associations between potential cost drivers and an array of expense categories. The only variable that was strongly correlated with total costs and statistically significant at the 0.01 level was government care subsidies. The care subsidies that facilities receive are based on the aged care assessment residents receive when they enter residential care or a re-assessment if their situation changes significantly once they are in residential care. Residents are assessed on their activities of daily living (nutrition, mobility, personal hygiene, toileting, and continence), behaviour (cognitive skills, wandering, verbal behaviour, physical behaviour, and depression), and complex health care (medication and other complex health requirements). Based on these assessments, residents are categorised as having high, medium, low, or nil requirements in each of the three categories and the aged care facility will then receive a government subsidy corresponding to the assessment level assigned to each resident. The higher the assessed needs of the resident, the greater the care subsidy paid to the aged care facility. Average care subsidy received can thus, in theory, be used as a proxy for the resident case-mix at each facility. Our analysis also found a strong positive correlation between care subsidies and care costs, as would be expected. The significance of this, however, is less clear. On one hand, it could be that residents with higher assessed care needs cost more to care for; the cost of care is higher, and therefore higher subsidies are required. On the other hand, it is also possible that facilities simply spend what they have. Facilities that are better able to maximise the subsidies received for each resident have a larger budget from which to operate their facility. There is no way to tease out causality from the analysis.

Looking to the existing literature, work by Grant Thornton found higher ACFI levels to be associated with better performing facilities overall, which they reasoned was due to ACFI uplifts in 2008 which resulted in funding being better matched to care needs, thus facilitating reinvestment in care delivery commensurate with the care needs of residents (Grant Thornton Australia, 2012). However, arguments have also been put forward that care subsidies are not a good proxy for resident case-mix. It has been suggested that facilities may vary in their capacity to maximise the ACFI subsidy for each resident (McNamee et al., 2017). Indeed, an internal review of ACFI funding growth patterns conducted by the Department of Health concluded that growth in ACFI funding could not be attributed in full to a natural increase in resident frailty (Department of Health, 2016a).

The locality of a facility, as determined by the ASGC Remoteness Area, displayed small negative correlations with costs, suggesting that more regional facilities may be associated with lower costs. This result is counterintuitive as we would expect more regional facilities to be associated with higher costs. This association, however, was not statistically significant, meaning the locality of a facility may not be a significant cost driver, or the sample size may not have been large enough to detect a significant relationship in either direction. The size of a facility, as measured by the total number of beds, displayed for the most part small positive correlations with costs, but as with locality, the relationships were not statistically significant. These findings are consistent with existing literature, which has struggled to find significant relationships between locality, size, and costs (H. L. Smith et al., 1992; Sulvetta & Holahan, 1986).

Nevertheless, given that only 17 facilities participated in the INSPIRED study, none of which were classified as rural or remote, it is possible that locality may be a significant cost driver of residential aged care costs. Similarly, facility size may play a significant role, but could not be detected in the small sample. In the Australian setting, the Grant Thornton review found facilities with 76 to 100 beds to be better performing than either larger or smaller facilities (Grant Thornton Australia, 2012). The review did not look at geographical variables. Warren Hogan did look briefly at costs by locality, finding rural providers to have higher labour costs on average (W. P. Hogan, 2005). A larger, more representative study sample is needed to clarify the relationships between facility size, locality, and costs in an Australian aged care setting.

Another way to consider geographical effects was to consider whether price levels between states had an effect on facility operational costs. In order to do this, Registered Nurse Level 1 wages rates were used as a rough proxy. The wage rate for the same position across different states could be expected to vary according to price level in that state. As all of the participating facilities employed registered nurses, this was the wage rate selected. Findings indicated there was a strong positive correlation between Registered Nurse Level 1 wage rates and care costs, as well as RN Level 1 wage rates and administration costs, with higher RN wage rates associated with higher costs of care and higher administration costs. There was also a moderate positive correlation between Registered Nurse Level 1 wage rates and total facility costs, though this was not found to be statistically significant. These findings, although using a crude proxy, suggest the price level differences between states may affect operating costs. Ideally, a more precise measure of price level between states would be a spatial price index. Such an index is currently under development according to the Australian Bureau of Statistics, but has not yet reached a stage where it is reliable enough for use.

8.6.3 Dementia-specific units

The conclusions which can be drawn from this analysis, in terms of the costs of caring for residents with dementia are limited by the absence of individual-level data in the Facility Cost Survey. The three available and relevant variables which could be considered in this analysis included the presence of a dementia-specific unit, the number of secure dementia beds per facility, and the ACFI behavioural subsidy received by the facilities. This information is valuable, given the lack of economic evidence in Australia relating to dementia care and related service needs. Neither the Hogan review (2004) nor the Grant Thornton review (2012) included analyses relating to the cost of caring for residents with dementia, though both cited its importance.

Looking first at facilities with secure dementia units, facilities with higher numbers of secure dementia beds were associated with lower laundry costs, catering costs, property and maintenance costs, and wage on-costs. Both average operating income and average operating expenses were higher for facilities with a secure dementia unit compared to facilities with no secure dementia areas, though these differences were not found to be statistically significant. Similarly, the number of secure dementia beds was moderately positively correlated with higher care costs and weakly positively correlated with higher total costs, but these relationships were not statistically significant.

In order to receive the highest behavioural subsidy, a resident must have a dementia diagnosis, provisional dementia diagnosis, psychiatric diagnosis or behavioural diagnosis received or re-assessed within the last 12 months. Accordingly, the BEH supplement received by each facility can be used as a rough proxy to indicate the prevalence of dementia at that particular site. Our analyses found higher behaviour subsidies to be associated with higher facility costs, higher administration costs, and lower catering costs. As noted above, causality cannot be ascertained from this analysis. In other words, it is unclear whether residents with dementia require more care, or if higher costs are a result of higher income received.

Nonetheless, this preliminary assessment of dementia care suggests that there may be additional costs associated with the provision of dementia-specific care. However, it is important to note that facility-level costing data are imperfect. In order to better assess the cost implications of caring for residents with dementia, individual resident-level data are required. This was not practical within the constraints of the INSPIRED study, as data at this level are not routinely available. The final two studies in this thesis incorporated individual-level health care sector data from South Australian residential aged care facilities in order to more directly examine the impacts of dementia from a broader health-care perspective.

8.7 System-level costs of residential aged care in Australia

Health system costs were collected and analysed for a subset of the INSPIRED cohort, which consisted of five residential aged care facilities belonging to one aged care organisation in South Australia. System-level costs consisted of ACFI subsidies, as well as MBS, PBS, and hospitalisation costs. Within this study sample, total system-level costs ranged from $19,000 up to $174,000 per resident per year. On average, the government was found to spend $60,000 per resident per year for older people living in residential aged care facilities.

In the introduction to this thesis, government spending on residential aged care in Australia was quantified at $10.8 billion in the 2014-15 financial year (Steering Committee for the Review of Government Service Provision (SCRGSP), 2016). This amount reflects only the funds provided directly to residential aged care, predominantly in the form of ACFI subsidies to cover the costs of daily care. What the system-level analysis in Chapter 6 showed, was that ACFI subsidies make up on average 85 per cent of the total costs, while costs to the health system make up the remaining 15 per cent. It is within this 15 per cent, however, where the greatest potential for variation lies. This is particularly the case with regard to hospitalisation costs.

In the 2014-15 financial year, basic ACFI subsidies were capped at a maximum of $208.68 per resident per day, which would be payable for a resident in the highest needs category for activities of daily living, behaviour, and complex health care. This maximum has increased to $214.06 for the 2016-17 financial year, reflecting a cost-of-living indexation of 2.5 per cent. The potential for unforeseen expenses in the aged care sector is low. Conversely, hospitalisation costs and pharmaceutical costs have much more potential to drive up total costs. While annual hospitalisation costs in the South Australian INSPIRED subset was $4,700 per resident, this cost ranged between $0 and $113,000 depending on the individual. Similarly, annual pharmaceutical costs where on average $2,500 per resident, but this ranged from $8 up to $51,000 on an individual basis.

While there may be little room to implement significant cost savings at a facility level, these findings highlight the potential for programs implemented at residential aged care facilities to produce cost savings at a health-system level. This mirrors a similar finding from the systematic review presented in Chapter 2 in which a number of studies found that programs implemented at the facility-level had the potential for cost savings to the health care sector more so than at the facility itself (Dorr et al., 2005; Przybylski et al., 1996; Schneider et al., 2007).

A number of recent Australian studies have focused on strategies to reduce the hospitalisation of older people living in residential aged care (Dwyer, Craswell, Rossi, & Holzberger, 2017; Fan et al., 2016; Hullick et al., 2016). The primary motivation for these studies included the overcrowding of emergency departments (Fan et al., 2016) and the quality of life improvements gained from avoiding hospitalisation (Dwyer et al., 2017; Hullick et al., 2016). Pharmaceutical reviews also continue to receive the attention of Australian researchers (Gilmartin, Marriott, & Hussainy, 2016), The potential for government cost savings adds further motivation and support for continuing research in this area.

No significant cost differences were found between metropolitan and regional facilities. These findings are consistent with existing literature, which has struggled to find significant relationships between locality, size, and costs (H. L. Smith et al., 1992; Sulvetta & Holahan, 1986). Although with only five facilities, all operated by the same organisation, you would not expect to see large cost differences between facilities.

8.8 Factors which contribute to system-level costs

To further explore the system-level costs of residential aged care, eight factors were input into a generalized linear model to determine which factors were associated with total government costs. The factors tested included age, sex, locality, facility size, diagnosis of dementia, cognitive impairment, physical function and neuropsychiatric symptoms. Two significant relationships were found: Increased physical impairments were associated with higher government costs, and female residents were associated with lower government costs than male residents.

The relationship between physical function and system-level costs makes sense intuitively. At the facility level, declining physical function would lead to a higher level of dependence on residential care staff for assistance with day-to-day activities such as bathing, dressing, and eating. Therefore it follows that higher levels of resident dependence at a care facility would require more care staff to cover the workload, resulting in higher costs of care. In terms of the broader health-care costs, a similar pattern would be expected.

Though not statistically significant, increased behavioural symptoms may be associated with higher government costs as well. This relationship appeared to be approaching significance with a p-value of 0.053. As with the relationship between physical dependence and costs, it makes sense that residents with more behavioural symptoms would require more care, and thus result in higher costs at both a facility and health-system level. A larger sample would be needed, however, to further investigate this relationship.

The literature surrounding dementia care costs have linked physical dependence to increased societal costs in numerous studies (Gustavsson et al., 2011; Mesterton et al., 2010; Scuvee-Moreau, Kurz, & Dresse, 2002; Vossius, Rongve, Testad, Wimo, & Aarsland, 2014), whereas the findings relating to behavioural symptoms have varied, though lower associations have typically been found (Dodel et al., 2015; Gustavsson et al., 2011; Mesterton et al., 2010).

Another possible explanation for the relationship between physical function, behavioural symptoms and system-level costs is that reported function and behaviour are two major components of the ACFI assessment. As ACFI subsidies comprise the highest proportion of government costs, these relationships could be a result of the ACFI assessment itself. This raises the question as to whether the ACFI continues to be an appropriate assessment of care need, which is something to consider moving forward. Indeed, a recent government-commissioned report finds this to be the case, and proposes an alternative classification system and funding model for future consideration (McNamee et al., 2017).

8.9 Factors which contribute to resident quality of life

The final study analysed the relationships between resident characteristics, system-level costs, and health-related quality of life. One of the key findings from this analysis was that regardless of the instrument used to measure quality of life, lower hospitalisation costs were associated with better quality of life. Hospitalisations were also a significant source of cost variability for the government. With this is mind, future research focussed on interventions aimed at reducing hospitalisations would be worthwhile, and any such studies conducted in a residential aged care setting should strongly consider including both health service costs and health-related quality of life as study outcomes.

Other factors which appeared to improve quality of life included better physical function and fewer behavioural symptoms. When looking at dementia-specific quality of life, reducing behavioural and psychological symptoms of dementia may have the potential to improve resident's quality of life and lower costs at the same time. The relationship between behavioural symptoms, and quality of life has been documented in a recent systematic review of factors associated with quality of life of people with dementia in residential care, whereas the relationship between physical function and quality of life was less well-defined (Beerens et al., 2013).

Higher pharmaceutical costs were also associated with better quality of life in both of the EQ-5D-5L models as well as the DEMQOL-U model. It is difficult to draw conclusions from this finding without a more in-depth investigation of the underlying pharmaceutical data. Higher pharmaceutical costs do not necessarily mean a larger number of drugs being prescribed or more frequent dosages, but may also represent the use of more costly medications. Further analysis of the medication use of individual residents, which was outside the scope of this study, would be required to explain this apparent relationship.

Facility size and locality had no clear association with quality of life. These finding are in line with a recently published article which found resident-level characteristics more highly associated with quality of life compared with facility-level characteristics (Shippee, Henning-Smith, Kane, & Lewis, 2015). Nor did resident age or sex show any clear association with quality of life. Age has previously been thought to have a u-shape relationship with quality of life, initially declining as age increases until later in life at which time it tends to increase with age, however this is not always the case (Steptoe, Deaton, & Stone, 2015). In fact, a recent longitudinal study conducted in Australia, Germany, and the UK found this age-based effect disappeared once individual factors were controlled for (Frijters & Beatton, 2012).

No association was found between cognitive impairment and quality of life. The literature is mixed in terms of whether cognitive function is related to quality of life, or more precisely, whether existing quality of life measures are able to capture changes in cognitive impairment. General population surveys undertaken to determine utility scores for the various stages of dementia indicate that the public does believe that an individual's quality of life declines as the severity of cognitive impairment increases (Tarride, Oremus, Pullenayegum, Clayton, & Raina, 2011; Xie, Oremus, & Gaebel, 2012). However the ability of existing instruments to capture these declines is unclear. Naglie, Hogan, Krahn, Black, et al. (2011), in a study of the EQ-5D-3L found that cognitive status (as measured by the MMSE) and functional status were not consistent predictors of self or proxy-rated QOL. Bosboom and Almeida (2014) found that changes in cognitive function were not associated with changes in health-related quality of life (as measured by the QoL-AD). Jönsson et al. (2006) found no association between cognitive impairment and self-rated quality of life measures (using the EQ-5D-3L and QoL-AD), however found that proxy-rated quality of life using the EQ-5D-3L declined as cognitive impairment increased. Beer et al. (2010) found a similar pattern using the QoL-AD in that no association was found between cognitive function and self-rated quality of life, but proxy-rated quality of life did indicate an association. Work by Rowen et al. (2015) concluded that the population used to produce health state values, specifically in the dementia-specific DEMQOL-U and DEMQOL-Proxy-U instruments, could impact utility scores and thus impact the results of cost-utility analyses because people with dementia and their carers gave systematically lower values than members of the general population.

One difficulty in investigating factors which influence quality of life is selecting the most relevant factors for inclusion in the study. Two potentially relevant factors which were not collected directly in the INSPIRED study are depression and pain. This challenge can be seen in the existing literature, for instance a study by Beer et al. (2010) which compared self-rated with proxy-rated quality of life included factors such as behavioural symptoms, reported pain, hospital presentations, documents restraints, and cognitive impairment, but did not include any measures of physical function or depression.

8.10 Implications for residential aged care in regional, rural, and remote areas

The results of the studies contained in this thesis support the finding that resident-level characteristics are more highly associated with quality of life than facility-level characteristics. While this finding was expected, given that quality of life data were collected at the individual level, there are a number of implications for residential aged care in regional, rural, and remote areas. Firstly, this finding would suggest that models of care found to be effective in metropolitan facilities should be adaptable for regional facilities. Secondly, a key component of an effective care model should include person-centred care that is tailored to the individual residents at each facility.

The major cost driver at a facility level was found to be the assessed level of care needs of the residents as determined by the aged care funding instrument. While it is possible that the ACFI does not accurately represent resident need, it was the best proxy available in this study. The implication of this is that if aged care residents in rural and remote areas have higher care needs due to the higher rates of disability and chronic conditions in these populations (Dixon & Welch, 2000; National Rural Health Alliance, 2011), it would follow that these facilities could have higher operating costs. So while no significant differences were found between regional and metropolitan facilities in terms of quality of life outcomes, these outcomes may be more costly to achieve in regional, rural and remote communities. In addition, regional and rural areas rely heavily on not-for-profit and government providers to ensure access to aged care services, as very few for-profit organisations operate in these localities (Aged Care Financing Authority, 2015). Rural and regional providers often report lower financial performance based on earnings before interest, tax, depreciation and amortisation (EBITDA) (Aged Care Financing Authority, 2015). This may be due, in part, to the smaller size of rural facilities compared with metropolitan facilities; Drawing from a smaller catchment, it may take longer to fill residential care places as they come available. Ideally, future costing studies should collect individualised cost data (that is, cost data collected at the level of individual residents and then aggregated up) for residential care facilities in regional, rural and remote localities, as facility-level data do not provide the necessary level of detail for this type of analysis. These data would need to be collected over a longer period of time to ensure any seasonality effects are appropriately captured.

8.11 Implications for economic evaluation methodology and practice

Three primary implications for economic evaluation methodology and practice have emerged from this research. These relate to the choice of health-related quality of life measure, the importance of the perspective chosen for economic evaluations, and the inclusion of residents with dementia.

8.11.1 Choice of health-related quality of life measure

With its strong association with physical functioning, the EQ-5D-5L instruments may be more suitable for the assessment of health-related quality of life in mixed residential care populations that include people with dementia but also people with co-morbidities, high levels of physical disability and frailty with good cognition. The DEMQOL-U and DEMOL-Proxy-U, on the other hand, may be suitable for dementia-specific interventions that are more psycho-social in nature.

One of the findings from the comparison of generic and preference-based health-related quality of life measures presented in Chapter 4 was that the EQ-5D-5L and DEMQOL measures capture distinct aspects of health-related quality of life. Both of these measures would also appear to complement, rather than substitute, the typical clinical outcome measures for people with dementia such as measures of cognitive function or behavioural symptoms. In the INSPIRED study sample, the EQ-5D-5L and its proxy version appeared to more closely reflect the typical clinical outcome measures for older people with cognitive impairment, dementia and disability whilst the DEMQOL-U and DEMQOL-Proxy-U appeared more reflective of the psychological and emotional well-being impacts associated with cognitive impairment and dementia.

Although these instruments were designed to measure the same concept of utility on an equivalent quality-adjusted life-years (QALY) scale, it is apparent that QALYs produced by the condition-specific DEMQOL-U and DEMQOL-Proxy-U are not directly comparable with QALYs produced by the EQ-5D-5L. Researchers and decision-makers should therefore be cautious in their interpretation of cost-utility analyses and pay careful attention to the outcome measures used in the assessment of effectiveness and the calculation of QALYs. Subsequent research may well provide clearer evidence on the appropriate choice of instrument.

8.11.2 Impact of study perspective for analysis

Results from the analyses of system-level costs in Chapter 6 and the synthesis of costs and outcomes in Chapter 7, found important relationships between health-systems costs such as hospitalisations and pharmaceuticals, and the quality of life of aged care residents. In order for economic evaluations conducted in a residential aged care setting to fully capture all relevant costs and outcome, a broader perspective is required for analysis. Simply put, researchers should aim to include all costs to the health system when undertaking economic evaluations in residential aged care. That being said, another important perspective to consider in future research, which was outside the scope of this thesis, is the costs to the individual residents themselves. On top of the basic daily fee for residential care, residents may also be required to make a means tested co-payment. In addition, there may be costs to the resident for health and social services outside the residential care facility, such as gap fees for outpatient appointments and GP visits, or allied health services such as physiotherapy. The financial burden to both the health system and the individual are important to consider to ensure a balance is struck when future funding models are being considered.

8.11.3 Inclusion of residents with dementia

One clear finding of this thesis is that people with dementia can and should be included in economic evaluations of residential aged care services. In the full INSPIRED study sample, 64 per cent of participants had a recorded diagnosis of dementia and 83 per cent had some level of cognitive impairment. The only way to conduct research in a residential aged care setting that is representative of the aged care population is to ensure the inclusion of people with cognitive impairment and dementia. Given the inherent differences between self and proxy-rated quality of life, self-rated and proxy rated utility scores should be clearly differentiated in economic evaluations in this setting. This research has demonstrated that self-assessment health-related quality of life is feasible for at least a proportion of people living in residential care. Self-assessment of health-related quality of life by residents themselves is preferable where possible (John Brazier et al., 2016), however proxy-rated measures of health-related quality of life may be a practical option for the elicitation of health state values for use in cost-utility analyses in a residential aged care setting in order to ensure a consistently representative study sample.

8.12 Conclusions

With the ongoing discussions of financial viability in the Australian residential aged care sector, and the emphasis on improving the quality of life of aged care residents, it is evident that health economic analyses can provide highly valuable information for government and other key stakeholders. The empirical results presented in this thesis were used to improve our understanding of the costs of providing care, the quality of life of older people living with cognitive decline, and the implications for economic evaluations conducted in a residential aged care setting.

In terms of the costs of providing care, labour costs were the biggest contributor to the daily running costs of residential aged care facilities. Running costs were primarily driven by each resident’s care needs, as determined by the Aged Care Funding Instrument. At a health-system level, hospitalisation costs and pharmaceutical costs provide the largest source of variation. With regard to resident quality of life, lower hospitalisation costs, better physical function, and fewer behavioural symptoms all had a positive association.

A key takeaway from this thesis, and the INSPIRED study as a whole, is that people with dementia can and should be included in economic evaluations of residential aged care services. The choice of health-related quality of life measure and choice of respondent will affect the utility scores produced, and thus requires careful consideration. Also, researchers should take a health-system or societal perspective to ensure all relevant costs and benefits are captured.

8.12.1 Areas for future investigation

Future analyses planned with the INSPIRED data set include delving deeper into hospitalisation data in terms of number of visits, the reasons for visits, and the lengths of stay in order to investigate the underlying causes of the large variability in hospitalisation costs and its relationship to quality of life. The broader INSPIRED study will also explore pharmaceutical data, including the use of potentially inappropriate medications. The more we can uncover about the nature of these important health-system costs, the better we can inform future study design.

As Australia’s population continues to age, demand for residential aged care services is likely to continue to grow. This will inevitably increase the pressure on the government budget, drawing attention to the need to provide the best value care with limited funds. With the advent of ‘Consumer Directed Care’ in the community, it is likely that future policy changes will include increased consumer choice and flexibility in the residential care setting as well. Quality of life is potentially going to become a very important distinguishing characteristic which could be used by consumers to vote with their feet between service providers and residential care facilities. Economic evaluation provides a useful framework to evaluate residential aged care services, and thus it is likely that we will see economic evaluation play an increasingly important role in the design and delivery of residential aged care services in the future.

To date, very few economic evaluations have been conducted to evaluate the design and delivery of Australian residential aged care facilities. This thesis investigated the two primary components which form an economic evaluation, the costs and the outcomes, in order to inform the design of future studies. The results presented in the cost studies contained in Chapters 5 and 6 highlight the flow-on effects from the residential aged care sector to the broader health care sector. While the running costs of residential aged care facilities are largely constrained by the amount of care subsidies received for each resident, this is not the case for costs to the health care system. As both the aged care and health care sectors in Australia are primarily funded by the government, future studies should be sure to include both sectors in the study design.

The results of the comparison of two health-related quality of life measures presented in Chapter 4 suggest that the generic EQ-5D-5L and dementia-specific DEMQOL-U provide complementary data despite being rated on the same theoretical 0 to 1 utility scale. This was one of only a few studies to date which compared generic and dementia-specific preference-based measures and further investigation is needed. In particular, there is still debate not only on which instrument to use, but also surrounding the question of whether self or proxy assessment is more appropriate in populations with a high prevalence of dementia, such as that found in residential aged care facilities. Future research should aim to identify whether there exists a ‘cognition threshold’ beyond which proxy assessment should be sought. A large-scale longitudinal study seeking direct participation from aged care residents across a range of cognitive levels in conjunction with a carer or family member proxy would allow further investigation into the reliability of self-rated responses over time and as cognitive impairment changes. Such a study would also allow for analyses of how generic and dementia-specific preference-based measures perform over time, and their sensitivity to changes in quality of life over time, building on the cross-sectional comparison provided in this thesis.

In Chapter 7 of this thesis, the costs and outcomes of aged care residents were combined in a generalized linear model to investigate the factors associated with quality of life. As quality of life data were only collected at a single time point, a full economic evaluation was outside the scope of this thesis; however the associations found in the generalized linear models could be used to inform a national, longitudinal study in the future. Based on the findings of this thesis, future research directions to potentially improve quality of life and lower costs should target interventions which improve physical function, reduce behavioural and psychological symptoms, and reduce hospitalisations. Each of these factors was found to be associated with both costs to the health care system and health-related quality of life.

A final area of future investigations is to address the costs of providing residential aged care at an individualised level rather than a facility level. While the Facility Cost Survey used in this thesis identified specific factors that influence costs, the aggregate nature of the data did not allow for a detailed understanding of cost distributions within facilities. Future research focused on facility costs should adopt a more detailed, bottom-up methodology in order to provide a more comprehensive understanding of individual residential aged care costs, specifically for those living with dementia.

To summarise, the key priorities for future research should include:

- Conducting full economic evaluations which include the measurement of quality of life;
- Identifying whether there exists a ‘cognition threshold’ beyond which proxy assessment of quality of life should be sought;
- Including both the aged care and health care sectors in study designs;

- Targeted interventions which improve physical function, reduce behavioural and psychological symptoms, and reduce hospitalisations; and
- Investigating the costs of providing residential aged care at an individualised level.

This thesis has presented a health economic perspective of residential aged care in Australia, and made a contribution to knowledge with regard to the costs of providing care and the quality of life of older people living with cognitive decline and dementia. Going forward, there is a need for longitudinal data collection to facilitate on-going economic evaluations of new service innovations in this sector. The importance of including people with dementia in in these future projects cannot be emphasized enough.

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APPENDICES

Appendix I: Medline Search Strategy

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

#	Searches
1	(extended care adj2 facilit*).tw.
2	(geriatric adj2 (home* or facilit* or institution*)).tw.
3	(long-term care adj2 (facilit* or institution* or setting* or resident* or provider*)).tw.
4	(LTC adj2 (facilit* or institution* or setting* or resident* or provider*)).tw.
5	(longterm care adj2 (facilit* or institution* or setting* or resident* or provider*)).tw.
6	(residential adj2 (home* or care or facilit*)).tw.
7	(long-stay adj2 (facilit* or institution* or resident*)).tw.
8	(Nursing home* or Institutionali* or institutional care or nursing facilit* or LTCF or care home* or rest home* or green house* or Eden alternative* or wellspring or formal care or aged care or dementia care unit*).tw.
9	residential facilities/ or homes for the aged/ or nursing homes/ or intermediate care facilities/ or skilled nursing facilities/ or Long-Term Care/ or Institutionalization/
10	or/1-9
11	aged/ or "aged, 80 and over"/ or frail elderly/
12	(aged or old* people or old* person* or old* resident* or elder* or geriatric*).tw.
13	or/11-12
14	economics/ or "costs and cost analysis"/ or cost-benefit analysis/ or health care costs/ or health expenditures/ or economics, medical/ or economics, nursing/ or models, economic/ or models, econometric/ or Quality-adjusted life years/
15	(cost* or adjusted life year* or QALY or "willingness to pay").tw.
16	(economic* and (analys* or evaluat* or model*)).tw.
17	or/14-16
18	10 and 13 and 17
19	adolescent/ or exp child/ or exp infant/
20	(adolescen* or teen* or p?ediatric* or child* or infan*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
21	or/19-20
22	18 not 21
23	limit 22 to english language
24	limit 23 to (addresses or autobiography or bibliography or biography or classical article or comment or dictionary or directory or editorial or festschrift or historical article or in vitro or interactive tutorial or interview or lectures or legal cases or legislation or news or newspaper article or patient education handout or periodical index or portraits or retracted publication or "retraction of publication" or webcasts)
25	**23 not 24**

Appendix II: JBI Data Extraction Form

JBI Data Extraction Form for Economic Evaluations

Reviewer _______________ Date _______

Author _______________ Year _______

Journal_______________ Record Number ______

Method of Evaluation Cost Minimisation ☐ Cost Effectiveness ☐
Cost Utility ☐ Cost Benefit ☐

Interventions

Comparator

Setting

Geographical

Participants

Source of effectiveness data

Authors Conclusions

Reviewers Comments

Extraction Complete Yes ☐ No ☐

Clinical Effectiveness Results

Study design

Year range of primary studies

Analysis used

Clinical outcome results

Economic Effectiveness results

Date/s of economic data

Modeling used

Measure of benefits used in economic evaluation

Direct costs

Indirect costs

Currency

Statistical analysis

Estimated benefits used in EE

Cost results

Synthesis of costs and results

Outcome category

		Clinical effectiveness		
		+	0	-
Cost	+	● A	○ B	○ C
	0	○ D	○ E	○ F
	-	○ G	○ H	○ I

Key

	Effectiveness	Cost
+	Better	Lower
0	Equal	Equal
-	Poorer	Higher

Appendix III: JBI Critical Appraisal Checklist

JBI Critical Appraisal Checklist for Economic Evaluations

Reviewer _______________________ Date _______________________

Author _________________________ Year______ Record Number ______

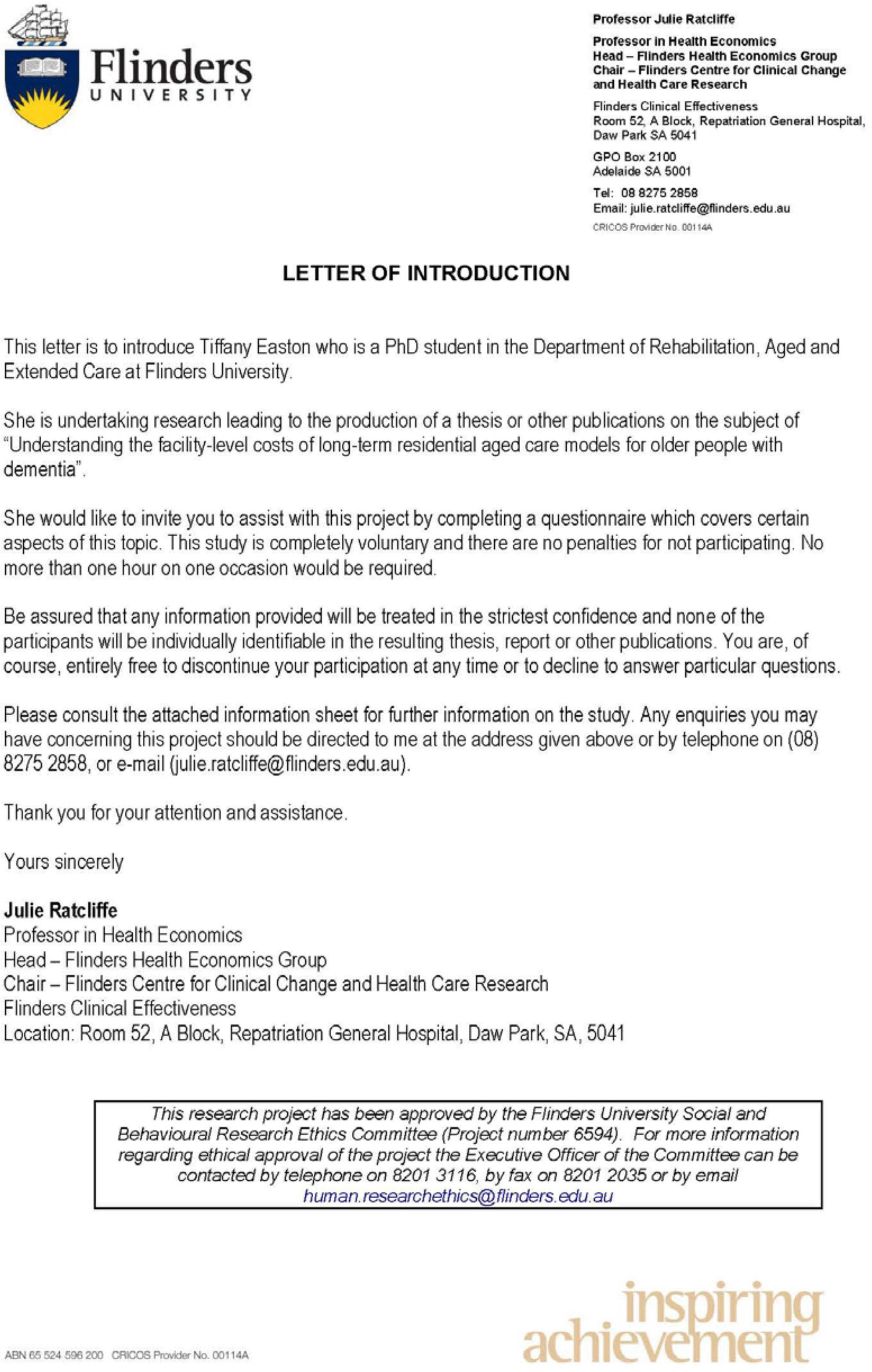
	Yes	No	Unclear	Not Applicable
1. Is there a well defined question?	☐	☐	☐	☐
2. Is there comprehensive description of alternatives?	☐	☐	☐	☐
3. Are all important and relevant costs and outcomes for each alternative identified?	☐	☐	☐	☐
4. Has clinical effectiveness been established?	☐	☐	☐	☐
5. Are costs and outcomes measured accurately?	☐	☐	☐	☐
6. Are costs and outcomes valued credibly?	☐	☐	☐	☐
7. Are costs and outcomes adjusted for differential timing?	☐	☐	☐	☐
8. Is there an incremental analysis of costs and consequences?	☐	☐	☐	☐
9. Were sensitivity analyses conducted to investigate uncertainty in estimates of cost or consequences?	☐	☐	☐	☐
10. Do study results include all issues of concern to users?	☐	☐	☐	☐
11. Are the results generalisable to the setting of interest in the review?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info. ☐

Comments (Including reasons for exclusion)

This tool is adapted from the work of Drummond:
Drummond MF. Allocating resources. Int J Technol Assess Health Care. 1990;6(1):77-92.

Appendix IV: Study Information Sheets



Flinders
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Professor Julie Ratcliffe

Professor in Health Economics
Head – Flinders Health Economics Group
Chair – Flinders Centre for Clinical Change and Health Care Research

Flinders Clinical Effectiveness
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Adelaide SA 5001

Tel: 08 8275 2858
Email: julie.ratcliffe@flinders.edu.au
CRICOS Provider No. 00114A

LETTER OF INTRODUCTION

This letter is to introduce Tiffany Easton who is a PhD student in the Department of Rehabilitation, Aged and Extended Care at Flinders University.

She is undertaking research leading to the production of a thesis or other publications on the subject of "Understanding the facility-level costs of long-term residential aged care models for older people with dementia".

She would like to invite you to assist with this project by completing a questionnaire which covers certain aspects of this topic. This study is completely voluntary and there are no penalties for not participating. No more than one hour on one occasion would be required.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Please consult the attached information sheet for further information on the study. Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on (08) 8275 2858, or e-mail (julie.ratcliffe@flinders.edu.au).

Thank you for your attention and assistance.

Yours sincerely

Julie Ratcliffe
Professor in Health Economics
Head – Flinders Health Economics Group
Chair – Flinders Centre for Clinical Change and Health Care Research
Flinders Clinical Effectiveness
Location: Room 52, A Block, Repatriation General Hospital, Daw Park, SA, 5041

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 6594). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

ABN 65 524 596 200 CRICOS Provider No. 00114A

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Faculty of Medicine, Nursing and Health Sciences
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CRICOS Provider No. 00114A

INFORMATION SHEET

Title: 'Understanding the facility-level costs of long-term residential aged care models for older people with dementia'

Investigators:
Ms Tiffany Easton
Rehabilitation, Aged and Extended Care
Flinders University
Ph: 8275 1103

Supervisor(s):
Professor Julie Ratcliffe
Flinders Clinical Effectiveness
Flinders University
Ph: 8275 2858

Professor Maria Crotty
Rehabilitation, Aged and Extended Care
Flinders University
Ph: 8275 1103

Ms Rachel Milte
Rehabilitation, Aged and Extended Care
Flinders University
Ph: 8275 1103

Description of the study:
This study is part of the project entitled '*Understanding the facility-level costs of long-term residential aged care models for older people with dementia'.* This project will investigate the real costs of aged care services from the perspective of the provider and determine the main sources of cost disparity between service configurations. This project is supported by Flinders University Rehabilitation, Aged and Extended Care Department in the School of Health Sciences.

Purpose of the study:
This project aims to provide a better understanding of the true cost of dementia care at residential aged care facilities. This understanding will be further enhanced by examining differences in facility profiles and service configurations, as well as identifying main sources of cost variation between various models of care.

What will I be asked to do?
You are invited to complete a paper-based survey. This survey includes 20 questions relating to your facility's operational costs, facility profile and services, and capital structure. It will require collation of the facility's existing financial and operational data, and will take approximately one hour to complete. An experienced staff member with operational knowledge and access to the facility's financials would be most suitable to complete the survey.

The survey will be posted to you directly at your facility. You may complete the survey yourself, or allocate portions of the survey for completion by one or more staff members with relevant knowledge. We ask for a contact name, phone number, and email address so that we may contact you if clarification is required on one or more of the answers. We do not need to know which staff member(s) filled out the survey. The survey can be returned to us in the reply-paid envelope that will be provided with the survey. You are free to cease the survey at any time or not answer any questions. This study is completely voluntary and there are no penalties for not participating.

What benefit will I gain from being involved in this study?
The sharing of your facility's costs and services will improve the planning of future aged care services and delivery of future programs. We are very keen to help improve services and resources so they are as useful as possible to people.

Will I be identifiable by being involved in this study?
We do require a contact name and contact details in case further clarification is needed on one or more of the survey answers. Once the survey data has been verified and no further clarification is required, we will detach your contact details from the rest of the survey and store them separately to the survey.

The information gained in this study will be included in a PhD thesis and also published in a journal. All personally-identifying information will be removed prior to reporting the research findings, and neither organisation nor facility names will be published. You will not be identified and your individual information will remain confidential. However, given the small number of facilities participating in this study, the anonymity of your organisation cannot be guaranteed.

Once any identifying information has been removed from the survey, the hard copy will be placed in a locked filing cabinet and a scanned file will be stored on a secure server at the department of Rehabilitation, Aged and Extended Care, Flinders University, Repatriation General Hospital, Daws Road, Daw Park, South Australia. All records will be stored for at least five years from the date of publication. Your comments will not be linked directly to you.

Are there any risks or discomforts if I am involved?
The investigator anticipates few risks from your involvement in this study. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the investigator.

How do I agree to participate?
Participation is voluntary. You may answer 'no comment' or refuse to answer any questions and you are free to withdraw from the survey at any time without effect or consequences. Whether you participate in the study or not will have no effect on your employment with Brightwater.

If you agree to participate please reply to my email (tiffany.easton@flinders.edu.au) and provide the postal address where you wish to receive the survey. You can indicate your consent to participate in the study by completing and returning the survey.

How will I receive feedback?
Outcomes from the project will be summarised and given to you by the investigator if you would like to see them. Please contact the investigators if you would like this to occur.

Funding
This research is supported by the National Health and Medical Research Council Partnership Centre on Dealing with Cognitive and Related Functional Decline in Older People. The researchers have no financial or other conflicts of interest to declare.

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 6594). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Resident

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http://www.flinders.edu.au/people/rachel.milte

CRICOS Provider No. 00114A

LETTER OF INTRODUCTION

Dear Sir/Madam,
I hold the position of Research Associate in the Rehabilitation, Aged, and Extended care Department at Flinders University.

We are undertaking research investigating the costs of providing residential care and the quality of care and quality of life of people living in residential care, and leading to the production of a thesis or other publications on this subject titled ‘INSPIRED (NSW and WA): Investigating services provided in the residential care environment for dementia’.

We would like to invite you to assist with this project by agreeing to complete some questionnaires regarding the quality of care you receive, your quality of life, and your physical functioning. We would also seek your permission to ask a family member about their perception of your quality of life. In addition, we would seek your permission to ask the staff here for information about your health, if you have been to hospital over the last year, and information from the Department of Human Services regarding how often you have used Medicare services (for example, a visit to the doctor) or used certain Pharmaceutical Benefits Scheme medications over the last year. No more than 65 minutes in total would be required and this could be split over as many smaller periods of time as you need to feel comfortable.

Be assured that the researchers are no way affiliated with HammondCare and participation will have no effect on the current (or future) treatment you are receiving at your residential care home. Any information provided to us will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. While we are unable to guarantee anonymity, any identifying information will only be used to organise an interview to collect the data or to facilitate access to the records or databases you have given us permission to collect health service usage information from. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on (08 8275 1067), fax (08 8275 1130) or e-mail (Rachel.milte@flinders.edu.au)

Thank you for your attention and assistance.

Yours sincerely

Rachel Milte
Research Associate
Rehabilitation, Aged and Extended Care Department

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project 6753). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Family Members

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CRICOS Provider No. 00114A

LETTER OF INTRODUCTION

Dear Sir/Madam,
I hold the position of Research Associate in the Rehabilitation, Aged, and Extended care Department at Flinders University.

We are undertaking research investigating the costs of providing residential care and the quality of care and quality of life of people living in residential care, and leading to the production of a thesis or other publications on this subject titled 'INSPIRED (NSW and WA): Investigating services provided in the residential care environment for dementia'.

We would like to invite you to assist with this project by agreeing for us to collect information from you and your family member living in residential care. We would ask your permission to ask either your family member living in residential care (if they are able to) or yourself to complete some questionnaires about the quality of care they receive, their quality of life, and their physical functioning. In addition, we would seek your permission to ask the staff here for information about their health, and how their mood and thinking have been going over the past year. We would look at your family member's case notes at this facility to get information on their health, medication use, marital status, level of education, how their thinking has been going, the type of care and services they receive here, and whether they have been to hospital over the past 12 months. We would also see your permission to get information from government databases about how often they have been to the doctor and used other health services including hospitals, or used certain medications over the last year. No more than 65 minutes in total would be required and this could be split over as many smaller periods of time as you or your family member needs to feel comfortable.

Be assured that the researchers are no way affiliated with HammondCare and participation will have no effect on the current (or future) treatment your family member is receiving at the residential care home. Any information provided to us will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. While we are unable to guarantee anonymity, any identifying information will only be used to organise an interview to collect the data or to facilitate access to the records or databases you have given us permission to collect health service usage information from. You and your family member are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on (08 8275 1067), fax (08 8275 1130) or e-mail (Rachel.milte@flinders.edu.au)

Thank you for your attention and assistance.

Yours sincerely

Rachel Milte
Research Associate
Rehabilitation, Aged and Extended Care Department

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LETTER OF INTRODUCTION

Dear Sir/Madam,
I hold the position of Research Associate in the Rehabilitation, Aged, and Extended care Department at Flinders University.

We are undertaking research investigating the costs of providing residential care and the quality of care and quality of life of people living in residential care, and leading to the production of a thesis or other publications on this subject titled 'INSPIRED (NSW and WA): Investigating services provided in the residential care environment for dementia'.

We would like to invite you to assist with this project by agreeing to complete some questionnaires regarding the quality of life, health and physical functioning of some of the residents in your facility, who have independently consented to participate in this work. No more than 25 minutes of your time per resident would be required.

Be assured that the researchers are no way affiliated with HammondCare and participation will have no effect your employment. Any information provided to us information you provide will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. While we are unable to guarantee anonymity, any identifying information will only be used to organise an interview to collect the data or to facilitate access to the records or databases the resident has given us permission to collect health service usage information from.

You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on (08 8275 1067), fax (08 8275 1130) or e-mail (Rachel.milte@flinders.edu.au)

Thank you for your attention and assistance.

Yours sincerely

Rachel Milte
Research Associate
Rehabilitation, Aged and Extended Care Department

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project 6753). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Residents

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CRICOS Provider No. 00114A

INFORMATION SHEET

Title: *INSPIRED (NSW and WA): Investigating services provided in the residential care environment for dementia*

Investigators:
Ms Rachel Milte
Rehabilitation, Aged and Extended Care
Flinders University
Ph: 08 8275 1067

Professor Maria Crotty
Rehabilitation, Aged and Extended Care
Flinders University
Ph: 08 82751103

Ms Tiffany Easton
Rehabilitation, Aged and Extended Care
Flinders University
Ph: 08 8275 1067

Description of the study:
This study is part of the project entitled '*INSPIRED (NSW and WA): Investigating services provided in the residential care environment for dementia'*. This project will investigate costs of providing residential care and the quality of care and quality of life of people living in residential care. This project is supported by Flinders University Rehabilitation, Aged and Extended Care department.

Purpose of the study:
This project aims to find out if how residential aged care is provided can affect the quality of care, quality of life, and use of hospital and health care services of the people living in residential care.

What will I be asked to do?
You are invited to attend a one-on-one interview with a researcher who will ask you a few questions about your quality of life, quality of care you receive, and your physical function. An example of a question we would ask you is "How much time are caregiving

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staff able to spend with me?" Sensitive questions like this, about your feelings about the care you currently receive, will only be asked in private by a researcher who is not an employee of HammondCare. Other questions, about your general health and functioning, such as whether you can go to the toilet by yourself or whether you need help, may be asked by a HammondCare carer who has been assigned to help us with this particular study and who will talk to you at a different time.

We would also seek your permission to ask a family member who knows you well about how they think your quality of life is at the moment. We would also ask the staff here about your general background, health, how your mood, memory and thinking has been going over the past year. We would look at your case notes at this facility to get information on your health, medication use, marital status, level of education, how your memory and thinking has been going, the type of care and services you receive here and whether you have been to hospital over the past 12 months. We would also seek your permission to get information from government databases about your recent use of health services. For example, how often you have been to the doctor or other Medicare services or when and why you may have been admitted to hospital recently. We also request your permission to collect information on your use of medications from the Pharmaceutical Benefits Scheme over the past year. You will be asked to fill out a consent form authorising the study access to your complete Medicare and Pharmaceutical Benefits Scheme (PBS) data. Medicare collects information on your doctor visits and the associated costs, while the PBS collects information on the prescription medications you have filled at pharmacies. The consent form is sent securely to the Department of Human Services who holds this information confidentiality. No more than 65 minutes of your time in total would be required and this could be split over as many smaller periods of time as you need to feel comfortable.

What benefit will I gain from being involved in this study?
It is hoped that the sharing of your experiences will improve the planning and delivery of future residential aged care services. We are very keen for residential care services to be as good quality and relevant as possible to people in the future. We cannot guarantee that you will be directly benefit from participating in this study, or that there will be any changes to services provided at your facility as a result of the information you provide.

Will I be identifiable by being involved in this study?
While we are unable to guarantee anonymity, only the research team will have access to your personal information to allow them to organise an interview with you or to facilitate access to the records and databases you have given us permission to collect your health service usage information from. Your contact details will be stored separately from the information we collect during the interview. All personal information will be treated in the strictest confidence. Electronic documents will be kept on a password protected computer that only the research team will have access to. The findings of the study will be published in a journal. All identifying information will be removed prior to reporting the research findings. All records will be stored for at least five years from the date of publication and PBS and Medicare data, both electronic and hard copy, will be destroyed at this point.

Are there any risks or discomforts if I am involved?
We anticipate few risks from your involvement in this study. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the

investigator. If participating in the interview brings up emotions of distress or anxiety for you, you can talk to your home's care staff, Chaplain or Pastoral Care workers. In addition, Life Line is a 24 hour free counselling service available across Australia for anyone and is able to be contacted via telephone on 13 11 14. Members of this research team can also refer you to a confidential counselling service via Alzheimer's Australia if you need further support.

How do I agree to participate?

Participation is entirely voluntary. You may answer 'no comment' or refuse to answer any questions and you are free to withdraw from the interview at any time without effect or consequences. If you wish to withdraw from the study, please notify a member of the research personnel. A consent form accompanies this information sheet. If you agree to participate in this study you can either return the consent form to a staff member or we can provide you with a reply paid envelope if you prefer.

How will I receive feedback?

Outcomes from the project will be summarised and given to you by the investigator if you would like to see them.

Funding

This research is supported by the National Health and Medical Research Council Partnership Centre on Dealing with Cognitive and Related Functional Decline in Older People. The researchers have no financial or other conflicts of interest to declare.

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 6753). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Family members

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INFORMATION SHEET

Title: *INSPIRED (NSW and WA): Investigating services provided in the residential care environment for dementia*

Investigators:
Ms Rachel Milte
Rehabilitation, Aged and Extended Care
Flinders University
Ph: 08 8275 1067

Professor Maria Crotty
Rehabilitation, Aged and Extended Care
Flinders University
Ph: 08 82751103

Ms Tiffany Easton
Rehabilitation, Aged and Extended Care
Flinders University
Ph: 08 8275 1067

Description of the study:

This study is part of the project entitled '*INSPIRED (NSW and WA): Investigating services provided in the residential care environment for dementia*'. This project will investigate costs of providing residential care and the quality of care and quality of life of people living in residential care. This project is supported by Flinders University Rehabilitation, Aged and Extended Care department.

Purpose of the study:

This project aims to find out if how residential aged care is provided can affect the quality of care, quality of life, and use of hospital and health care services of the people living in residential care.

What will I be asked to do?

We would like to ask your permission to conduct some research involving your family member living in residential care at the moment. We would like to ask you and your

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family member some questions in a one-on-one interview with a researcher about your family member's quality of life, the quality of care they receive, and their physical function. An example of a question we would ask about your family member is "How much time are caregiving staff able to spend with <your family member>?" Sensitive questions like this, about the care your family member currently receives, will only be asked in private by a researcher who is not an employee of HammondCare. Other questions, about your family member's general health and functioning, such as whether they can go to the toilet by themselves or whether they need help, may be asked by a HammondCare carer who has been assigned to help us with this particular study and who will talk to you or your family at a different time.

We would also ask the staff at the facility your family member is living in about their general background, health, and how their mood, memory, and thinking has been going over the past year. We would look at your family member's case notes at this facility to get information on their health, medication use, marital status, level of education, how their thinking has been going, the type of care and services they receive here and whether they have been to hospital over the past 12 months. We would also seek your permission to get information from government databases about how often they have been to the doctor and used other health services including hospitals, and if they have used certain types of medication (those on the Pharmaceutical Benefits Scheme) over the past year. You will be asked to fill out a consent form authorising the study access to your family member's complete Medicare and Pharmaceutical Benefits Scheme (PBS) data. Medicare collects information on your doctor visits and the associated costs, while the PBS collects information on the prescription medications you have filled at pharmacies. The consent form is sent securely to the Department of Human Services who holds this information confidentiality. No more than 65 minutes of your time in total would be required and this could be split over as many smaller periods of time as you or your family member needs to feel comfortable.

What benefit will I gain from being involved in this study?
It is hoped that the sharing of your experiences will improve the planning and delivery of future residential aged care services. We are very keen for residential care services to be as good quality and relevant as possible to people in the future. We cannot guarantee that you or your family member will be directly benefit from participating in this study, or that there will be any changes to services provided at their facility as a result of the information provided.

Will I be identifiable by being involved in this study?
While we are unable to guarantee anonymity, only the research team will have access to your and your family member's personal information to allow them to organise an interview to collect the data or to facilitate access to the records or databases you have given us permission to collect health service usage information from. Your and your family member's contact details will be stored separately from the information we collect during the interview. All personal information will be treated in the strictest confidence. Electronic documents will be kept on a password protected computer that only the research team will have access to. The findings of the study will be published in a journal. All identifying information will be removed prior to reporting the research findings. All records will be stored for at least five years from the date of publication and PBS and Medicare data collected, both electronic and hard copy, will be destroyed at this point.

Are there any risks or discomforts if I am involved?

We anticipate few risks from your and your family member's involvement in this study. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the investigator. If participating in the interview brings up emotions of distress or anxiety for you, you can talk to the home's care staff, Chaplain or Pastoral Care workers. In addition, Life Line is a 24 hour free counselling service available across Australia for anyone and is able to be contacted via telephone on 13 11 14. Members of this research team can also refer you to a confidential counselling service via Alzheimer's Australia if you need further support.

How do I agree to participate?

Participation is entirely voluntary. You and your family member may answer 'no comment' or refuse to answer any questions and are free to withdraw from the interview at any time without effect or consequences. If you or your family member wishes to withdraw from the study, please notify a member of the research personnel. A consent form accompanies this information sheet. If you agree to participate in this study you can either return the consent form to a staff member or we can provide you with a reply paid envelope if you prefer.

How will I receive feedback?

Outcomes from the project will be summarised and given to you by the investigator if you would like to see them.

Funding

This research is supported by the National Health and Medical Research Council Partnership Centre on Dealing with Cognitive and Related Functional Decline in Older People. The researchers have no financial or other conflicts of interest to declare.

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

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Staff

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CRICOS Provider No. 00114A

INFORMATION SHEET

Title: *INSPIRED (NSW and WA): Investigating services provided in the residential care environment for dementia*

Investigators:
Ms Rachel Milte
Rehabilitation, Aged and Extended Care
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Ph: 08 8275 1067

Professor Maria Crotty
Rehabilitation, Aged and Extended Care
Flinders University
Ph: 08 82751103

Ms Tiffany Easton
Rehabilitation, Aged and Extended Care
Flinders University
Ph: 08 8275 1067

Description of the study:
This study is part of the project entitled '*INSPIRED (NSW and WA): Investigating services provided in the residential care environment for dementia'*. This project will investigate costs of providing residential care and the quality of care and quality of life of people living in residential care. This project is supported by Flinders University Rehabilitation, Aged and Extended Care department.

Purpose of the study:
This project aims to find out if how residential aged care is provided can affect the quality of care, quality of life, and use of hospital and health care services of the people living in residential care.

What will I be asked to do?
You are invited to attend a one-on-one interview with a researcher who will ask you a few questions about the quality of life, health and physical functioning of some of the residents in your facility, who have independently consented to participate in this work.

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achievement

An example of the more sensitive questions you may be asked is whether or not the resident can perform personal hygiene tasks sufficiently by themselves or whether they need help, or whether or not the resident has hallucinations or is depressed. No more than 25 minutes of your time per resident would be required.

What benefit will I gain from being involved in this study?
It is hoped that the sharing of your knowledge will improve the planning and delivery of future residential aged care services. We are very keen for residential care services to be as good quality and relevant as possible to people in the future. We cannot guarantee that you will be directly benefit from participating in this study, or that there will be any changes to services provided at your facility as a result of the information you provide.

Will I be identifiable by being involved in this study?
While we are unable to guarantee anonymity, only the research team will have access to your personal information to allow them to organise an interview with you. Your contact details will be stored separately from the information we collect during the interview. All personal information will be treated in the strictest confidence. Electronic documents will be kept on a password protected computer that only the research team will have access to. The findings of the study will be published in a journal. All identifying information will be removed prior to reporting the research findings. All records will be stored for at least five years from the date of publication and PBS and Medicare data, both electronic and hard copy, will be destroyed at this point.

Are there any risks or discomforts if I am involved?
We anticipate few risks from your involvement in this study. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the investigator. If participating in the interview brings up emotions of distress or anxiety for you, you can talk to your facility's Chaplain or Pastoral Care workers. In addition, Life Line is a 24 hour free counselling service available across Australia for anyone and is able to be contacted via telephone on 13 11 14. Members of this research team can also refer you to a confidential counselling service via Alzheimer's Australia if you need further support.

How do I agree to participate?
Participation is entirely voluntary. You may answer 'no comment' or refuse to answer any questions and you are free to withdraw from the interview at any time without effect or consequences. If you wish to withdraw from the study, please notify a member of the research personnel. A consent form accompanies this information sheet. If you agree to participate in this study you can either return the consent form to a staff member or we can provide you with a reply paid envelope if you prefer.

How will I receive feedback?
Outcomes from the project will be summarised and given to you by the investigator if you would like to see them.

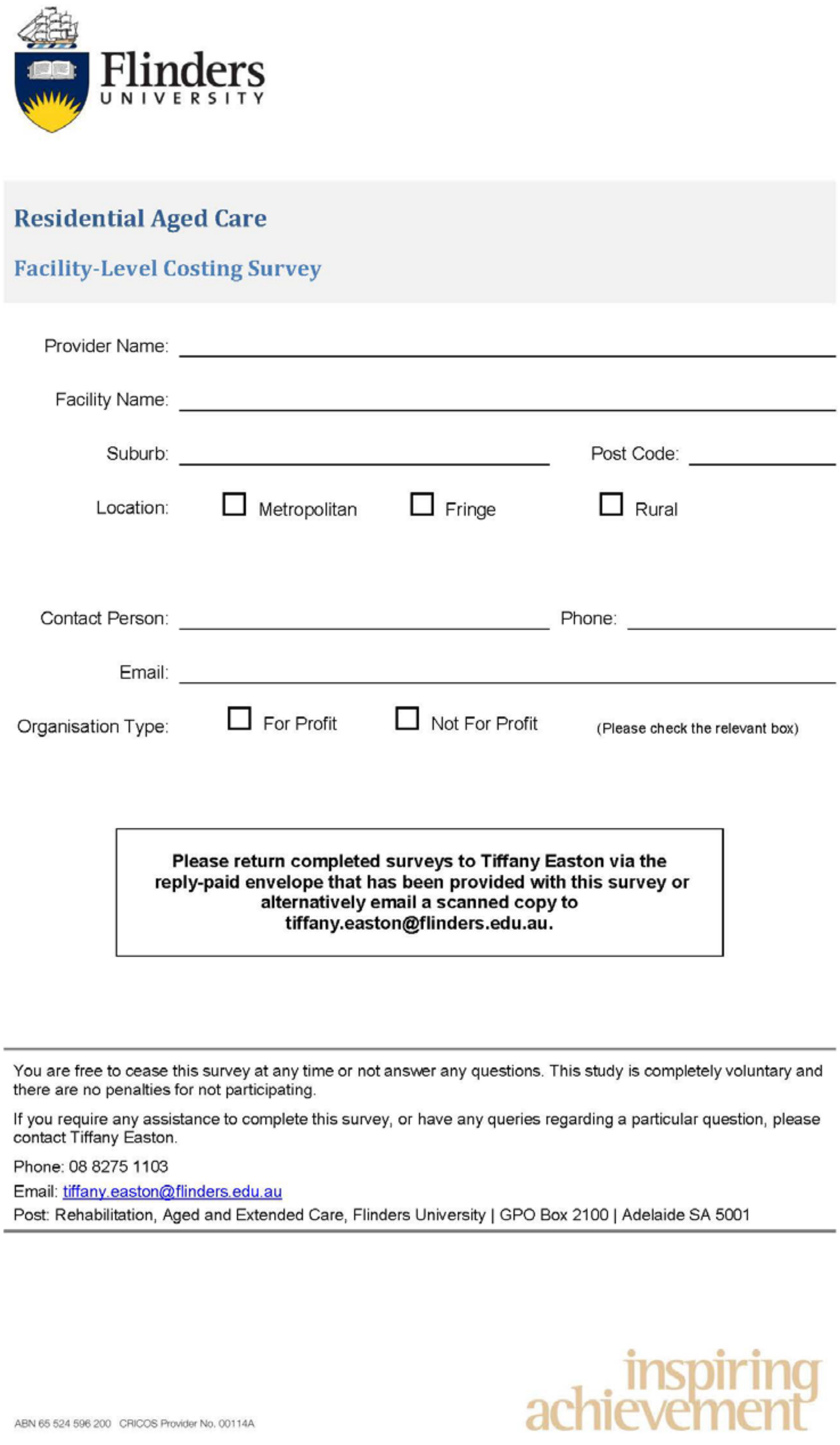
Funding
This research is supported by the National Health and Medical Research Council Partnership Centre on Dealing with Cognitive and Related Functional Decline in Older People. The researchers have no financial or other conflicts of interest to declare.

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 6753). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix V: Questionnaires & Data Collection Forms

Facility Cost Survey



Flinders
UNIVERSITY

Residential Aged Care

Facility-Level Costing Survey

Provider Name: ____________________

Facility Name: ____________________

Suburb: ____________________ Post Code: __________

Location: ☐ Metropolitan ☐ Fringe ☐ Rural

Contact Person: ____________________ Phone: __________

Email: ____________________

Organisation Type: ☐ For Profit ☐ Not For Profit (Please check the relevant box)

Please return completed surveys to Tiffany Easton via the reply-paid envelope that has been provided with this survey or alternatively email a scanned copy to tiffany.easton@flinders.edu.au.

You are free to cease this survey at any time or not answer any questions. This study is completely voluntary and there are no penalties for not participating.

If you require any assistance to complete this survey, or have any queries regarding a particular question, please contact Tiffany Easton.

Phone: 08 8275 1103
Email: tiffany.easton@flinders.edu.au
Post: Rehabilitation, Aged and Extended Care, Flinders University | GPO Box 2100 | Adelaide SA 5001

ABN 65 524 596 200 CRICOS Provider No. 00114A

inspiring achievement

Operational Costs

1. Number of Physical Beds

	30 June 2013	30 June 2014
Total Number of Physical Beds		
Breakdown:		
Secure Dementia		
Extra Services		
Respite		
Transition Care		
Other (Describe):		

2. Occupancy (Actual)

	30 June 2013	30 June 2014
Average Total Site Occupancy Rate (%pa)	%	%
Average Annual Turnover (%pa)	%	%

3. Resident Profile

Please enter the current number of residents in each category based on their most recent ACFI appraisal.

Level	Activities of Daily Living (ADL)	Behaviour (BEH)	Complex Health Care (CHC)
Nil			
Low			
Medium			
High			

4. Staffing Arrangements & Turnover (Actual)

For the year ended:	30 June 2013	30 June 2014	
Agency Rate	%	%	*agency workers as a percentage of total workers*
Proportion of staff on casual contracts	%	%	
Annual Staff Turnover (%pa)	%	%	

5. Volunteers

	30 June 2014
Average number of volunteers	
Average hours <u>per fortnight</u> per volunteer	

6. Staffing – Current Roster

Please enter the average number of Full-Time Equivalent (FTE) employees rostered for each type of employee during the given periods. Only include hours for your own staff (not external contractor hours).	Number of rostered workers (FTE) per period					
	AM	PM	Night	Saturday	Sunday	Public Holiday
Direct Care Workers						
Nurse Practitioners (NP)						
Registered Nurses (RN)						
Enrolled Nurses (EN)						
Personal Care Attendants (PCA)						
Allied Health Professional (AHP)						
Allied Health Assistant (AHA)						
Other (Specify):						
Ancillary care workers						
Chefs (Qualified)						
Cooks (Unqualified)						
Kitchen Hands						
Cleaning staff						
Laundry staff						
Maintenance (Property & Gardens)						
Other (Specify):						
Non-direct care workers						
Care Manager/Co-ordinator						
Management						
Administration						
Spiritual/pastoral care						
Other (Specify):						

7. Rostered Non-PAYG Workers

If applicable, please enter the average number of Full-Time Equivalent (FTE) workers rostered for each type of Non-PAYG worker during the given periods.	Number of rostered workers (FTE) per period					
	AM	PM	Night	Saturday	Sunday	Public Holiday
Agency/Brokered Workers						
Registered Nurses (RN)						
Enrolled Nurses (EN)						
Personal Care Attendants (PCA)						
Allied Health Professional (AHP)						
Other (Specify):						

8. Catering

(Please check the relevant box)

Insourced ☐ Catering is primarily performed by the facility's own staff.

Outsourced ☐ Catering is primarily performed by an outside contractor's staff.

9. Laundry

(Please check the relevant box)

Insourced ☐ Laundry services are primarily performed by the facility's own staff.

Outsourced ☐ Laundry services are primarily performed by an outside contractor's staff.

10. Corporate costs

Have a portion of the corporate (head office) costs been charged to this facility? ☐ Yes ☐ No

How were the charges calculated: (Please check the relevant box)

Based on the number of beds ☐

As a % of head office costs ☐

Other assessment ☐ Details: ____________________

What is the approximate breakdown of corporate (head office) costs?

	Proportion of corporate costs
Executive	%
Finance	%
IT	%
HR	%
Learning & development	%
Risk Management	%
Marketing	%
Pastoral Care	%
Property Management	%
Other	%

Facility Profile & Services

11. Room Configuration

Room Type	Number of Rooms	Average Room Size (Sq m)
Single Rooms		
Double Rooms		
Multi-Bed Rooms		
Kitchens		
Lounge rooms		

Number of Floors in the Facility ____ (Only include floors occupied by residents)

Total Facility Floor Area ____ Sq m

12. Age of Facility

Year Constructed ____

Has the facility undergone any significant* refurbishments completed on or after 20 April 2012? ☐ Yes ☐ No

** To be considered significant, the refurbishment must provide benefit to at least 40% of residents, or involve an increase of at least 25% of the number of rooms at the facility.*

13. Construction & Fit-out Costs

Year of Construction/Refurbishment		
Construction Cost	$	Construction cost includes architects, consultants & other establishment/planning fees.
Fit-Out Costs	$	The cost of fittings, beds, carpets and furniture.
Land	$	

14. Staff Training – Direct Care Workers

In the 2013/14 financial year, how much was spent on staff training for **direct care workers**?

Wage-related training & development costs	$
Other training & development costs	$

Did your facility provide training to Direct Care Workers in any of the following areas in the 2013/14 financial year? Please check all that apply.

Area of training	**No training**	**Mandatory training**	**Non-mandatory training**
Dementia training*	☐	☐ *	☐ *
Palliative care	☐	☐	☐
Management & leadership training	☐	☐	☐
Wound management	☐	☐	☐
Mental Health	☐	☐	☐
Allied health	☐	☐	☐
Other (Specify):	☐	☐	☐

*If the facility provides dementia training, please provide further details.

Frequency of training sessions:
(Once-off for new employees, annual, etc.) ____________________

Duration of training:
(Full-day, several hours, etc.) ____________________

Format:
(Online, workshop, etc) ____________________

15. Continuity of Care

Do direct care workers have a permanent roster (i.e. they are assigned to a designated unit) or do they regularly rotate to various parts of the facility?

(Please check the relevant box)

Direct Care Worker	**Work facility-wide**	**Assigned to designated unit(s)**
Nurse Practitioners (NP)	☐	☐
Registered Nurses (RN)	☐	☐
Enrolled Nurses (EN)	☐	☐
Personal Care Attendants (PCA)	☐	☐
Allied Health Professional (AHP)	☐	☐
Allied Health Assistant (AHA)	☐	☐
Other (Specify):	☐	☐

16. Resident Amenities

Which resident amenities are available at the facility? Please check all that apply.

☐ GP services
☐ Allied health suites
☐ Library
☐ Museum
☐ Art Gallery
☐ Family meeting areas
☐ Private dining areas
☐ Church services
☐ Café
☐ Bar
☐ Grocery store
☐ Craft shop
☐ Gift shop
☐ Shops – other
☐ Internet café
☐ Gardens
☐ Hairdressing
☐ Beauty therapies
☐ Massage services
☐ Hydro spas
☐ Mini golf

Please provide details of any other resident amenities available at the facility.

____

____

____

____

17. Social Activities

Who is responsible for program/activity decisions at the facility? Please check all that apply.

☐ Facility staff

☐ Facility residents

☐ Management (on-site)

☐ Management (off-site)

☐ Other (Specify): ____________________

Capital Structure

18. Consolidated Information for the year ending 30 June 2014

Total Equity	$
Total Borrowings	$
Total Interest Bearing Debt	$
Interest Expense	$
Total Accommodation Bonds	$
Total Interest Revenue on Accommodation Bonds	$

Total number of Bonds for facility	

Tax Status: ☐ Tax Paying ☐ Non-Tax Paying (Please check the relevant box)

Summary of Income and Expenses

The following section collects similar data to the ***StewartBrown Aged Care Financial Performance Survey***.

If your organisation participates in the StewartBrown Aged Care Financial Performance survey, you may submit a copy of the facility report for the period ended 30 June 2014 (and 30 June 2013 if available) in lieu of answering this final section of questions.

19. Profitability data

	30 June 2013	30 June 2014
Revenue		
Resident fees		
Accommodation charges		
Extra services amounts		
Other resident revenue		
Government subsidies - ACFI		
Government subsidies - other		
Other government revenue		
Total operating revenue		
Overall EBITDA per bed per annum		

20. Summary of Expenses – Year Ended 30 June 2014

** Note: **Wages** costs include total wages amounts EXCEPT superannuation and workers compensation expenses. Include leave entitlements paid to employees here. Movement in provision of leave entitlements should be included in wages-oncosts.*

Care		
Wages*	$	Include all wages costs related to the direct delivery of care to residents. Include DON, DOC and Care Managers.
Other Care Expenses	$	Include all other costs related to the delivery of care. e.g. medical supplies, craft & activity supplies, incontinence aids & kylies
Cleaning		
Wages*	$	Include all wages & associated wage costs related to cleaning.
Cleaning Contracts	$	Include waste disposal.
Cleaning Materials	$	Not incontinence products.
Other Expenses	$	Include all cleaning costs not included above.
Laundry		
Wages*	$	Include all wages & associated wage costs related to laundry.
Laundry Contracts	$	Include all costs charged by external laundry contractors.
Other Expenses	$	Include all laundry costs not included above.

Summary of Expenses Continued – Year Ended 30 June 2014

Catering

Wages*	$	Include all wages & associated wage costs related to catering & kitchen staff.
Food Costs	$	
Nutritional Supplements	$	
Food contracts	$	Include all costs charged by external catering contractors.
Other Expenses	$	Include all catering costs not included above.

Property & Maintenance

Wages*	$	Include all wages & associated wage costs related to property & maintenance.
Utility Charges	$	Include all utility charges. e.g. electricity, water, gas, etc.
Other Expenses	$	Include all property & maintenance costs not included above.

Administration

Wages*	$	Include all wages & associated wage costs related to administration at the facility. Include CEO (other than DON).
Corporate Costs	$	Portion of corporate (head office) costs charged to this facility.
Other Expenses	$	Include audit, accounting fees, insurance (not Workers' Comp). Exclude interest expense, depreciation, facility rental/lease & taxation.

Wage on costs

Conference & education	$	Include travel, accom, etc. Do not include wages.
Staff Recruitment costs	$	
Other Expenses	$	Include payroll tax, staff on-costs, superannuation, Workers' Comp/Workcover.

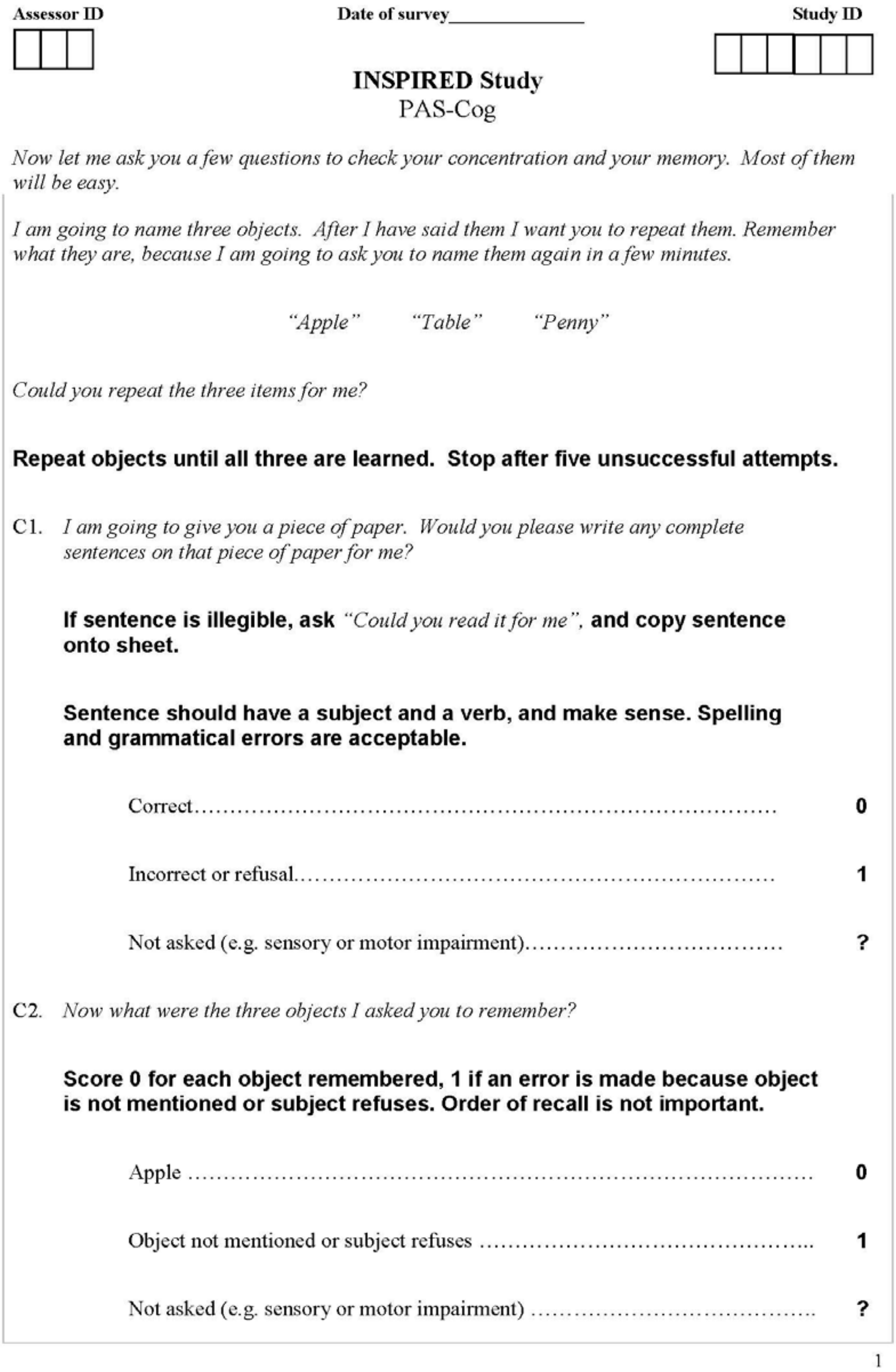
Total Expenses	**$**

21. Further comments

If you have any further comments with regard to this survey, please provide below.

Thank you for completing this survey.

PAS-Cog



Assessor ID ☐☐☐ **Date of survey**______________ **Study ID** ☐☐☐☐☐☐

INSPIRED Study
PAS-Cog

Now let me ask you a few questions to check your concentration and your memory. Most of them will be easy.

I am going to name three objects. After I have said them I want you to repeat them. Remember what they are, because I am going to ask you to name them again in a few minutes.

"Apple" "Table" "Penny"

Could you repeat the three items for me?

Repeat objects until all three are learned. Stop after five unsuccessful attempts.

C1. *I am going to give you a piece of paper. Would you please write any complete sentences on that piece of paper for me?*

If sentence is illegible, ask *"Could you read it for me",* **and copy sentence onto sheet.**

Sentence should have a subject and a verb, and make sense. Spelling and grammatical errors are acceptable.

Correct……………………………………………………………………	**0**
Incorrect or refusal……………………………………………………………	**1**
Not asked (e.g. sensory or motor impairment)………………………………	**?**

C2. *Now what were the three objects I asked you to remember?*

Score 0 for each object remembered, 1 if an error is made because object is not mentioned or subject refuses. Order of recall is not important.

Apple …………………………………………………………………………	**0**
Object not mentioned or subject refuses ………………………………………..	**1**
Not asked (e.g. sensory or motor impairment) …………………………………..	**?**

Table …………………………………………………………………………… **0**

Object not mentioned or subject refuses ……………………………………… **1**

Not asked (e.g. sensory or motor impairment) ………………………………. **?**

Penny …………………………………………………………………………… **0**

Object not mentioned or subject refuses ………………………………………... **1**

Not asked (e.g. sensory or motor impairment) ………………………………... **?**

Please listen carefully to the following name and address, then repeat it:

John Brown, 42 West Street, Kensington.

Repeat address until learned. Stop after five unsuccessful attempts.

Please go on remembering this name and address and I will ask you about it later.

C3. *I am now going to say the names of some people who were famous and I would like you to tell me who they were or why they were famous in the past.*

Score is 0 for each person correctly identified, 1 if the answer is incorrect or subject refuses.

Charlie Chaplin……………………………………………………………….. **0**
(Actor, comedian, film star, comic)

Incorrectly identified or refused………………………………………………… **1**

Not asked (e.g. sensory or motor impairment)…………………………………... **?**

INSPIRED Study

PAS-Cog

Joseph Stalin …………………………………………………………………………….. (Soviet, Russian, WWII leader, Communist leader)	**0**
Incorrectly identified or refused………………………………………………………	**1**
Not asked (e.g. sensory or motor impairment) …………………………………..	**?**
Captain Cook ………………………………………………………………………… (Explorer, sailor, navigator, discoverer)	**0**
Incorrectly identified or refused ………………………………………………..	**1**
Not asked (e.g. sensory or motor impairment) …………………………………..	**?**
Adolf Hitler …………………………………………………………………………... (German, Nazi, WWII leader)	**0**
Incorrectly identified or refused …………………………………………………	**1**
Not asked (e.g. sensory or motor impairment) …………………………………..	**?**

C4. *New Year's day falls on what date?*

First of January/first day of the new year ………………………………………..	**0**
A wrong date, does not know, refusal …………………………………………..	**1**
Not asked (e.g. sensory or motor impairment) …………………………………..	**?**

Assessor ID ☐☐☐ **Date of survey**______________ **Study ID** ☐☐☐☐☐☐

INSPIRED Study
PAS-Cog

C5. *What is the name and address I asked you to remember a short time ago?*

Score 0 for each component remembered, 1 if a component is not mentioned or subject refuses. Order of recall is not important.

John	**0**
Component not mentioned or subject refuses	**1**
Not asked (e.g. sensory or motor impairment)	**?**
Brown	**0**
Component not mentioned or subject refuses	**1**
Not asked (e.g. sensory or motor impairment)	**?**
42	**0**
Component not mentioned or subject refuses	**1**
Not asked (e.g. sensory or motor impairment)	**?**
West Street	**0**
Component not mentioned or subject refuses	**1**
Not asked (e.g. sensory or motor impairment)	**?**
Kensington	**0**

Component not mentioned or subject refuses …………………………………..	**1**
Not asked (e.g. sensory or motor impairment) ………………………………...	**?**

C6. *Here is a drawing. Please make a copy of it here.*

Hand subject the paper with 2 five-sided figures and point to the space underneath it.

Correct if 2 five-sided figures intersect to make a four-sided figure.

Correct…………………………………………..……………………………	**0**
Incorrect or refusal……………………..……………………..………………	**1**
Not asked (e.g. sensory or motor impairment)……………..…………………..	**?**

C7. *Read aloud the words on this page and then do what it says.*

Hand subject the sheet with the words "close your eyes".

Correct (subject closes eyes)……………………………………………………	**0**
Incorrect or refusal………………………………..………….………………	**1**
Not asked (e.g. sensory or motor impairment)……………..…………………..	**?**

C8. *Now, read aloud the words on this page and then do what it says.*

Hand subject the sheet with the words "cough hard".

Correct (subject coughs)………………………..……………………………	**0**
Incorrect or refusal…………………………………...………………………	**1**
Not asked (e.g. sensory or motor impairment)………………..…………………	**?**

Assessor ID ☐☐☐

Date of survey_______________

Study ID ☐☐☐☐☐☐

INSPIRED Study

PAS-Cog

C9. *Tell me what objects you see in this picture?*

Hand the four-object sheet to the subject.

Score 0 for each object identified, 1 if an object is not mentioned or subject refuses. Order of identification is not important.

Teapot, kettle	**0**
Object not mentioned or subject refuses	**1**
Not asked (e.g. sensory or motor impairment)	**?**
Telephone	**0**
Object not mentioned or subject refuses	**1**
Not asked (e.g. sensory or motor impairment)	**?**
Scissors	**0**
Object not mentioned or subject refuses	**1**
Not asked (e.g. sensory or motor impairment)	**?**
Fork	**0**
Object not mentioned or subject refuses	**1**
Not asked (e.g. sensory or motor impairment)	**?**

That brings us to the end of the interview. Thank you very much for your time.

Assessor ID	Date of survey_______________	Study ID
☐☐☐		☐☐☐☐☐☐

INSPIRED Study
PAS-Cog

Now calculate PAS Cognitive Impairment Score (C)

Add response boxes for C1 to C9	☐	C
Number of boxes with ? 's	☐	?
If ? is not zero, score should be pro-rated using formula: 21xC/(21-?).. $\boxed{\frac{21 \times C}{(21-?)}}$	☐	C'

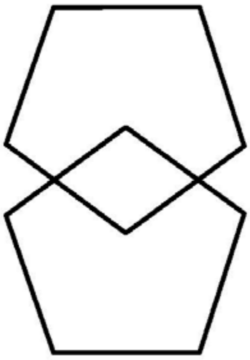
7

Assessor ID ☐☐☐

Date of survey_______________

Study ID ☐☐☐☐☐☐

INSPIRED Study
PAS-Cog



Assessor ID ☐☐☐

Date of survey_______________

Study ID ☐☐☐☐☐☐

INSPIRED Study

PAS-Cog

Close your eyes

9

Assessor ID ☐☐☐

Date of survey_______________

Study ID ☐☐☐☐☐☐

INSPIRED Study
PAS-Cog

Cough hard

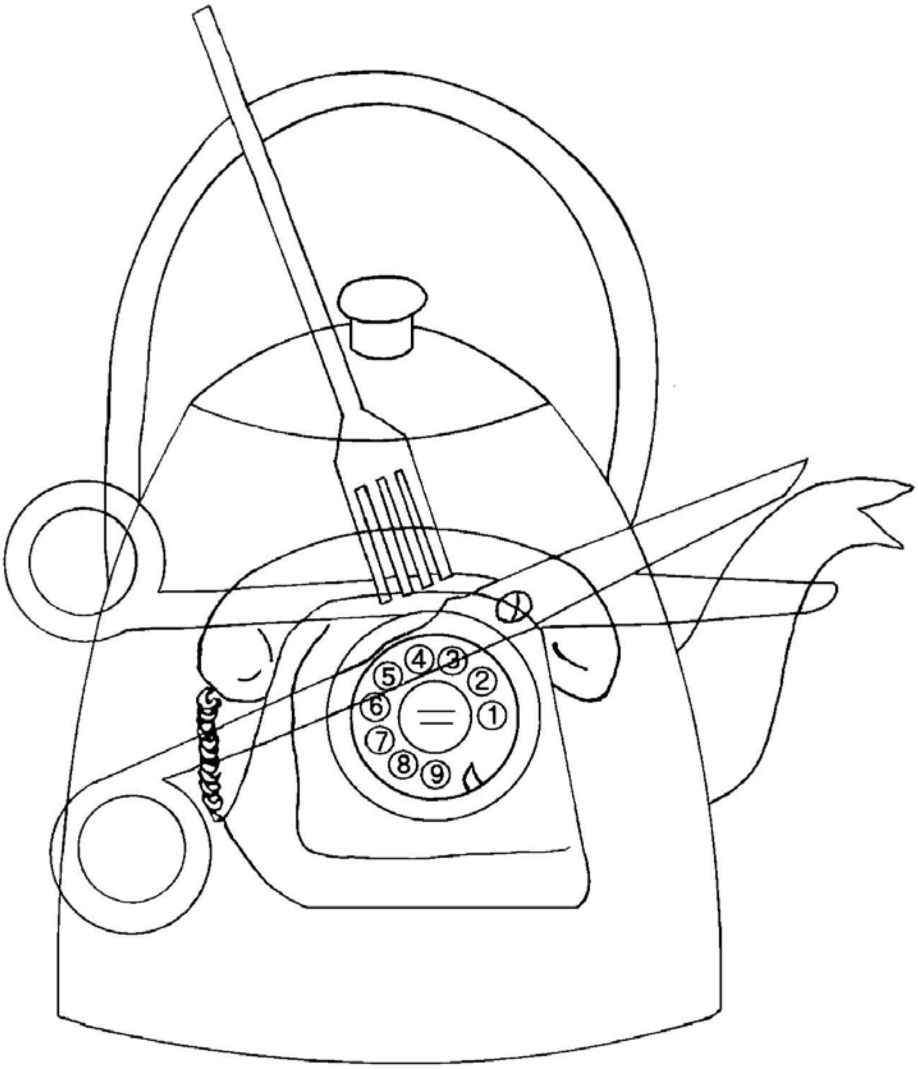
Assessor ID ☐☐☐

Date of survey_______________

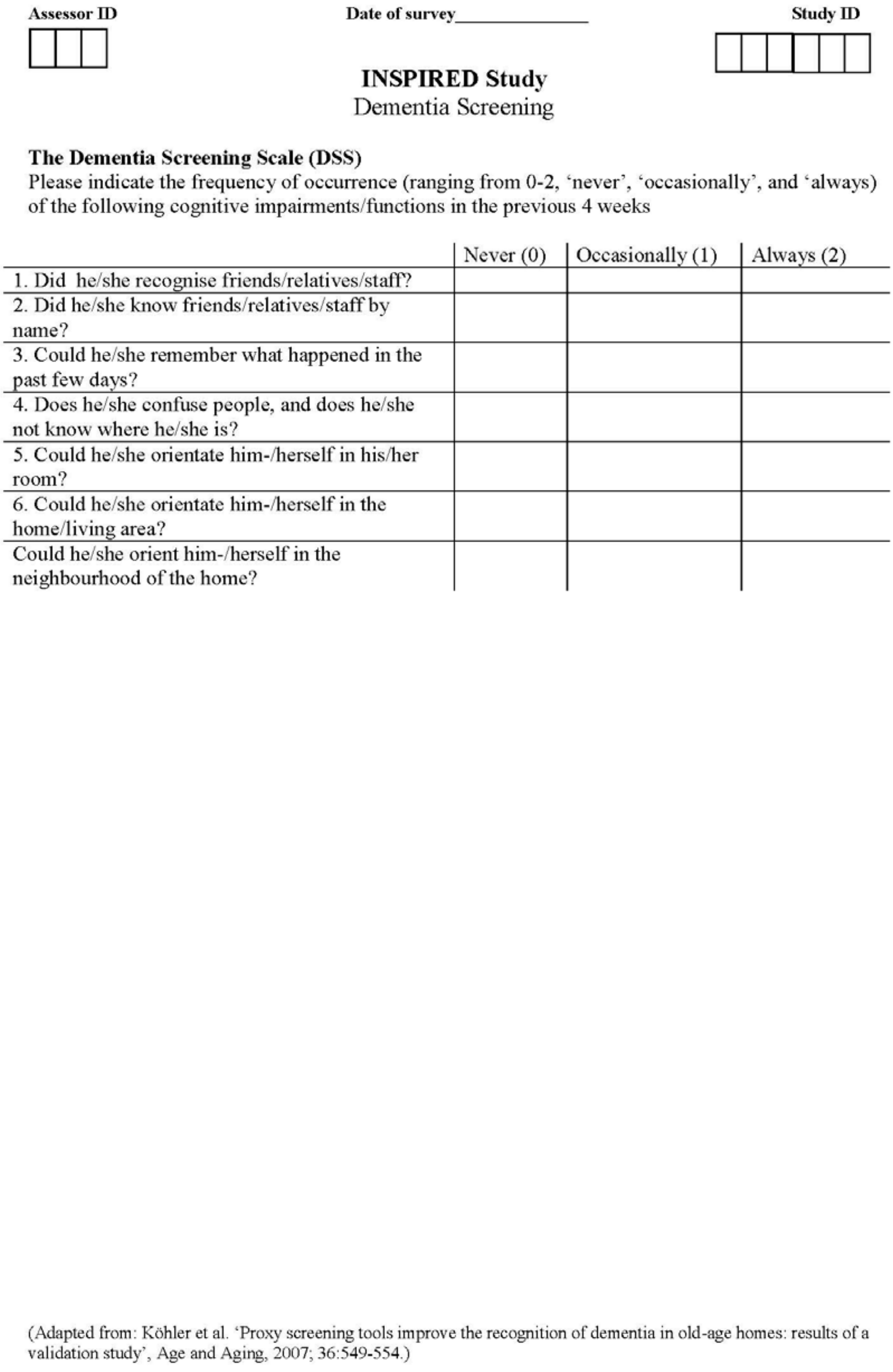
Study ID ☐☐☐☐☐☐

INSPIRED Study

PAS-Cog



Dementia Screening Scale (DSS)



Assessor ID ☐☐☐ **Date of survey**_______________ **Study ID** ☐☐☐☐☐☐

INSPIRED Study

Dementia Screening

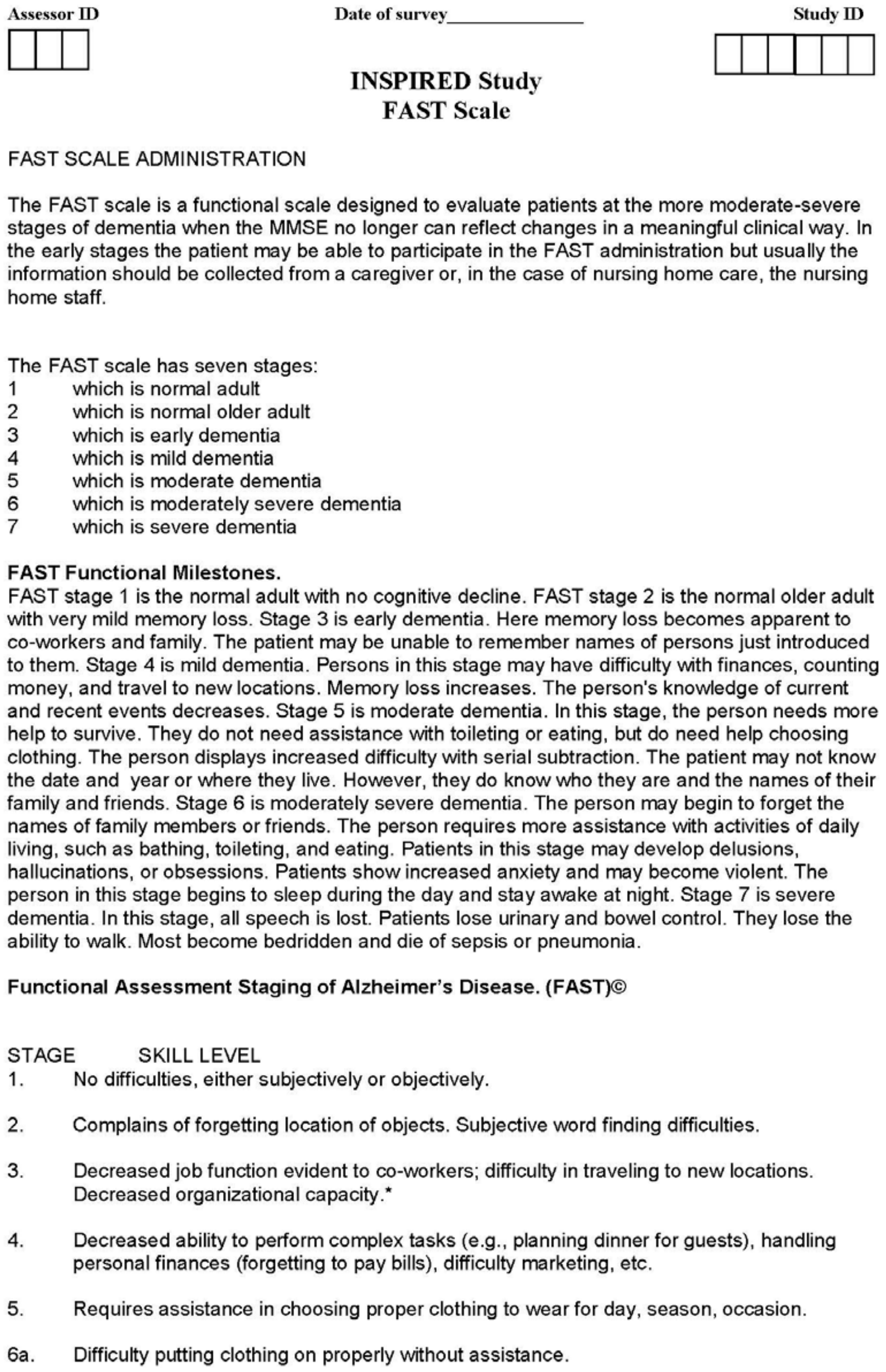
The Dementia Screening Scale (DSS)

Please indicate the frequency of occurrence (ranging from 0-2, 'never', 'occasionally', and 'always') of the following cognitive impairments/functions in the previous 4 weeks

	Never (0)	Occasionally (1)	Always (2)
1. Did he/she recognise friends/relatives/staff?			
2. Did he/she know friends/relatives/staff by name?			
3. Could he/she remember what happened in the past few days?			
4. Does he/she confuse people, and does he/she not know where he/she is?			
5. Could he/she orientate him-/herself in his/her room?			
6. Could he/she orientate him-/herself in the home/living area?			
Could he/she orient him-/herself in the neighbourhood of the home?			

(Adapted from: Köhler et al. 'Proxy screening tools improve the recognition of dementia in old-age homes: results of a validation study', Age and Aging, 2007; 36:549-554.)

Functional Assessment Staging (FAST) scale



Assessor ID ☐☐☐   Date of survey______________   Study ID ☐☐☐☐☐☐

INSPIRED Study
FAST Scale

FAST SCALE ADMINISTRATION

The FAST scale is a functional scale designed to evaluate patients at the more moderate-severe stages of dementia when the MMSE no longer can reflect changes in a meaningful clinical way. In the early stages the patient may be able to participate in the FAST administration but usually the information should be collected from a caregiver or, in the case of nursing home care, the nursing home staff.

The FAST scale has seven stages:

1 which is normal adult
2 which is normal older adult
3 which is early dementia
4 which is mild dementia
5 which is moderate dementia
6 which is moderately severe dementia
7 which is severe dementia

FAST Functional Milestones.
FAST stage 1 is the normal adult with no cognitive decline. FAST stage 2 is the normal older adult with very mild memory loss. Stage 3 is early dementia. Here memory loss becomes apparent to co-workers and family. The patient may be unable to remember names of persons just introduced to them. Stage 4 is mild dementia. Persons in this stage may have difficulty with finances, counting money, and travel to new locations. Memory loss increases. The person's knowledge of current and recent events decreases. Stage 5 is moderate dementia. In this stage, the person needs more help to survive. They do not need assistance with toileting or eating, but do need help choosing clothing. The person displays increased difficulty with serial subtraction. The patient may not know the date and year or where they live. However, they do know who they are and the names of their family and friends. Stage 6 is moderately severe dementia. The person may begin to forget the names of family members or friends. The person requires more assistance with activities of daily living, such as bathing, toileting, and eating. Patients in this stage may develop delusions, hallucinations, or obsessions. Patients show increased anxiety and may become violent. The person in this stage begins to sleep during the day and stay awake at night. Stage 7 is severe dementia. In this stage, all speech is lost. Patients lose urinary and bowel control. They lose the ability to walk. Most become bedridden and die of sepsis or pneumonia.

Functional Assessment Staging of Alzheimer's Disease. (FAST)©

STAGE	SKILL LEVEL
1.	No difficulties, either subjectively or objectively.
2.	Complains of forgetting location of objects. Subjective word finding difficulties.
3.	Decreased job function evident to co-workers; difficulty in traveling to new locations. Decreased organizational capacity.*
4.	Decreased ability to perform complex tasks (e.g., planning dinner for guests), handling personal finances (forgetting to pay bills), difficulty marketing, etc.
5.	Requires assistance in choosing proper clothing to wear for day, season, occasion.
6a.	Difficulty putting clothing on properly without assistance.

Assessor ID ☐☐☐ **Date of survey**______________ **Study ID** ☐☐☐☐☐☐

INSPIRED Study
FAST Scale

b. Unable to bathe properly; e.g., difficulty adjusting bath water temperature) occasionally or more frequently over the past weeks.*

c. Inability to handle mechanics of toileting (e.g., forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue) occasionally or more frequently over the past weeks.*

d. Urinary incontinence, occasional or more frequent.

e. Fecal Incontinence, (occasional or more frequently over the past week).

7a. Ability to speak limited to approximately a half dozen different words or fewer, in the course of an average day or in the course of an intensive interview.

b. Speech ability limited to the use of a single intelligible word in an average day or in the course of an interview (the person may repeat the word over and over).

c. Ambulatory ability lost (cannot walk without personal assistance).

d. Ability to sit up without assistance lost (e.g., the individual will fall over if there are no lateral rests [arms] on the chair).

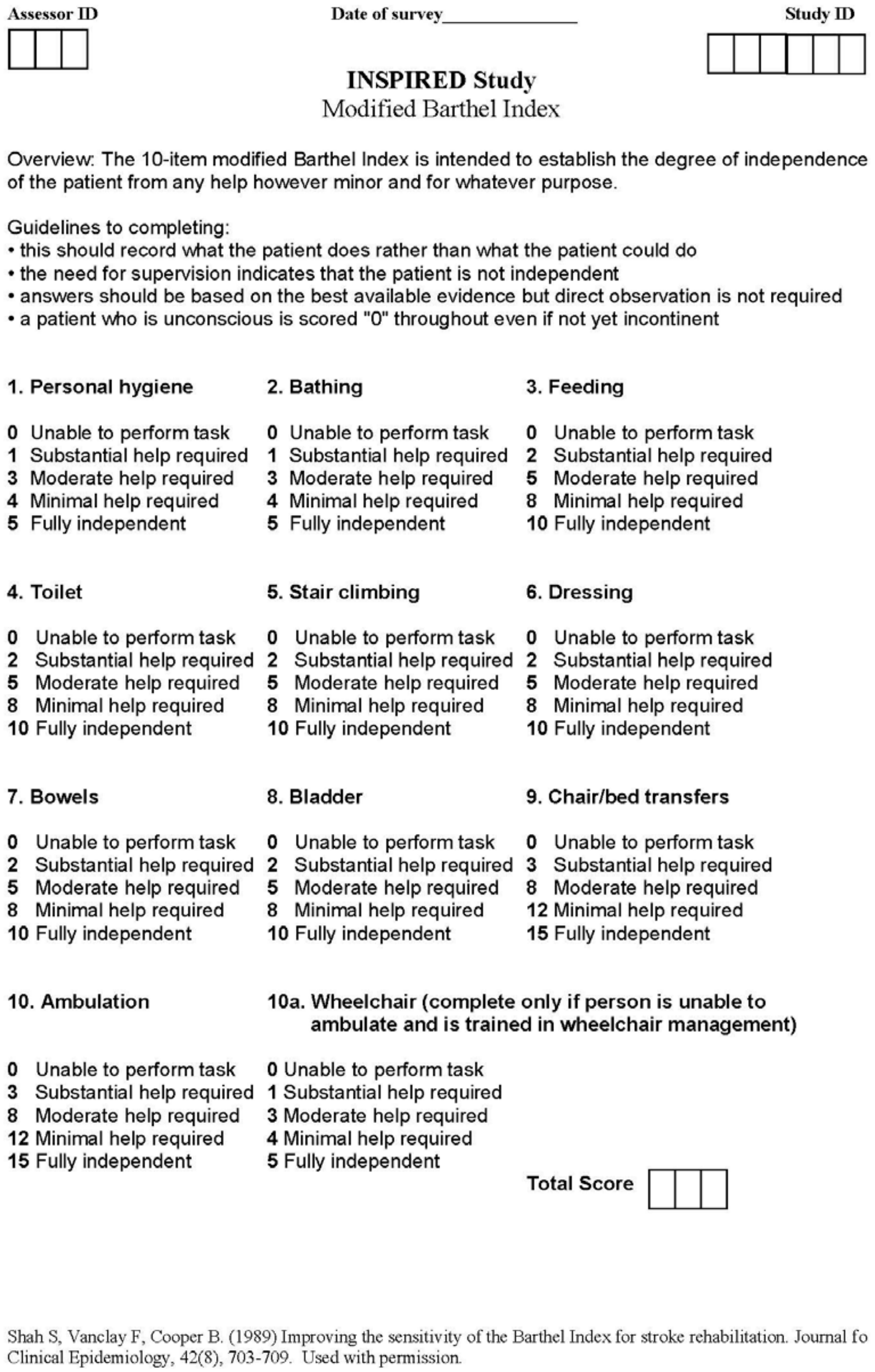
e. Loss of the ability to smile.

STAGE ____

*Scored primarily on the basis of information obtained from a knowledgeable informant and/or caregiver.

Reisberg, B. Functional Assessment Staging (FAST). Psychopharmacology Bulletin. 1988:24: 653-659.

Modified Barthel Index (MBI)



Assessor ID ☐☐☐ **Date of survey**______________ **Study ID** ☐☐☐☐☐☐

INSPIRED Study

Modified Barthel Index

Overview: The 10-item modified Barthel Index is intended to establish the degree of independence of the patient from any help however minor and for whatever purpose.

Guidelines to completing:
- this should record what the patient does rather than what the patient could do
- the need for supervision indicates that the patient is not independent
- answers should be based on the best available evidence but direct observation is not required
- a patient who is unconscious is scored "0" throughout even if not yet incontinent

1. Personal hygiene

0 Unable to perform task
1 Substantial help required
3 Moderate help required
4 Minimal help required
5 Fully independent

2. Bathing

0 Unable to perform task
1 Substantial help required
3 Moderate help required
4 Minimal help required
5 Fully independent

3. Feeding

0 Unable to perform task
2 Substantial help required
5 Moderate help required
8 Minimal help required
10 Fully independent

4. Toilet

0 Unable to perform task
2 Substantial help required
5 Moderate help required
8 Minimal help required
10 Fully independent

5. Stair climbing

0 Unable to perform task
2 Substantial help required
5 Moderate help required
8 Minimal help required
10 Fully independent

6. Dressing

0 Unable to perform task
2 Substantial help required
5 Moderate help required
8 Minimal help required
10 Fully independent

7. Bowels

0 Unable to perform task
2 Substantial help required
5 Moderate help required
8 Minimal help required
10 Fully independent

8. Bladder

0 Unable to perform task
2 Substantial help required
5 Moderate help required
8 Minimal help required
10 Fully independent

9. Chair/bed transfers

0 Unable to perform task
3 Substantial help required
8 Moderate help required
12 Minimal help required
15 Fully independent

10. Ambulation

0 Unable to perform task
3 Substantial help required
8 Moderate help required
12 Minimal help required
15 Fully independent

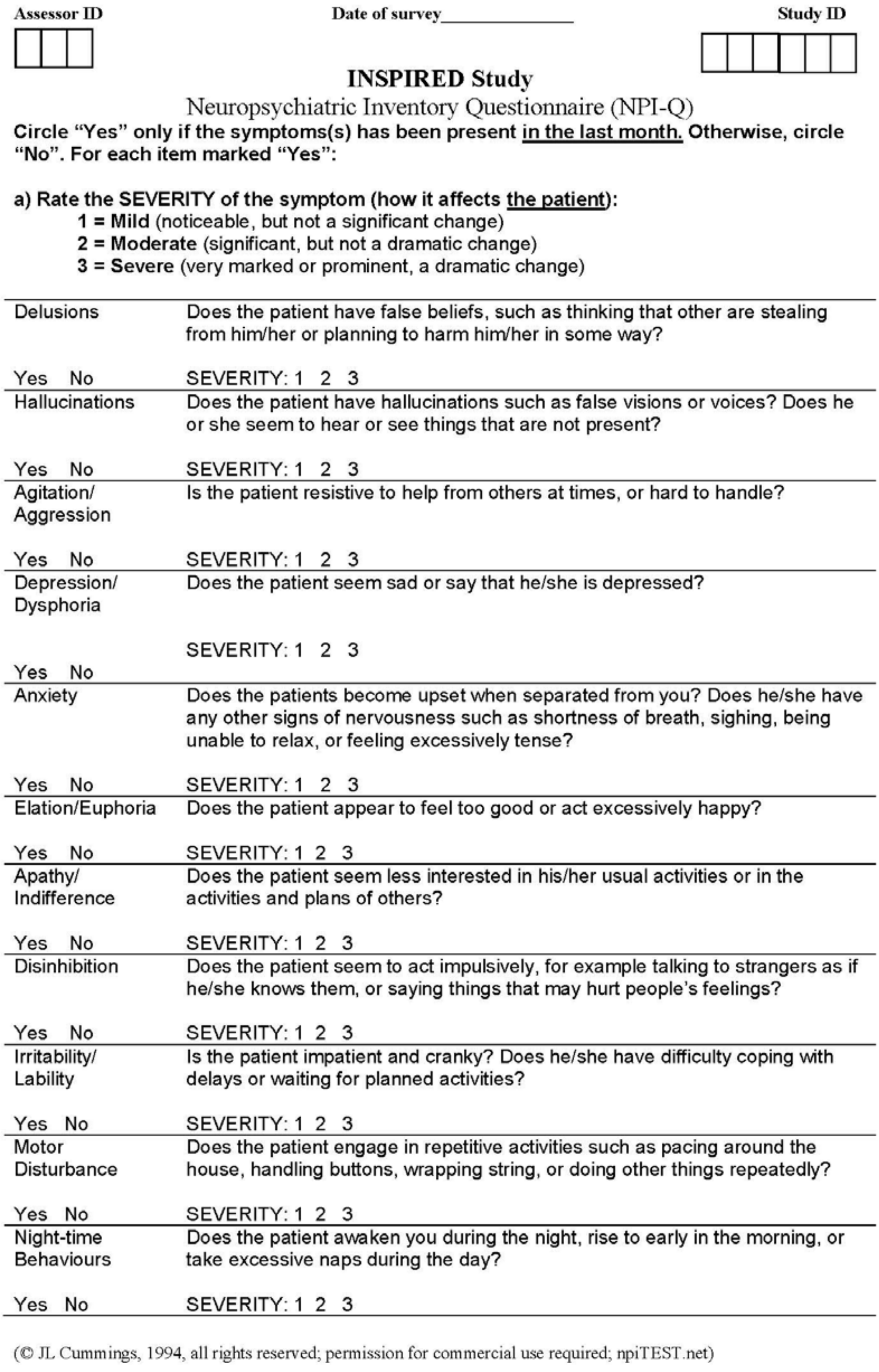
10a. Wheelchair (complete only if person is unable to ambulate and is trained in wheelchair management)

0 Unable to perform task
1 Substantial help required
3 Moderate help required
4 Minimal help required
5 Fully independent

Total Score ☐☐☐

Shah S, Vanclay F, Cooper B. (1989) Improving the sensitivity of the Barthel Index for stroke rehabilitation. Journal fo Clinical Epidemiology, 42(8), 703-709. Used with permission.

Neuropsychiatric Inventory Questionnaire (NPI-Q)



Assessor ID ☐☐☐   **Date of survey**______________   **Study ID** ☐☐☐☐☐☐

INSPIRED Study

Neuropsychiatric Inventory Questionnaire (NPI-Q)

Circle "Yes" only if the symptoms(s) has been present in the last month. Otherwise, circle "No". For each item marked "Yes":

a) Rate the SEVERITY of the symptom (how it affects the patient):

- **1 = Mild** (noticeable, but not a significant change)
- **2 = Moderate** (significant, but not a dramatic change)
- **3 = Severe** (very marked or prominent, a dramatic change)

Delusions	Does the patient have false beliefs, such as thinking that other are stealing from him/her or planning to harm him/her in some way?
Yes No	SEVERITY: 1 2 3
Hallucinations	Does the patient have hallucinations such as false visions or voices? Does he or she seem to hear or see things that are not present?
Yes No	SEVERITY: 1 2 3
Agitation/ Aggression	Is the patient resistive to help from others at times, or hard to handle?
Yes No	SEVERITY: 1 2 3
Depression/ Dysphoria	Does the patient seem sad or say that he/she is depressed?
	SEVERITY: 1 2 3
Yes No	
Anxiety	Does the patients become upset when separated from you? Does he/she have any other signs of nervousness such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?
Yes No	SEVERITY: 1 2 3
Elation/Euphoria	Does the patient appear to feel too good or act excessively happy?
Yes No	SEVERITY: 1 2 3
Apathy/ Indifference	Does the patient seem less interested in his/her usual activities or in the activities and plans of others?
Yes No	SEVERITY: 1 2 3
Disinhibition	Does the patient seem to act impulsively, for example talking to strangers as if he/she knows them, or saying things that may hurt people's feelings?
Yes No	SEVERITY: 1 2 3
Irritability/ Lability	Is the patient impatient and cranky? Does he/she have difficulty coping with delays or waiting for planned activities?
Yes No	SEVERITY: 1 2 3
Motor Disturbance	Does the patient engage in repetitive activities such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?
Yes No	SEVERITY: 1 2 3
Night-time Behaviours	Does the patient awaken you during the night, rise to early in the morning, or take excessive naps during the day?
Yes No	SEVERITY: 1 2 3

Appendix VI: Publications arising from this thesis

Easton *et al. BMC Health Services Research* (2017) 17:226
DOI 10.1186/s12913-017-2165-8

BMC Health Services Research

RESEARCH ARTICLE Open Access

Where's the evidence? a systematic review of economic analyses of residential aged care infrastructure

Tiffany Easton[1,2,3*], Rachel Milte[2,3,4], Maria Crotty[2,3] and Julie Ratcliffe[2,4]

Abstract

Background: Residential care infrastructure, in terms of the characteristics of the organisation (such as proprietary status, size, and location) and the physical environment, have been found to directly influence resident outcomes. This review aimed to summarise the existing literature of economic evaluations of residential care infrastructure.

Methods: A systematic review of English language articles using AgeLine, CINAHL, Econlit, Informit (databases in Health; Business and Law; Social Sciences), Medline, ProQuest, Scopus, and Web of Science with retrieval up to 14 December 2015. The search strategy combined terms relating to nursing homes, economics, and older people. Full economic evaluations, partial economic evaluations, and randomised trials reporting more limited economic information, such as estimates of resource use or costs of interventions were included. Data was extracted using predefined data fields and synthesized in a narrative summary to address the stated review objective.

Results: Fourteen studies containing an economic component were identified. None of the identified studies attempted to systematically link costs and outcomes in the form of a cost-benefit, cost-effectiveness, or cost-utility analysis. There was a wide variation in approaches taken for valuing the outcomes associated with differential residential care infrastructures: 8 studies utilized various clinical outcomes as proxies for the quality of care provided, and 2 focused on resident outcomes including agitation, quality of life, and the quality of care interactions. Only 2 studies included residents living with dementia.

Conclusions: Robust economic evidence is needed to inform aged care facility design. Future research should focus on identifying appropriate and meaningful outcome measures that can be used at a service planning level, as well as the broader health benefits and cost-saving potential of different organisational and environmental characteristics in residential care.

Trial registration: International Prospective Register of Systematic Reviews (PROSPERO) registration number CRD42015015977.

Keywords: Systematic review, Ageing, Long-term care, Infrastructure, Economic evaluation

Background

In most Organisation for Economic Co-operation and Development (OECD) countries, aged care accounts for approximately 1 to 1.5% of gross domestic product (GDP) in terms of government funding alone [1], and on average roughly two-thirds of this funding is allocated to residential care (incorporating care homes, intermediate care facilities, skilled nursing facilities, nursing homes, residential aged care facilities, and residential homes) [2]. Despite the ongoing research and development of alternatives to residential care, including initiatives to enable older people to remain at home for as long as possible [3–6], the number of older people receiving care in a residential facility has continued to grow [2]. Residential care settings tend to cater for individuals living with higher levels of disability and care needs than those in alternative settings such as community care [7, 8]. For

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instance, it is estimated that over 50% of residents in residential care have a recorded diagnosis of dementia [7, 9]. Recent literature suggests that for people with dementia with high levels of physical dependence, residential care can be less costly to provide at a societal level than home-based care [10–12]. This is primarily because of the high informal care costs for society arising from time spent by family and friends on supervision and care in home based settings [10, 11].

The organisational environment or infrastructure is widely discussed in residential aged care settings, in terms of both characteristics of the organisation (such as proprietary status, size, and location), and the physical environment. Structural design choices in residential aged care have been found to directly influence resident outcomes [13]. Improvements in areas such as behaviour, function, well-being, and care outcomes have been linked to specialised environmental design interventions [14]. In contrast, higher rates of depressive symptoms have been linked to larger facilities as well as facilities located in non-urban areas [15].

Economic evaluation research is increasingly being used in the health and aged care sectors in an effort to promote efficiency in the design and delivery of services [16–19]. Health economic evaluation is defined as the comparative analysis of alternative interventions in terms of both their costs (resource use) and outcomes [20]. In an economic evaluation, costs are expressed in terms of the benefit received, typically in the form of an incremental cost-effectiveness ratio (ICER). For example, in a cost-utility analysis, results are presented as the cost per quality-adjusted life year (QALY) gained in which the unit of effect is a 'year in full health'. Outcomes can also be measured in 'natural' units, such as life-years gained or improvements in cognitive functioning, which can be incorporated into a cost-effectiveness analysis. Governmental agencies in healthcare, such as the National Institute for Health and Care Excellence (NICE) and similar bodies around the world, require cost-effectiveness evidence in the form of incremental cost per QALY [21].

While economic evaluation is well established for the evaluation of health technologies and interventions, techniques for assessing the economic value of health or quality of life benefits from infrastructure are much less common and tend to vary widely in the methodologies applied [22, 23]. In addition, economic evaluations conducted with older populations with high rates of dementia or cognitive impairment tend to encounter methodological issues arising from the reduced ability of this population to provide informed consent [24] and self-report their own quality of life [25, 26]. The measurement and valuation of resident outcomes in a residential aged care setting is a complex undertaking due to the majority of residents living with cognitive impairment and dementia [7, 9, 27, 28] however fully appraising these effects is important for evidence-based policy making.

Recent projections estimate that long-term care spending in OECD countries will more than double on average over the next 50 years [1, 29]. Given the ageing of the population [1] and the substantial amount of current and future funding governments provide and are projected to provide for residential care [1, 29], research in this area is warranted. The main objective of this review was to provide a systematic and narrative summary of the existing literature of economic evaluations of residential aged care infrastructure.

Methods

Protocol and registration

This review was conducted in accordance with the Joanna Briggs Institute (JBI) guidance for the systematic review of economic evaluation evidence [30]. A protocol for this systematic review was registered with the PROSPERO International Prospective Register of Systematic Reviews on 30 January 2015 (http://www.crd.york.ac.uk/PROSPERO; registration number CRD42015015977).

Eligibility criteria

Eligible studies included full economic evaluations (e.g. cost-effectiveness analyses, cost-utility analyses, cost-benefit analyses), partial economic evaluations (e.g. cost analyses, cost minimisation analyses, cost consequences analyses), and randomised trials reporting more limited information, such as estimates of resource use or costs of interventions, pertaining to organisational and environmental characteristics aimed at improving the quality of care for older adults in a residential aged care setting. *Organisational characteristics* related to the overall business structure of the aged care provider, and included attributes such as demographics, proprietary status, size, and affiliation. *Environmental characteristics* referred to the physical setting and included tangible attributes such as private rooms, access to outdoors, familiar home-like components, and secure units.

Search and study selection

Eight electronic bibliographic databases were searched from inception to 8 October 2014, including AgeLine, the Cumulative Index of Nursing and Allied Health Literature (CINAHL), Econlit, Informit (databases in Health; Business and Law; Social Sciences), Medline, ProQuest, Scopus, and Web of Science. An update search was run on 14 December 2015.

The search strategies were developed and reviewed with the assistance of two Health Sciences Librarians with expertise in systematic reviews. The strategy combined terms relating to nursing homes, economics, and older people, limited to English language. No study design or date limits were imposed on the search. The full search strategy is available on PROSPERO (http://www.crd.york.ac.uk/PROSPEROFILES/15977_STRATEGY_20150030.pdf).

Due to the large number of results retrieved when searching the multidisciplinary database ProQuest, limits to source type (scholarly journals, reports, dissertations and theses, conference papers and proceedings, and working papers) were applied to this database that were not part of the original search strategy. Newspapers, trade journals, wire feeds, magazines, other sources, books, and encyclopaedias and reference works were excluded.

Titles and abstracts of studies retrieved were reviewed in full by the primary author (T.E.). A second reviewer (see Acknowledgements) independently screened 10% of the titles and abstracts (L.P.L). Full text reports were retrieved for all citations that appeared to meet the inclusion criteria. All full text reports retrieved were reviewed independently by the primary author and second reviewer (T.E. and L.P.L.). Disagreement was resolved through discussion and consultation with a third reviewer (R.M.). Reasons for excluding studies were documented. The reference lists of included studies were hand searched for additional studies by the primary author (T.E.).

Data extraction

The JBI Data Extraction Form for Economic Evaluations was used to extract data from the included studies (http://joannabriggs.org/assets/docs/jbc/operations/dataExtractionForms/JBC_Form_DataE_EconEval.pdf) [31]. Standardised data items extracted included descriptive data about the study and analysis including (i) study population/participants, intervention, comparator(s) and outcomes; (ii) study methods including prices and currency used for costing, time period, sensitivity analyses and measures of resource use; (iii) study context (geographical, health care and broader service delivery setting and culture); (iv) analysis methods. Results for the resource use and/or cost and/or cost-effectiveness measures and the author conclusions were also extracted. The primary author (T.E.) extracted all data. Neither the study selection nor the data extraction was blinded.

Risk of bias assessment

Critical appraisal of studies was undertaken using the JBI Critical Appraisal Checklist for Economic Evaluations (http://joannabriggs.org/assets/docs/critical-appraisal-tools/JBI_Critical_Appraisal-Checklist_for_Economic_Evaluations.pdf) [31], adapted from the Drummond checklist [32], which addressed: the study question; description of alternatives; identification of costs and outcomes; establishment of clinical effectiveness; accuracy, credibility and timing of costs and outcomes; incremental analysis; sensitivity analyses; and generalizability. Studies were rated as 'yes', 'no', or 'unclear' in terms of their compliance with each quality criterion in light of the objective of the study. For instance, a study which was designed to focus only on costs would by definition not have considered outcomes and so it may still score a 'yes' on item 3 which considers whether all relevant costs and outcomes have been identified. A study which was designed as a full economic evaluation on the other hand would need to identify both costs and outcomes to meet this criterion. As the search strategy did not impose date limits, the purpose of this appraisal was not to exclude studies that pre-dated the use of current economic evaluation methods. Rather the purpose of appraisal was to identify methodological issues with the study design that may result in biased measures of cost and/or effect in order to inform the interpretation of study results.

The JBI Critical Appraisal Checklist for Economic Evaluations was chosen for the current study as it covers the same ten items as the Drummond checklist with the addition of an eleventh item which addresses the generalizability of results to the setting of interest for the review [31]. The appraisal was conducted by the primary author (T.E.) and ratified by a second reviewer (R.M.). Disagreements were resolved through discussion between the primary and secondary reviewer.

Data synthesis

Data extracted from included studies were analysed and synthesized in a narrative summary to address the stated review objective. Synthesis included (1) key findings pertaining to organisational and environmental characteristics aimed at improving the quality of care for older adults in a residential aged care setting; (2) a review of approaches taken to include health and quality of life effects in the identified economic analyses; (3) a review of approaches taken to include residents with dementia in the identified economic analyses; and (4) consideration of key methodological issues for consideration in the future design and conduct of economic evaluations of residential aged care infrastructure. This review was prepared in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [33].

Results

Search and study selection

The study selection process is presented in Fig. 1. The electronic database search yielded a total of 23,059 citations; an additional 4 citations were identified through searches of reference lists of included studies. A total of 14,012 unique citations were identified after duplicate removal. After title and abstract screening 13,809 records did not meet eligibility criteria and 7 studies were excluded as the full texts were not available. Full text reviews were conducted for 196 articles and 14 studies, from 16 publications, met the inclusion criteria. The unit of analysis for the purpose of this review was the study, rather than individual publications. We report the findings of this review in accordance

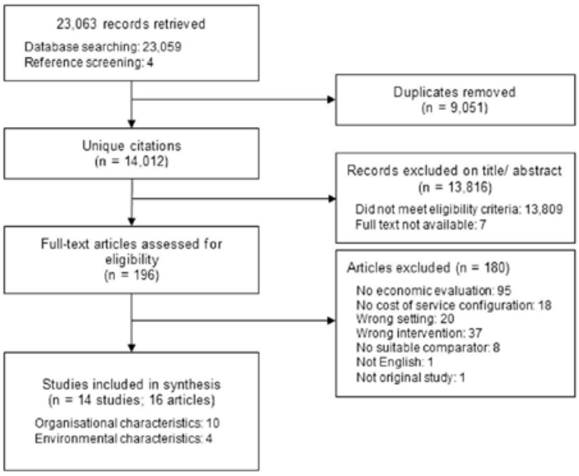

Fig. 1 Flow diagram of study selection

with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [33]. The completed PRISMA checklist is included in Additional file 1.

Overview of studies

Table 1 presents the main characteristics of studies included in the review. All 14 studies contained a partial economic evaluation in the form of a cost analysis. None of the identified studies undertook a full economic evaluation in the form of a cost-benefit, cost-effectiveness, or cost-utility analysis. The majority of studies ($n = 13$) were evaluated from an institutional perspective, and only costs occurring within the facilities themselves were considered. Two of the studies were specific to residents with dementia, in which all residents participating in the study had a recorded diagnosis [34, 35].

Ten of the studies evaluated specific organisational characteristics, while four focused on environmental characteristics. The most frequent study design was cross-sectional ($n = 11$). Other study designs included a cluster-randomised controlled trial ($n = 1$), cross-sectional time series ($n = 1$), and prospective cohort ($n = 1$). Twelve studies pertaining to organisational characteristics were undertaken in the United States with cost data from large data sets collected during the 1970s and 1980s. Only two studies were conducted outside the United States: one study conducted in Switzerland using cost data for the period 1993–2001 [36] and one study conducted in the United Kingdom during 1990–1992 [37]. Three of the studies evaluating environmental characteristics were conducted in the United States [35, 38, 39], while the fourth was conducted in Australia [40].

The number of participating facilities per study ranged from 1 to 3,492 (mean: 424; median: 150). Of the three studies that recruited resident participants, sample sizes varied widely ($n = 44$ [35]; $n = 601$ [40]; $n = 2{,}405$ [37]). The 11 studies that did not recruit resident participants collected facility-level data only, such as operating costs or staff time. Clinical outcome measures - defined as outcomes involving measurable changes in a resident's health or quality of life - were reported in 3 studies (across 4 articles) [40–43]. A summary of main clinical outcomes for the 3 studies are reported in Table 2 and include measures of agitation, quality of life, social interactions and behaviour, cognitive status, function, and a composite measure of poor quality based on rates of decubitus ulcers, catheterization, physical restraints, chemical restraints, and drug errors.

Organisational characteristics

Interventions reported in studies pertaining to organisational characteristics fell into four broad categories: proprietary status, affiliation, size, and location.

Proprietary status

Of the seven studies that focused upon proprietary status, six compared for-profit facilities to one or more alternative proprietary status, and all studies indicated that for-profit facilities provided care at the lowest cost [37, 41, 44–47]. One study compared private not-for-profits to public (i.e. government-owned) not-for-profits and found no significant cost differences [36]. In three of the studies, clinical and process-related outcomes were utilized as markers for the quality of care provided [41, 45, 46]. These proxy

Table 1 Characteristics of included studies

Source, Country	Interventions/ Comparator[a]	Facility n	Participant n	Study design[a]	Type of economic evaluation; analytic viewpoint	Date/source/currency of economic data[a]	Dementia specific	Setting[a]
Studies of Organisational Characteristics ($n = 10$)								
Arling 1987 [44] United States	Chain-affiliated Independent for-profit Government-owned/ not-for-profit	150	N/A	Cross-sectional	Cost analysis; Institutional	1984–1985 ; Medicaid cost reports; *USD*	No	ICF
Bland 1992 [37] United Kingdom	Government-owned For profit Not-for-profit	Phase 1: 100 Phase 2: 6	Phase 1: 2,405 Phase 2: 156	Cross-sectional	Cost analysis; Institutional	1990; Annual reports, accounts, and individual financial returns; *GBP*	No	RH
Davis 1993 [41] United States	For profit Not-for-profit	178	N/A	Cross-sectional	Cost analysis; Institutional	1989; Medicaid Certification inspection surveys and cost reports; *USD*	No	NH
Farsi 2004 [36] Switzerland	Government-owned Not-for-profit	36	N/A	Cross-sectional time series	Cost analysis; Institutional	1993–2001; Annual accounting reports converted to year 2000 Swiss Francs; *CHF*	No	NH
Holmes 1996 [45] United States	Chain-affiliated Proprietary non-chain Freestanding not-for-profit Government-owned Hospital-based	393	N/A	Cross-sectional	Cost analysis; Institutional	1989; Medicaid Certification inspection surveys and cost reports; *USD*	No	NH
Smith 1992 [50] United States	Rural location Urban location	52	N/A	Cross-sectional	Cost analysis; Institutional	1987–1988; Medicaid cost reports; research questionnaire to gather performance, strategy, and strategic planning data; *USD*	No	NH
Sulvetta 1986 [49] United States	Hospital-based Freestanding	3,492	N/A	Cross-sectional	Cost analysis; Institutional	1980; Medicare cost reports, projected to 1983; *USD*	No	SNF
Ullmann 1984 [46] United States	For profit Not-for-profit Government-owned	308	N/A	Cross-sectional	Cost analysis; Institutional	1977; National Nursing Home Survey; *USD*	No	SNF
Ullmann 1986 [48] United States	Independent Chain-affiliated	265	N/A	Cross-sectional	Cost analysis; Institutional	1977; National Nursing Home Survey; *USD*	No	SNF
Ullmann 1987 [47] United States	For profit Not-for-profit Government-owned	494	N/A	Cross-sectional	Cost analysis; Institutional	1976; Source not stated; *USD*	No	SNF

Table 1 Characteristics of included studies *(Continued)*

Studies of Environmental Characteristics ($n = 4$)								
Calkins 2007 [38] United States	Private room s Enhanced shared rooms Traditional shared rooms	N/A	189 (bedrooms)	Cross-sectional	Cost analysis; Institutional	Date not disclosed.; Standard commercial-grade-construction assumptions for the Cleveland, Ohio area; *USD*	No	NH
Chenoweth 2014 [40] Australia	Person-centred care (PCC) Person-centred environment (PCE) Both PCC + PCE Usual care	38	601	Cluster Randomised Controlled Trial	Cost analysis; Institutional	2009–2011; Resource use measured and unit costs assigned using market rates; *AUD*	Yes	RACF
Jenkens 2011 [39] United States	Green House model Usual care	7	N/A	Cross-sectional	Cost analysis; Institutional	2008; Commercial construction costs sourced from Reed Construction Data; *USD*	No	SNF
Maas 1998 [35]; Swanson 1993 [42]; Swanson 1994 [43] United States[b]	Special care unit Traditional unit	1	44	Prospective cohort study	Cost analysis; Health care	Date not disclosed; Resource use measured and unit costs assigned - source of unit cost data not disclosed; *USD*	Yes	NH

Settings: ICF, intermediate care facility; SNF, skilled nursing facility; NH, nursing home; RACF, residential aged care facility; RH, residential home

[a] Headings taken from the JBI Data Extraction Form for Economic Evaluations (http://joannabriggs.org/assets/docs/jbc/operations/dataExtractionForms/JBC_Form_DataE_EconEval.pdf)

[b] All three publications are from the same study

Table 2 Summary of clinical outcomes, measurement instrument used, and effectiveness for studies reporting a clinical outcome

Intervention, Study	Outcome	Measurement instrument	Effectiveness results as measured by measurement instrument (baseline; follow-up)
Proprietary status, Davis 1993 [41]	Composite measure of poor quality based on rates of decubitus ulcers, catheterization, physical restraints, chemical restraints, and drug error rates.	Composite index *Higher scores indicate poorer quality*	*Mean (SD)* For-profit: 0.34 (2.30) Not-for-profit: −0.57 (1.87)
Person-centred environment (PCE), Chenoweth 2014 [40]	Agitation	Cohen Mansfield Agitation Inventory (CMAI) *Higher score indicates greater agitation*	*Mean (95% CI)* Control: 52 (43–61); 51 (41–62) PCE: 65 (57–73); 55 (46–64); $p = 0.04$
	Quality of life	DemQol-proxy *Higher score indicates improved quality of life*	*Mean (95% CI)* Control: 101 (98–104); 103 (99–106) PCE: 101 (99–104); 106 (103–109); $p = 0.02$
	Social interactions and behaviour	Care interaction quality (QUIS) *% interactions positive*	*Mean (95% CI)* Control: 78 (73–83); 82 (76–88) PCE: 78 (74–83); 82 (76–87); $p = 0.55$
		Emotional responses in care (ERIC) *% positive*	*Mean (95% CI)* Control: 25 (20–30); 25 (18–31) PCE: 23 (18–28); 26 (21–32); $p = 0.63$
Special care unit (SCU), Swanson 1993 [42] Swanson 1994 [43]	Cognitive status	Alzheimer's Disease Assessment Scale (ADAS) *Cognitive dimension, higher scores indicate lower cognitive ability*	*Mean (SD)* Traditional: 45.38 (15.64); 52.88 (17.89) SCU: 56.67 (12.94); 59.69 (12.95)
	Social interactions and behaviour	Individual Incident Reports (IIR) *Number of catastrophic reactions*	*Mean (SD)* Traditional: 82; 46 SCU: 156; 48
	Function	Functional Abilities Checklist (FAC) *Higher score indicates greater function*	*Mean (SD)* Traditional: 73.67 (15.41); 71.63 (12.25) SCU: 76.15 (12.35); 76.23 (9.76)
		Geriatric Rating Scale (GRS) *Higher score indicates reduced function*	*Mean (SD)* Traditional: 30.89 (8.18); 35.13 (10.22) SCU: 32.69 (7.76); 35.39 (7.38)

measures of care quality varied widely and included rates of decubitus ulcers, catheterisation, physical restraints, chemical restraints, drug error, number of regulatory deficiencies, skill level of persons in charge of nursing shifts, range of therapies provided, and number of people waitlisted. One study sourced quality measures from a state-wide composite rating scale which combined three quality assessment tools administered by interdisciplinary survey teams to evaluate compliance with the state hospital code, federal regulations, and individual resident medical reviews [47] to give an overall rating of either "very good", "good", "needs improvement", or "unsatisfactory". Results indicated a distinct lack of variation amongst the quality ratings for the 494 facilities included in the study, with over 95% of facilities receiving a rating of "good" for overall quality.

A study by Bland and colleagues [37] attempted to link costs to quality across Scottish residential homes for older people in three sectors: public (government-owned), for-profit and not-for-profit. The study concluded that there were no readily identifiable patterns of trade-offs between cost and quality across the three sectors. However, through a comparison of operating costs, the study suggested that the for-profit sector was a low-cost operator, the not-for-profit sector operated in the mid-range for costs, and the public sector operated at the highest cost. Analysis of quality of care data found that larger facilities (within respective sectors) and government-owned facilities (between sectors) were associated with better care. Quality of care was assessed on 130 primary variables through a combination of interview with the facility's officer-in-charge and researcher observation. The quality of care scale was classified into 8 groups: building; procedures; regime; medical care; promotion of continence; care of dementia sufferers; general services; and interviewer-observation.

Affiliation, size and location

Affiliation refers to both hospital-based facilities and facilities owned as part of a chain, as compared with free-standing or independent facilities. Freestanding facilities are those which are not part of a hospital. Independent facilities are those which are not affiliated with a chain. Chain affiliation is defined as membership in a group of facilities operating under one authority or ownership. The minimum number of facilities required to meet this definition varied between studies ranging from three or more facilities [44] to five or more facilities [45] while a third study did not specify a particular number [48]. While there is some evidence to suggest hospital-based facilities have relatively lower capital costs compared with non-hospital based (freestanding) facilities [45], both operating costs and total costs were found to be higher in hospital-based facilities when compared with freestanding institutions [45, 49]. Three studies evaluated the effects of chain-affiliations on operating and total costs, with conflicting results reporting chain-affiliated facilities as having no difference in costs [44], higher costs [45], and lower costs [48] when compared with independent facilities.

Out of four affiliation studies identified by this review [44, 45, 48, 49], process-related outcome measures designed to give an indication of the quality of care provided at the facility were examined in three of the studies and included number of regulatory deficiencies [45], presence of rehabilitation services and nurse-to-bed ratios [49], and facility age, number of therapies provided, and the facility's wait-list size [48]. Chain and free-standing facilities had the highest average annual deficiencies, while hospital-based facilities had the least [45]. Hospital-based facilities were also found to have more rehabilitation services and higher nurse-to-bed ratios [49], which was suggested to indicate higher quality care.

One study compared rurally located nursing homes ($n = 34$) with urban-based facilities ($n = 18$) and found no significant cost differences [50]. No effectiveness data was collected; rather comparisons were made based on facility profits. A second study reported urban-based facilities as having higher total costs than rural facilities [49]. Process-related outcome measures of quality in this study found rural facilities to have higher nurse-to-bed ratios but fewer rehabilitation services.

Only one study was identified which specifically focused on the costs associated with the size of facility. Marginally lower average costs were reported for facilities with 100–199 beds compared with 0–49 beds, 50–99 beds, and 200 or more beds [46]. No effectiveness or quality data were reported.

Environmental characteristics

Interventions reported in studies pertaining to environmental characteristics fell into two broad categories, functional modifications and home-like environments.

Functional modifications

Two studies examined the effects of functional modifications on residents with dementia. Interventions consisted of adjustments to existing spatial configurations with the aim of improving the safety, accessibility and utility of both indoor and outdoor spaces. One study undertook a cluster-randomised controlled trial examining the effects of both person-centred care and person-centred environments for residents with dementia [40]. Modifications varied between participating facilities ($n = 38$), and included changes such as extending activity spaces, modifying internal walls to increase visual access to bedrooms and activity spaces, increasing ease of access to courtyards and gardens, building partitions to reduce overstimulation in large group spaces, and improving gardens and landscaped exteriors with paving, new sitting areas, and covered spaces. It was estimated that all environmental modifications (implemented between 2009 and 2011) cost less than 10,000 Australian Dollars per facility to implement, with the average facility spending 9,198 Australian Dollars.

Outcome measures collected included: quality of life (DemQol and DemQol-proxy), agitation (CMAI - Cohen Mansfield Agitation Inventory), emotional responses (Emotional Responses to Care instrument), and quality of care interactions (QUIS instrument). Results for outcome measures were inconsistent although small statistically significant improvements were found for some participants in levels of agitation, with CMAI scores decreasing from 65 pre-intervention to 55 at the 8-month follow-up in the environmental intervention group compared with the control group which reported CMAI scores of 52 and 51 at pre-intervention and follow-up respectively ($p = 0.04$) [40].

A cost analysis of special care units (SCUs) for residents with dementia conducted by Maas and colleagues [35] provided data on SCU construction and remodelling costs. In this study, participants with dementia were matched by age and cognitive function, and randomly assigned to the SCU or one of the traditional units at the same facility. Modifications to the SCU included redecorating, door modifications and installation of a security system, new walls in the lounge and dining areas, bedroom privacy curtains and special furniture, and installation of a fence in the outdoor area. Total remodelling costs on the SCU (home to 37 residents) were 89,700 US Dollars (date of cost data unknown).

Effectiveness measures from the SCU study were examined in two additional publications [42, 43]. Primary outcome measures included cognitive status (Alzheimer's Disease Assessment Scale) and functional abilities (Functional Abilities Checklist and the Geriatric Rating Scale). No significant differences in cognition or function were found between residents on the SCU, and those in the traditional units [43]. However, the number of catastrophic reactions reduced significantly on the SCU compared with traditional units with the number of reactions decreasing from 156 pre-intervention to 48 at the 12-month follow-up in the SCU group compared with the control group which reported catastrophic reactions of 82 and 46 at pre-intervention and follow-up respectively ($p = 0.035$) [42]. A catastrophic reaction in dementia is defined as an excessive reaction to a seemingly normal, non-threatening situation (e.g. a question asked of the person, bathing, dressing) and is characterised by mood changes or reactions such as weeping, blushing, anger, or agitation [42]. Catastrophic reactions were recorded for each resident on an Individual Incident Record by nursing staff.

Home-like environments

Two studies examined costs associated with providing more home-like care environments. An analysis of bedroom plans conducted by Calkins and Cassella [38] examined room size and construction cost differences between private rooms, shared rooms, and enhanced shared rooms (designed to give the resident a well-defined and generally exclusive territory within the shared room). Findings indicated that private rooms cost more to construct on a per resident basis than shared or enhanced shared rooms. No quantitative quality measures were included in the study. Rather the authors examined the effectiveness of private rooms through a systematic review, interviews and focus groups, the results of which indicated better outcomes associated with private rooms, with evidence indicating that older adults have a strong preference for private bedrooms [38, 51]. Clinical outcomes associated with private rooms, identified as part of the authors' systematic review, included reduced risk of infection such as influenza and gastroenteritis [52, 53].

One study examined the Green House model, which is an alternative living environment to the traditional skilled nursing facilities in the United States that aims to provide a more person-centred, consumer-driven environment. In the Green House model, ten to twelve residents live in a self-contained residence designed to look and feel like a private home. Each resident has a private bedroom and bathroom, and each residence has an open kitchen, living room, and dining room, as well as access to outdoors through a patio or balcony. An analysis of capital costs conducted by Jenkens and colleagues [39] concluded that the Green House model incurred slightly higher capital costs than traditional skilled nursing facilities largely as a result of the increased square foot requirements (an additional 300 square feet per resident, on average). Facility type, size, labour rates, and site-specific preparation costs were found to be the primary drivers of capital costs. No quality or outcome measures were included alongside the measurement of costs assessed in this study.

Critical appraisal

Table 3 presents the results of the assessment of methodological quality of the included studies. The methodological quality of included studies varied widely and a high level of uncertainty was found in the generalisability and transferability of findings. The primary methodological issues identified included: a failure to establish clinical effectiveness in any of the studies, the absence of incremental analysis of costs and consequences in all studies, and a lack of sensitivity analyses to assess the robustness of the base case results to variations in key parameters. Although no studies established clinical effectiveness, two studies (in three articles) did provide effectiveness estimates for the interventions conducted [40, 42, 43], while eight studies utilized clinical or process-related outcomes or observable qualities such as staff-to-resident ratios as markers for quality of care [36, 37, 41, 45–49].

Table 3 Critical appraisal results for included studies using the JBI Critical Appraisal Checklist for Economic Evaluations

Source	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11
	Well-defined question	Comprehensive description of alternatives	All important and relevant costs and outcomes for each alternative identified	Clinical effectiveness established	Costs and outcomes measured accurately	Costs and outcomes valued credibly	Costs and outcomes adjusted for differential timing	Incremental analysis of costs and consequences	Sensitivity analyses conducted	Study results include all issues of concern to users	Results are generalizable
Arling 1987 [44]	Yes	Yes	Yes	No	Unclear	Yes	No	No	No	Yes	No
Bland 1992 [37]	Yes	Yes	Yes	No	Yes	Yes	No	No	No	Yes	Unclear
Davis 1993 [41]	Yes	Yes	Yes	No	Yes	Yes	No	No	No	Yes	No
Farsi 2004 [36]	Yes	Yes	Yes	No	Yes	Yes	No	No	No	Yes	Unclear
Holmes 1996 [45]	Yes	Yes	Yes	No	Yes	Yes	No	No	No	Yes	No
Smith 1992 [50]	Yes	Yes	Yes	No	Yes	Yes	No	No	No	Yes	Unclear
Sulvetta 1986 [49]	Yes	Yes	Yes	No	Yes	Yes	No	No	No	No	Unclear
Ullmann 1984 [46]	Yes	Yes	Yes	No	Yes	Yes	No	No	No	Yes	Unclear
Ullmann 1986 [48]	Yes	No	Yes	No	Yes	Yes	No	No	No	Yes	Unclear
Ullmann 1987 [47]	Yes	Yes	Yes	No	Unclear	Yes	No	No	No	Yes	Unclear
Calkins 2007 [38]	Yes	Yes	Yes	No	Yes	Unclear	No	No	No	No	Yes
Chenoweth 2014 [40]	Yes	Yes	No	No	Unclear	Yes	No	No	No	No	Unclear
Jenkens 2011 [39]	Yes	Yes	Yes	No	Yes	Yes	No	No	Yes	Yes	Yes
Maas 1998 [35]; Swanson 1993 [42]; Swanson 1994 [43]	Yes	Yes	Yes	No	Unclear	Unclear	No	No	No	No	Unclear

Further methodological issues were identified in relation to the reporting of resource use and costs. Four studies reported mean costs but did not provide a measure of variation or dispersion in the cost results (e.g. standard deviation) [35, 38, 40, 49], two studies did not fully disclose the source of their cost data [35, 47] and two studies did not disclose the date for their cost data collection [35, 38]. Out of ten studies addressing organisational characteristics, only one study reported on resource use, reporting mean staff time per resident per week [37]. Similarly, of the four studies relating to environmental characteristics, only one study reported resource use which was reported in the form of room size measurements [38].

Discussion

A total of 14 studies pertaining to organisational and environmental characteristics in residential care were identified by this review, all of which contained partial economic evaluations in the form of cost analyses. The quality of study designs varied across the included studies, and as such study results should be treated with caution. Eight studies utilized various clinical or process-related outcomes as proxies for the quality of care provided, and two studies focused on resident outcomes including agitation, quality of life, and the quality of care interactions. However none of the identified studies attempted to systematically link costs and outcomes in the form of a cost-benefit, cost-effectiveness, or cost-utility analysis. The majority of studies ($n = 12$) did not specifically highlight organisational and/or environmental characteristics pertaining to residents living with dementia.

Formalising these issues within the framework of a systematic review has highlighted the paucity of evidence in this area. The usefulness of studies containing only partial economic evaluations is limited for policy and decision makers, in that they do not present the case on whether the costs of a course of action is worthwhile in terms of benefits provided to improve quality of care, leaving this aspect up to the reader to decide. The studies identified by this review provide a starting point from which to develop future economic studies and the methodological issues discussed throughout this section emphasize the need to do a better job of collecting and reporting data that is helpful for decision makers.

Key findings pertaining to organisational and environment characteristics

In terms of organisational factors, the available literature suggests that for-profit facilities operate at lower costs than not-for-profit and government-owned facilities, while hospital-based facilities may have lower running costs than free-standing facilities. It is important that these results be interpreted with caution firstly because the cost data presented in these studies are dated, having been collected between 1976 and 1989. Secondly, all but one of the studies addressing proprietary status and affiliation were conducted in the United States and therefore their transferability to other aged care systems around the world is unclear. That being said, the value of investigating the cost-effectiveness of organisational characteristics should not be dismissed. While the evidence pointing to cost differences may be dated, there is current literature which identifies variation in outcomes based on organisational factors. For instance, for-profit facilities have been associated with higher staff turnover [54, 55], lower nursing staff levels [55], and lower quality care overall [56]. Given the available literature indicating differences in both costs and effectiveness, future research which aims to link quality measures with cost data for differing proprietary status may provide insight into questions such as whether additional resources allocated in a not-for-profit organisation are producing better outcomes, or if perhaps these organisations are operating less efficiently.

There is a paucity of evidence regarding the impact of location or size on the running costs and cost-effectiveness of residential care facilities. Our review found only two studies related to locality and one study which investigated facility size and thus it is difficult to draw conclusions. There have been a number of studies, however, which have looked at associations between these organisational factors and clinical outcomes. For instance, in a study investigating the use of feeding tubes among residents with advanced cognitive impairment, residents living in urban facilities and residents living in facilities with more than 100 beds were found to have an increased likelihood of having a feeding tube despite empirical data suggesting that feeding tubes are not beneficial in this population [57]. Facilities with more than 100 beds have also been linked to higher staff turnover which has been found to be detrimental to overall quality of care [55]. In light of evidence which links quality outcomes to size and location, future economic evaluation studies are warranted.

The body of evidence examining the impact of the physical environment on people with dementia has been well documented, and environmental design interventions have been shown to affect behaviour, function, well-being, social abilities, orientation, and care outcomes [14]. SCUs have been linked to lower hospitalisation rates [58] and lower likelihood of using feeding tubes [57]. However, economic evaluations of environmental characteristics and dementia-specific facility designs are scant; our review identified only four studies in this domain. Environmental modifications in the identified studies included homelike environments (e.g. single bedrooms, private bathrooms, decorating, and access to outdoors) and functional modifications (e.g. increasing visual access to bedrooms and activity rooms, extending activity spaces, and building partitions to reduce overstimulation). The economic evidence in this review indicates that environmental modifications come at an additional cost, but are weakly associated with better outcomes in the form of reduced agitation and improved social interactions. It is important for future studies investigating the effectiveness of a particular environmental intervention to conduct economic evaluations alongside these trials in order to build a more robust evidence base surrounding the value of investing in specialised designs.

The inclusion of health and quality of life effects

One very prominent methodological issue that emerged from this review was the heterogeneous range of outcomes that have been used. Some of the direct outcomes measured included agitation, improved social interactions, quality of life, behaviour, function, well-being, depressive symptoms, quality of care, rates of decubitus ulcers, catheterisation, physical restraints, and chemical restraints. Other outcomes, which could be presumed to impact on health, included drug errors, number of regulatory deficiencies, skill level of persons in charge of nursing shifts, range of therapies provided, and number of people waitlisted. The development of guidance towards a more consistent methodology for economic assessment of residential aged care infrastructure is needed, specifically with the inclusion, where possible, of the health and quality of life benefits measured from the perspective of the residents themselves including people with dementia.

There have been numerous instruments developed to measure health benefits such as behaviour, function, well-being, care outcomes, and health-related quality of life, for example. Consequently, it is important for the chosen outcome to be an appropriate measure of achievement for the desired objective. For instance, the desired objective of aged care infrastructure may be to improve the quality of life for the residents who live there. The question then becomes what is the most reliable outcome measure to capture improvements in the lives of residents?

One approach may be to present an array of outcome measures for each alternative, allowing the decision-makers to make their own trade-offs between measures of effectiveness. This is commonly known as a cost-consequences analysis. Another possibility is incorporating a generic measure of incremental benefit, such as the QALY. The main benefit of utilising QALYs in this context would be their applicability to all aged care residents, which would allow decision makers to make comparisons across differing programs. Cost-utility analyses, which use QALYs as the outcome measure, are the recommended economic evaluation in national guidelines developed by government agencies in healthcare such as NICE in the UK [21], and the Canadian Agency for Drugs and Technologies in Health in Canada [59]. While these guidelines were developed for economic evaluations of health technologies, they could potentially be applied to aged care infrastructure, for instance where meaningful differences in health-related quality of life between the intervention and comparator have been demonstrated.

It may also be worthwhile to consider a social context, rather than a health context, as potentially more appropriate in a residential care setting. Current research has acknowledged factors outside of health status such as dignity, independence, and having control over their daily lives as important contributors to residents' quality of life [60, 61]. A recent systematic review of instruments for measuring outcomes in economic evaluations within aged care recommends the use of a generic preference based measure of health related quality of life such as the EQ-5D to obtain QALYs in combination with an instrument with a broader quality of life focus to capture dimensions of social well-being, such as the Adult Social Care Outcomes Toolkit (ASCOT) designed to evaluate interventions in social care, or the ICEpop CAPability measure for Older people (ICECAP-O) which measures capability in older people [62]. Ultimately, it is important that the chosen method is sensitive enough to measure changes for this population, and broad enough to allow comparisons to be made at a service planning level.

The inclusion of residents with dementia

Twelve studies identified by this review did not disclose whether residents with dementia had participated. While it is uncertain whether these studies included participants with dementia, the omission suggests that no consideration was given to this subgroup during study design. One study specified that residents were only approached to participate if judged by staff to be capable of self-completing the study questionnaire [37], which suggests cognitively impaired residents were excluded. When designing economic evaluations, it must be ensured that the study sample is representative for the population being assessed. The quality of an economic evaluation is highly dependent on the source of data used, and its ability to be transferred to other settings. In residential care settings, the exclusion of residents with dementia raises serious concerns regarding the representativeness of data given that over 50% of those residing in aged care facilities have a recorded diagnosis of dementia [7, 9].

Further methodological issues

In addition to the issues discussed surrounding the measurement of health and/or quality of life effects, and increasing the representativeness of data by ensuring the inclusion of residents with dementia, an important methodological issue to consider is study design. The common methodology used in the health care sector for implementation research is a cluster randomised design, as participant-level randomisation can introduce bias through exposure of the control group to the intervention [63]. Only one of the studies identified used a cluster randomised design [40]. Employing a randomised design to focus upon the impact of organisational characteristics is often not achievable in the aged care sector. It is not feasible to randomize attributes such as the proprietary status or location of an aged care facility. As shown by this review, observational study designs are much more practical in this setting. However, a cross-sectional study design, which was the most frequently used design in included studies, can identify associations but not causality due to the absence of a time dimension. Well-designed observational studies with a temporal dimension (i.e. prospective or retrospective rather than cross-sectional) have been shown to produce comparable results to randomised controlled trials [64, 65].

An alternative option when randomised controlled trials are not feasible or for extrapolating beyond the time frame of a clinical trial is decision modelling [66, 67]. Using a decision modelling approach, costs and outcomes can be predicted using data synthesised from disparate sources and models can be built to extrapolate long term estimates of costs and benefits. While none of the studies identified in this review utilised a decision modelling approach, this may be a viable direction for future research [67].

Transparency in reporting study methods and results is another area that is important when assessing the validity and reliability of economic evaluations. This is not specific to residential care or to infrastructure, but nonetheless an important consideration. A clear example is the cost analysis of special care units published in 1998 by Maas and Buckwalter [35] which failed to disclose the date the cost data was collected or whether costs were adjusted for inflation. The exact date of this study was not stated, though the first preliminary results were published in 1988 [68], 10 years prior to the cost analysis publication. Future economic evaluations in this area should strive to meet the quality standard for reporting economic evaluation as specified in the Consolidated Health Economic Evaluation Reporting Standards (CHEERS) statement [69] including the quantities of resources used in addition to costs and incorporating the measurement and valuation of service outcomes and quality of life. Disclosures should also be included to indicate the timing of cash flows and the sources of cost data.

Strengths and limitations of the review

This systematic review had a broad scope in order to provide a comprehensive summary of the evidence, and as such we can be confident that we have captured the majority of studies on this subject. The main strength of this review was the systematic and transparent approach which, in combination with the breadth of the objective, allowed for a thorough synthesis of existing economic evaluations of residential aged care infrastructure. The review was conducted to a high methodological standard and met the quality standards set within the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement. Critical appraisal of studies was undertaken using the JBI Critical Appraisal Checklist for Economic Evaluations which is a well-recognised and highly regarded Checklist for assessing the quality of economic evaluation studies previously utilised in other high quality systematic reviews published previously [70, 71]. However, the broad scope of this review, and the incorporation of economic evidence meant that it was necessarily time-intensive, requiring more resources for the search process, data extraction, and analysis compared with a narrow scope review. For pragmatic reasons, one author took responsibility for both the initial examination of all citations and for all data extracted from included studies, and as such it is possible that errors occurred. This review had limitations to analysis imposed by the heterogeneity of interventions, methods, and outcomes in the included studies. A meta-analysis was not possible; rather the review relied on a narrative analysis of the included studies. This is a reflection of the research that has been conducted to date, and again highlights the need for future evaluation research to be carefully planned such that the data collected and reported is useful for decision makers.

Conclusions

This research highlights a gap in economic evidence, and this evidence is needed to inform future aged care sector facility design and development. Despite the high cost of providing care to older people in residential care facilities, there is a lack of robust economic evidence on the value of organisational and environmental design features. There is a shortage of research linking costs to outcomes. The quality of existing cost analyses and economic evidence is varied, and much of the existing research is outdated which limits the usefulness of the data.

Key methodological issues for consideration in the design of economic evaluations of residential care infrastructure include robust study designs, valuing health and/or quality of life effects in a meaningful way, and increasing the representativeness of data by ensuring the inclusion of residents with dementia.

Future research should focus on identifying appropriate and meaningful outcome measures that can be used at a service planning level, as well as the broader health benefits and cost-saving potential of different organisational and environmental characteristics in residential care.

Additional file

Additional file 1: PRISMA checklist (DOC 63 kb)

Abbreviations

ADAS: Alzheimer's Disease Assessment Scale; ASCOT: Adult Social Care Outcomes Toolkit; AUD: Australian Dollar; CHEERS: Consolidated Health Economic Evaluation Reporting Standards; CHF: Swiss Franc; CINAHL: Cumulative Index of Nursing and Allied Health Literature; CMAI: Cohen Mansfield Agitation Inventory; ERIC: Emotional Responses in Care; FAC: Functional Abilities Checklist; GBP: British Pound; GDP: Gross domestic product; GRS: Geriatric Rating Scale; ICECAP-O: ICEpop CAPability measure for Older people; ICER: Incremental cost-effectiveness ratio; ICF: Intermediate care facility; IIR: Individual incident reports; JBI: Joanna Briggs Institute; NH: Nursing home; NHMRC: National Health and Medical Research Council; OECD: Organisation for Economic Co-operation and Development; PCC: Person-centred care; PCE: Person-centred environment; PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses; QALY: Quality-adjusted life year; QUIS: Quality of care interactions; RACF: Residential aged care facility; RH: Residential home; SCU: Special care units; SNF: Skilled nursing facility; USD: United States Dollar

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Availability of data and materials

Details of the review protocol and full search strategy are available on PROSPERO (http://www.crd.york.ac.uk/PROSPERO; registration number CRD42015015977).

Authors' contributions

TE, RM, MC and JM. contributed to the conception, design, analysis and interpretation of data, as well as critical revisions of the manuscript. TE was responsible for the acquisition of the data and drafting the manuscript. TE and RM contributed to the screening of titles/abstracts, full-text reviews, and critical appraisal. All authors read and approved the final manuscript.

Competing interests

The authors declare that they have no competing interests.

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Cost Effectiveness and
Resource Allocation

REVIEW **Open Access**

Advancing aged care: a systematic review of economic evaluations of workforce structures and care processes in a residential care setting

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Abstract

Long-term care for older people is provided in both residential and non-residential settings, with residential settings tending to cater for individuals with higher care needs. Evidence relating to the costs and effectiveness of different workforce structures and care processes is important to facilitate the future planning of residential aged care services to promote high quality care and to enhance the quality of life of individuals living in residential care. A systematic review conducted up to December 2015 identified 19 studies containing an economic component; seven included a complete economic evaluation and 12 contained a cost analysis only. Key findings include the potential to create cost savings from a societal perspective through enhanced staffing levels and quality improvement interventions within residential aged care facilities, while integrated care models, including the integration of health disciplines and the integration between residents and care staff, were shown to have limited cost-saving potential. Six of the 19 identified studies examined dementia-specific structures and processes, in which person-centred interventions demonstrated the potential to reduce agitation and improve residents' quality of life. Importantly, this review highlights methodological limitations in the existing evidence and an urgent need for future research to identify appropriate and meaningful outcome measures that can be used at a service planning level.

Keywords: Systematic review, Long-term care, Economic evaluation

Background

The United Nations has reported population ageing in nearly every country in the world and projections suggest that the number of people aged 60 and over will more than double the 2013 level by 2050 [1]. Even greater will be the expected growth in the so-called 'oldest old' or those aged 80 years and older, with the population in this age group expected to rise from 4 to 10% of the population [2]. Two likely consequences of the ageing population will be an increase in the prevalence of dementia and a growing demand for residential aged care. Dementia prevalence increases dramatically with age from roughly 3% in those aged 70–74 to over 20% for those aged 85 and over [3]. Expert consensus estimates the number of people living with dementia will almost double every 20 years, reaching over 81 million people worldwide by 2040 [3].

Aged care is a significant responsibility for governments. In most OECD countries, aged care accounts for roughly 1–1.5% of GDP in terms of government funding [4], and on average roughly two-thirds of this funding is allocated to residential care [5]. The proportion of the population receiving long-term care has also grown, rising to 2.3% of the population in OECD countries in 2013 [2]. Given the high prevalence of use of these services among older people, especially the rapidly growing 'oldest old', the need for these services is expected to continue to grow, although to what extent is likely to depend upon the health status of individuals as they age, the

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presence of dementia, as well as other social trends, such as the ability of family members to provide informal care. It is estimated that over 50% of residents residing in residential aged care facilities have a recorded diagnosis of dementia [6–9], and thus it is imperative for people with dementia to be included in research studies conducted in this setting. Several recent studies have indicated that for people with dementia with high levels of physical dependence, residential care can be less costly to provide than home-based care [10–12].

Residential care is in the midst of a 'culture change' movement, involving organisational change and a move toward providing more person-centred, individualised care [13]. Person-centred care is also increasingly being recognised as an important focus for the care of individuals living with dementia. A social-psychological theory of dementia care, developed by Kitwood and Bredin [14], links agitation to negative contextual stimuli that neglect personhood. According to the theory, warm and compassionate care interactions should increase well-being, while disrespectful and disengaged care interactions are thought to lead to decreased well-being and increased agitation. Questions remain, however, as to the optimal implementation approaches and staffing configurations to achieve a high quality residential care experience for residents.

The framework of economic evaluation is increasingly being applied in health and aged care services in an effort to promote efficiency in the design and delivery of services. Knowledge of the incremental costs and effectiveness of differing program design features is essential for well-informed resource allocation decisions in residential care. Program design features can be broken down into subcategories to assist in the assessment of quality (see Donabedian [15]). This review focuses on the economic evidence of program features which directly relate to how care is provided in terms of the workforce and its operations (structures of care) and the services provided (processes of care).

To this end, the main objectives of this review were to answer the following questions:

1. Which structures and processes in residential aged care settings have been demonstrated to be cost effective?
2. How have the costs and outcomes for residents with dementia been assessed in economic evaluations?

Methods

Protocol and registration

A protocol for this systematic review was registered with the PROSPERO International Prospective Register of Systematic Reviews on 30 January 2015 (http://www.crd.york.ac.uk/PROSPERO; registration number CRD42015015977).

Eligibility criteria

Eligible studies included full economic evaluations (e.g. cost-effectiveness analyses, cost-utility analyses, cost-benefit analyses), partial economic evaluations (e.g. cost analyses), and randomised trials reporting more limited information, such as estimates of resource use or costs of interventions, pertaining to structures and processes of care aimed at improving the quality of care for older adults in a residential aged care setting.

Structures of care were defined as the workforce and its operations, and included level of staffing, expertise of staff, hours of care per resident per day, and continuity of care. *Processes of care* included activity programs and services implemented in the context of care provision. These definitions were adapted from Donabedian's quality of care model incorporating structure, process, and outcome [15].

Studies pertaining to interventions that did not apply at a facility or unit level such as individualised pharmaceutical interventions and feeding tubes were excluded from this review.

Search and study selection

Eight electronic bibliographic databases were searched from inception to the 8th October 2014, including AgeLine, CINAHL, Econlit, Informit (databases in Health; Business and Law; Social Sciences), Medline, ProQuest, Scopus, and Web of Science. An update search was run on 14 December 2015.

The search strategies were developed and reviewed with the assistance of two Health Sciences Librarians with expertise in systematic reviews. The strategy combined terms relating to nursing homes, economics, and older people, limited to English language. No study design or date limits were imposed on the search. The full search strategy is available on PROSPERO.

Due to the large number of results retrieved when searching the multidisciplinary database ProQuest, results were limited to scholarly journals, reports, dissertations and theses, conference papers and proceedings, and working papers. Newspapers, trade journals, wire feeds, magazines, other sources, books, and encyclopedias and reference works were excluded.

Titles and abstracts of studies retrieved were reviewed in full by the primary review author. A second reviewer independently screened 10% of the titles and abstracts. The overall agreement was then calculated using Cohen's kappa statistic [16]. Full text reports were retrieved for all citations that appeared to meet the inclusion criteria, or where there was any uncertainty. All full text reports retrieved were reviewed independently by two review authors. Disagreement or uncertainty was resolved through discussion and consultation with a third review author. Reasons for excluding studies were documented.

Data extraction

The Joanna Briggs Institute Data Extraction Form for Economic Evaluations was used to extract data from the included studies [17]. The primary review author extracted all data. Neither the study selection nor the data extraction was blinded.

Data items extracted included descriptive data about the study and analysis including (i) study population/participants, intervention, comparator(s) and outcomes; (ii) study methods including prices and currency used for costing, time period, sensitivity analyses and measures of resource use; (iii) study context (geographical, health care and broader service delivery setting and culture); (iv) analysis methods.

Results for the resource use and/or cost and/or cost-effectiveness measures and the author conclusions were also extracted.

Risk of bias assessment

Critical appraisal of studies was undertaken using the Joanna Briggs Institute Critical Appraisal Checklist for Economic Evaluations [17], adapted from the Drummond checklist [18], which addressed: the study question; description of alternatives; identification of costs and outcomes; establishment of clinical effectiveness; accuracy, credibility and timing of costs and outcomes; incremental analysis; sensitivity analyses; and generalizability. The appraisal was conducted by the primary review author and ratified by a second reviewer.

Data synthesis

Data extracted from included studies were analysed and synthesized in a narrative summary to address the stated review objectives. No meta-analysis was conducted due to significant heterogeneity of service configurations in the included studies.

Results

Study selection

The study selection process is presented in Fig. 1. The electronic database search yielded a total of 23,059 citations; an additional 4 citations were identified through searches of reference lists of included studies. A total of 14,012 unique citations were identified after duplicate removal. Full text reviews were conducted for 196 articles and 19 studies, from 22 publications, met the inclusion criteria. The chance-corrected agreement between the abstracts selected by the primary and secondary reviewers was almost perfect with a kappa statistic of 0.88 [19].

Overview of studies

Table 1 presents the characteristics of studies included in the review. Of the 19 studies included in the review, 12 contained a partial economic evaluation in the form of a cost analysis. Seven studies conducted full economic evaluations, including three cost-benefit analyses, two cost-effectiveness analyses, one cost-utility analysis, and one cost-minimisation analysis. Approximately half of included studies (10/19) were evaluated from an institutional perspective, and only costs occurring within the facility itself were considered. Three studies were evaluated from a health care perspective, with resource use and costs calculated for items such as drugs, hospitalisations and outpatient visits. Four studies were evaluated from a societal perspective, which implies that wider costs for resources consumed in all relevant sectors such as the residential facility, the heath care sector, and by the residents and family members themselves were taken into account. One study took a health and social services perspective, which included resources consumed in the health care sector as well as social services such as audiology, chiropody, and speech therapy. Two studies took the perspective of the insurance providers, including health insurance and long-term care insurance.

Ten (53%) of the included studies were conducted in the United States, three in the Netherlands, two in Canada, two in Australia, one in Germany, and one in the United Kingdom. Ten of the studies involved interventions pertaining to processes of care, while nine examined structures of care. Six studies identified examined dementia-specific service configurations.

Study designs were varied. The most frequent study design was a cluster-randomised controlled trial (7/19), followed by cross-sectional (3/19), randomised controlled trial (2/19), and quasi-experimental (2/19). Other study designs included controlled before-and-after, non-randomised experimental trial, prospective cohort, retrospective cohort, and a Markov simulation model.

The number of participating facilities per study ranged from 1 to 177 (mean: 30; median: 11). Thirteen of the studies recruited resident participants, with sample sizes ranging from 44 to 6663 (mean: 912; median: 301), while five studies assessed facility-level data only.

Risk of bias

Table 2 presents the results of the assessment of methodological quality of the included studies. The methodological quality of included studies was varied. Some notable deficiencies were found in two of the four studies which indicated their analysis was undertaken from a

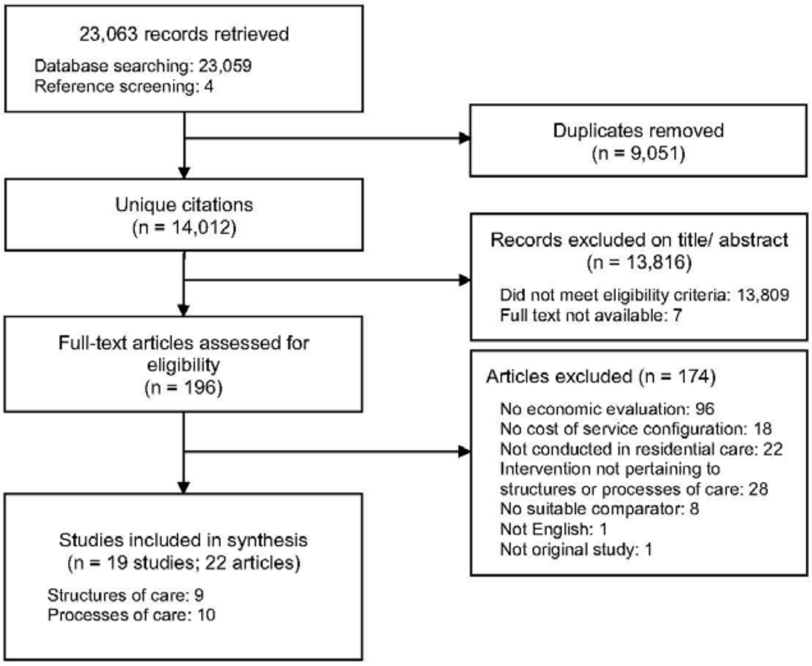

Fig. 1 Flow diagram of study selection

societal viewpoint. A societal viewpoint is the broadest perspective that can be taken for an economic evaluation and resources consumed in all relevant sectors should ideally be captured using this approach. In an evaluation of enhanced Registered Nurse time, costs beyond the aged care facility e.g. informal carer time or social services consumption were excluded [20]. In a study evaluating the integration of residents with care staff via increased participation in daily activities (e.g. cooking), Paulus and colleagues [21] included costs for formal (staff) and informal (family and friends) care time, but did not include other relevant costs such as medications or hospitalisations.

In a study evaluating a multidisciplinary integrated care model, MacNeil Vroomen and colleagues [22] also chose a societal viewpoint. This study provides an example of a well-conducted robust analysis that captures all relevant resource use items and costs incurred in all relevant sectors including general practitioner, physical therapy, psychosocial therapy, medical specialists, admission to hospital, informal care, as well as intervention-specific implementation costs.

In terms of the reporting of resource use and costs there were notable deficiencies in a number of studies. Six out of 19 of the included studies did not disclose the date for their cost data collection [21, 23–27]. Three studies did not disclose the source of their cost data [22, 23, 28], and one study also failed to disclose the currency used in the analysis [28]. There were also deficiencies in the source of cost data in two studies [29, 30]. In a study of dementia-care mapping, Van de Ven and colleagues [30] calculated nursing home staff costs for their analysis of 11 nursing homes based on the gross costs of a single nursing home. In this scenario, it is unclear whether the costs from a single facility can reliably be generalised to the 11 nursing homes which were included in the study. In an implementation study of evidence based education, Teresi and colleagues [29] were unable to obtain site-specific data for the 45 facilities that participated. Aggregated local estimates combined with cost data from published literature were utilised in lieu of site-specific data, which may not have been representative of the facilities included in the analysis.

Table 1 Characteristics of included studies

Source, country	Intervention/ comparator	Facility n	Participant n	Study design	Type of economic evaluation; analytic viewpoint	Time horizon	Date/source/currency of economic data	Dementia specific	Setting	Economic outcome
Structures of care										
Dorr et al. [20], USA	Registered Nurse (RN) direct care time per resident per day: 30–40 min Less than 10 min	82	1376	Retrospective cohort study	Cost-benefit analysis; societal; institutional	1 year	2001; Secondary sources including national databases, with true costs obtained where possible; *USD*	No	NH	Annual net societal benefit of $3191 per resident per year in nursing home units with 30–40 min of RN direct care time per resident per day compared to less than 10 min
Grabowski and O'Malley [34], USA	Off-hours physician coverage via telemedicine vs. on-call physician	11	N/A	Cluster randomised controlled trial	Cost-benefit analysis; insurance provider (medicare)	2 years	Oct 2009–Sep 2011; Estimated cost of hospitalizations to Medicare from recent literature; *USD*	No	NH	15.1 hospitalisations avoided. Net savings of $120,000 per facility per year
Jenkens et al. [36], USA	Green House model Usual care	7	N/A	Cross-sectional	Cost analysis; institutional	N/A	2009; Wages derived from salary.com and payscale.com with 5% increase applied to Green House CNA wage; *USD*	No	SNF	GH facilities use 1.97–2.49% more staff than traditional nursing homes
Maas et al. [23]; Swanson et al. [38]; Swanson et al. [44], USA	Special care unit Traditional unit	1	44	Prospective cohort study	Cost analysis; health care	1 year	Date not disclosed; Resource use measured and unit costs assigned—source of unit cost data not disclosed; *USD*	Yes	NH	Costs of care for residents with dementia in special care units were 29% higher than cost of care on traditional units

Table 1 continued

Source, country	Intervention/comparator	Facility n	Participant n	Study design	Type of economic evaluation; analytic viewpoint	Time horizon	Date/source/currency of economic data	Dementia specific	Setting	Economic outcome
Mehr and Fries [24], USA	Special care unit Traditional unit	177	6663	Cross-sectional	Cost analysis; institutional	N/A	Date not disclosed; Resource use data from the resident status measure database, a preliminary version of the national nursing home minimum Data set; *USD*	Yes	NH	Unadjusted resource use was 18% lower on SCUs than other units in the facility; when adjusted for case mix no significant difference in resource use was found
Przybylski et al. [28], CAN	Physical Therapy (PT) & Occupational Therapy (OT) staffing levels: 1.0 FTE PT and 1.0 FTE OT per 50 beds 1.0 FTE PT and 1.0 FTE OT per 200 beds	1	115	Randomised controlled trial	Cost analysis; institutional	2 years	1993/1994; Direct care nursing costs calculated based on the Alberta resident classification system (case mix measure) which estimates average amount of nursing care required per category. Source of wage data not disclosed; *Currency not disclosed.*	No	NH	PT/OT delivered at a 1:50 ratio was more effective at promoting, maintaining, or limiting decline in functional status. The resulting reduction in required care delivery resources was estimated to provide an annual cost saving of $283 per bed (a 1% cost reduction)
Schneider et al. [35], GBR	1.0 FTE occupational therapist Usual care	8	190	Non-randomised experimental trial	Cost analysis; health and social services	1 year	2002–2003; Published unit costs, inflated to 2005; *GBP*	No	CH	Intervention group showed a significant increase in the likelihood of using social services. At 2005 levels, net cost of providing occupational therapy was £16 per resident per week

Table 1 continued

Source, country	Intervention/ comparator	Facility n	Participant n	Study design	Type of economic evaluation; analytic viewpoint	Time horizon	Date/source/currency of economic data	Dementia specific	Setting	Economic outcome
Sharkey et al. [37], USA	Green House model Usual care	27	240	Cross-sectional	Cost analysis; institutional	N/A	2008–2009; Observational, interview, and survey methods at participating facilities; *N/A*	No	SNF	Total staffing time (excluding administration) in Green House facilities was 18 min less per resident per day that traditional facilities. CNAs in Green House facilities spent 24 min per resident per day more time in direct care activities than CNAs in traditional facilities
Teresi et al. [29], USA	Implementation of an evidence-based education and best practice program: Training staff vs. training staff and nursing home inspectors vs. usual training	45	N/A	Quasi-experimental	Cost-benefit analysis; Societal	2.5 years	2008; Aggregate cost data based on local estimates and published literature; *USD*	No	NH	Training staff was associated with a 15% reduction in annual falls, while training staff and inspectors was associated with a 10% reduction in falls. Range of estimates for the cost-benefit analysis is between a net loss of $26,000 and a net savings of $52,000
Processes of care										
Chenoweth et al. [39], AUS	Person-centred care (PCC) Person-centred environment (PCE) Both PCC + PCE Usual care	38	601	Cluster randomised controlled trial	Cost analysis; institutional	8 months	2009–2011; Resource use measured and unit costs assigned using market rates; *AUD*	Yes	RACF	PCC: 7169 per home; PCE: 9198 per home; PCC + PCE: 22,857 per home. Reduced agitation and improvements in resident quality of life for care homes which instituted PCC and PCE. The PCC + PCE intervention produced significant improvements in quality of care interactions and care responses, but no improvements in agitation or quality of life

Table 1 continued

Source, country	Intervention/comparator	Facility n	Participant n	Study design	Type of economic evaluation; analytic viewpoint	Time horizon	Date/source/currency of economic data	Dementia specific	Setting	Economic outcome
Chenoweth et al. [31]; Norman et al. [32], AUS	Person-centred care (PCC) Dementia-care mapping (DCM) Usual care	15	289	Cluster randomised controlled trial	Cost-effectiveness analysis; institutional	8 months	2008; Pharmaceutical costs: Australian pharmaceutical benefit schedule Training costs: Bradford University, UK Staff costs: Commonwealth Government Aged Care Nurses' Award; *AUD*	Yes	RACF	Dementia care mapping was found to be a more expensive and less effective intervention than person-centred care. The cost per negative behaviour averted in the person-centred care group was $8.01 post-intervention and $6.43 at follow-up relative to usual care
MacNeil Vroomen et al. [22], NED	Multidisciplinary Integrated Care (MIC) Usual care	10	301	Cluster randomised controlled trial	Cost-effectiveness analysis; societal	6 months	2007; Health care utilisation collected via patient/proxy interview and medical records. Source of cost data not disclosed. CPI figures sourced from the Dutch bureau of statistics; *EUR*	No	RH	For functional health and QALYs, multidisciplinary integrated care was not found to be cost-effective compared to usual care. For patient-related quality of care, the probability that the intervention was cost-effective compared to usual care was 0.95 or more for ceiling ratios greater than €129
Molloy et al. [25], CAN	Advance Directive program Usual care	6	1292	Cluster randomised controlled trial	Cost analysis; health care	1.5 years	Date not disclosed; Unit prices sourced from local and provincial fee schedules; *CAD*	No	NH	Intervention nursing homes reported 44% fewer hospitalisations per resident (0.27 versus 0.48), and 33% less resource use ($3490 versus $5239) than the control facilities.

Table 1 continued

Source, country	Intervention/comparator	Facility n	Participant n	Study design	Type of economic evaluation; analytic viewpoint	Time horizon	Date/source/currency of economic data	Dementia specific	Setting	Economic outcome
Müller et al. [33], DEU	Multifactorial fracture prevention program Usual care	N/A	N/A	Markov-based simulation model	Cost-utility analysis; insurance provider	20 years	2012; Retrospective dataset of costs for NH residents from an insurance fund ($n = 60{,}091$), a public German dataset for fracture treatment costs, and catalogue of non-physician care for physical therapy costs; *EUR*	No	NH	Base-case analysis of multifactorial fall prevention resulted in a cost-effectiveness ratio of €21,353 per QALY
Ouslander et al. [43], USA	INTERACT II tools (Interventions to Reduce Acute Care Transfers)	36	N/A	Controlled before-and-after	Cost analysis; institutional	6 months	2010; Wages based on national data; *USD*	No	NH	Intervention group reported 17% reduction in hospitalisation rates. The average cost of the 6-month intervention was $7700 per facility
Paulus et al. [21], NED	Integrated care Traditional care	2	342	Quasi-experimental	Cost analysis; societal	1.2 years	Date not disclosed; Activity based costing, data obtained from participating nursing homes and a published guide for cost research; *EUR*	No	NH	Integrated care had 31% lower informal direct care costs per resident. Total average costs per resident were on average 4% higher in integrated care than traditional care
Rantz et al. [26], USA	Multilevel intervention with expert nurses vs. monthly info packs on ageing and physical assessment	58	N/A	Cluster randomised controlled trial	Cost analysis; institutional	2 years	Date not disclosed; Medicaid cost reports; *USD*	No	SNF	Total costs per resident per day increased 6% in the intervention group, and decreased 3% in the control. The intervention demonstrated improvements in quality of care, pressure ulcers and weight loss

Table 1 continued

Source, country	Intervention/ comparator	Facility n	Participant n	Study design	Type of economic evaluation; analytic viewpoint	Time horizon	Date/source/currency of economic data	Dementia specific	Setting	Economic outcome
Rovner et al. [27], USA	A.G.E. dementia care program (activities, medication guidelines, educational rounds) vs. usual care	1	81	Randomised controlled trial	Cost analysis; institutional	6 months	Date not disclosed; Monthly billing records; *USD*	Yes	ICF	At 6 months, intervention residents were more than 10 times more likely to participate in activities than controls. Additional cost of the intervention was $8.94 per resident per day
van de Ven et al. [30], NED	Dementia-care mapping (DCM) Usual care	11	318	Cluster randomised controlled trial	Cost-minimisation analysis; health care	1.5 years	2010–2012; Data collected over a period of 18 months. Sources included the Dutch manual of health care cost, and cost prices delivered by a pharmacy and a nursing home; *USD (EUR 1.00 = USD 1.318)*	Yes	NH	No significant effect on total costs for the intervention

Countries AUS Australia; *CAN* Canada; *CHE* Switzerland; *DEU* Germany; *GBR* United Kingdom; *NED* Netherlands; *USA* United States

Settings CH care home; *ICF* intermediate care facility; *SNF* skilled nursing facility; *NH* nursing home; *RACF* residential aged care facility; *RH* residential home

Five studies conducted sensitivity analyses [20, 22, 29, 31–33]. Eight studies were undertaken over a time horizon greater than one year [21, 25, 26, 28–30, 33, 34], of which one study made adjustments for differential timing of costs over the study period [33].

Structures of care

Table 3 provides a summary of the economic results reported in studies pertaining to structures of care.

Staffing levels

Four studies evaluated the costs and effects of enhanced staffing levels, including increasing the amount of direct nursing care time for each resident [20], employing a full-time occupational therapist [35], increasing the staffing level of both physical and occupational therapists [28], and implementing off-hours physician coverage via telemedicine [34]. Results suggest that enhanced staffing levels, whilst being associated with increases in staffing costs provide the potential for cost savings in other areas. For example, one study found that increasing registered nurse staffing in nursing homes to ensure 30–40 min of direct care time per resident per day reduced the incidence of pressure ulcers, hospitalisations, and urinary tract infection rates resulting in a net societal benefit of US$3191 per resident per year [20]. Similarly, another study reported that increasing the staff to resident ratio for physical therapists and occupational therapists was more effective at promoting, maintaining, or limiting decline in functional status. The resulting reduction in required care delivery resources was estimated to provide an annual cost saving to the institution of $283 per resident [28]. A third study which evaluated the benefit of a full-time occupational therapist reported a significant reduction in secondary health care costs (including hospital admissions) and an increase in the use of social services, though the cost of providing occupational therapy was not offset by the savings in health care [35]. Finally, a fourth study found that increasing the availability of physician care during the off-hours via a dedicated telemedicine service decreased annual hospitalisations by 11.3% annually [34]. Based on an average nursing home size of 113 beds, net savings to US Medicare were estimated to be $120,000 per annum for facilities which utilised the telemedicine service to a greater extent [34].

Another important finding from this review was the assimilation of currently available evidence relating to the costs and effectiveness of staffing levels in specialised models of residential care, including Green House facilities and dementia special care units [23, 24, 36, 37]. Green House facilities provide a small, home-like model of care as an alternative living environment to the traditional skilled nursing facilities in the United States. In the Green House model, ten to twelve residents live in a self-contained residence designed to look and feel like a private home. Dementia special care units (SCUs) are separate units within a residential care facility that have been adapted specifically for people living with dementia.

Three out of four studies which evaluated staffing levels in specialised models of care (Green House facilities and dementia special care units) reported that these types of specialised models generally provided more direct care time to residents compared to traditional facilities [23, 36, 37]. Resource use and cost implications associated with staffing levels in specialised models of care, however, were conflicting across studies with no clear results. With regard to special care units, one study reported no difference in resource use once adjusted for case mix [24], while the other reported higher resource use but made no adjustments for case mix [23]. Of the two studies on Green House facilities, one reported lower staffing requirements than traditional units [37] while the other reported increased staffing requirements of 2.0–2.5% compared to traditional facilities [36]. None of the studies evaluating staffing levels in specialised facilities established clinical effectiveness. Swanson, Maas and Buckwalter [38] did report significant results found with indirect outcome measures in the form of reduced catastrophic reactions and increased social interactions on special care units with the number of reactions decreasing from 156 pre-intervention to 48 at the 12-month follow-up in the SCU group compared to the control group which reported catastrophic reactions of 82 and 46 at pre-intervention and follow-up respectively ($p = 0.035$).

Staff education

One study evaluated the implementation of an evidence based staff education and best practice program targeting 'vision awareness' to improve staff knowledge of visual impairments and to reduce the incidence of falls [29]. It was estimated that the intervention resulted in a reduction in the number of annual falls between 5 and 12 in a typical 200-bed nursing home in New York State. Depending on estimates used for the cost of falls, the net societal benefit ranges between a net loss of US$26,000 and a net saving of US$52,000 calculated in 2008 US dollars.

Processes of care

Table 4 provides a summary of the economic results reported in studies pertaining to processes of care.

Dementia-specific care

Four studies evaluated dementia-specific care interventions compared to usual care. These interventions included person-centred care implemented through staff

Table 2 Critical appraisal results for included studies using the JBI critical appraisal checklist for economic evaluations

Source	Q1 Well-defined question	Q2 Comprehensive description of alternatives	Q3 All important and relevant costs and outcomes identified	Q4 Clinical effectiveness established	Q5 Costs and outcomes measured accurately	Q6 Costs and outcomes valued credibly	Q7 Costs and outcomes adjusted for differential timing	Q8 Incremental analysis of costs and consequences	Q9 Sensitivity analyses conducted	Q10 Study results include all issues of concern to users	Q11 Results are generalizable
Chenoweth et al. [31]; Norman et al. [32]	Yes	Yes	Yes	Yes	Yes	Yes	N/A	Yes	Yes	Yes	Yes
Chenoweth et al. [39]	Yes	Yes	No	No	Unclear	Yes	N/A	No	No	No	Unclear
Dorr et al. [20]	Yes	Yes	No	Yes	No	Yes	N/A	No	Yes	No	Yes
Grabowski and O'Malley [34]	Yes	Yes	Yes	Yes	No	Unclear	No	No	No	No	Unclear
Jenkens et al. [36]	Yes	Yes	Yes	No	Yes	Yes	N/A	No	No	Yes	Yes
Maas et al. [23]; Swanson et al. [38]; Swanson et al. [44]	Yes	Yes	Yes	No	Unclear	Unclear	N/A	No	No	No	Unclear
MacNeil Vroomen et al. [22]	Yes	Yes	Yes	Yes	Unclear	Yes	N/A	Yes	Yes	Yes	Unclear
Mehr and Fries [24]	Yes	Yes	Yes	No	Yes	Unclear	N/A	No	No	Yes	Unclear
Molloy et al. [25]	No	Yes	Yes	No	Yes	Unclear	No	No	No	Yes	Unclear
Müller et al. [33]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Ouslander et al. [43]	No	Yes	Yes	Yes	Yes	Yes	N/A	No	No	Yes	Unclear
Paulus et al. [21]	Yes	Yes	No	No	Yes	Unclear	Unclear	No	No	No	Unclear
Przybylski et al. [28]	Yes	Yes	Yes	Yes	Unclear	Unclear	No	No	No	Yes	Unclear
Rantz et al. [26]	Yes	Yes	No	Yes	No	Unclear	No	No	No	No	No
Rovner et al. [27]	Yes	Yes	Yes	Yes	Unclear	Unclear	N/A	No	No	Yes	Unclear
Schneider et al. [35]	No	Yes	Yes	No	Yes	Yes	N/A	No	No	Yes	No
Sharkey et al. [37]	Yes	Yes	Yes	No	Yes	Yes	N/A	No	No	No	Unclear
Teresi et al. [29]	Yes	Yes	No	Yes	No	Unclear	Unclear	No	Yes	No	No
van de Ven et al. [30]	No	Yes	Yes	Yes	Yes	Unclear	No	No	No	Unclear	Unclear

training [31, 32, 39] or dementia-care mapping [30, 31], and a dementia care program which aimed to reduce behaviour disorders [27].

Supporting personhood has been identified as a foundation for quality care for people living with dementia [40]. Person-centred care centres on relationships with others and the theory that warm and compassionate care interactions should increase well-being, while disrespectful and disengaged care interactions are thought to lead to decreased well-being and increased agitation [14]. Person-centred care can be implemented at residential care facilities in different ways.

Two methods of implementing person-centred care were evident from the identified studies. One method, which researchers called 'person-centred care' involved off-site staff training followed by a period of on-site supervision and telephone support [31, 39]. The second, more resource-intensive method was dementia-care mapping which required selected staff members to become certified through basic and advanced training. The mappers then completed systematic observation of residents with dementia, from which feedback was given to care staff and managers in order to assist with planning, implementation and assessment of person-centred care [30, 31]. Chenoweth and colleagues [31] found that the first method of training and support dominated dementia-care mapping, as their results showed dementia-care mapping to be more expensive and less effective. Van de Ven and colleagues [30] on the other hand, found dementia-care mapping to be a cost-neutral endeavour.

The most common primary outcome assessed in this subgroup was agitation using the Cohen Mansfield Agitation Inventory (CMAI) [30, 31, 39]. Van de Ven [30] and Chenoweth [31] both found that dementia-care mapping had no significant effect on agitation with study follow-up times of 18 and 8 months respectively. Two studies by Chenoweth and colleagues [31, 39] reported small statistically significant decreases in agitation as a result of their person-centred care intervention, with follow up conducted at 14 and 8 months.

Other outcomes assessed (and measurement tools used) across this subgroup included emotional responses in care (ERIC), quality of life (DemQol, DemQol-proxy, Qualidem, EQ-5D, and QUALID), care interaction quality (Quality of Interactions Schedule), psychiatric symptoms (neuropsychiatric inventory), behavioural symptoms (Psychogeriatric Dependency Rating Scale Behaviour Subscale), antipsychotic drug and restraint use, cognition (mini-mental state examination, MMSE), level of nursing care (resource utilisation groups, RUG-II), and activity participation rates. Some small improvements were found in quality of care interactions, resident care responses, and quality of life measured with the DemQol-proxy [39].

Rovner and colleagues [27] evaluated a dementia care initiative consisting of organised 'day-care' activities from 10AM-3PM daily, combined with psychotropic medication guidelines, and educational rounds performed by a psychiatrist. In contrast to the person-centred care interventions, the dementia care program was not based exclusively on relationships but was developed to provide structure and stimulation through scheduled activities such as music and games. While the study did not find any cost reductions to offset the intervention costs, the authors did report that intervention residents were over ten times more likely to participate in activities than the comparison group. The intervention was also found to decrease the prevalence of behaviour disorders and the use of antipsychotic drugs and restraints.

Integrated care

Two studies evaluating integrated care delivery found higher costs in the intervention group compared to usual care [21, 22]. Integration strategies aim to provide a level of service that is more individualised and sensitive to the personal circumstances of the resident [41], and can be applied to residential care at a number of levels [42].

Paulus and colleagues [21] examined integrated care in the sense of integration between residents and care staff. Residents lived in smaller-scale facilities with increased levels of social activities, more flexibility in daily routines, and the opportunity to engage in daily activities such as cooking, cleaning and laundry. Integrated care was shown to have lower informal care costs (care provided by family and friends) when compared to traditional care, while both the costs of formal care (provided by staff) and total average costs were higher in integrated care.

MacNeil Vroomen and colleagues' [22] integrated care model focused on the integration of health disciplines through case-conferencing. The intervention included a quarterly assessment of all residents by nursing assistants, multidisciplinary meetings with a primary care physician, nursing home physician, nurse, psychotherapist, and other disciplines involved in resident care, and a multidisciplinary consultation for those residents with more complex health needs. Three outcomes were measured: quality of care, functional health, and quality of life. This study found that for functional health and quality-adjusted life years (utility scores calculated from the SF-6D), integrated care was not cost-effective compared to usual care. However, for patient-related quality of care, the probability that integrated care was cost-effective compared to usual care was 0.95 or more for ceiling ratios greater than €129.

Table 3 Summary of results pertaining to structures of care

Intervention	Source	Effectiveness	Cost	Randomised design	Key findings
Enhanced staffing levels					
30–40 min of RN direct care time per resident per day vs. less than 10 min	[20]	+	–	No	Enhanced staffing levels have the potential to create cost savings from a societal perspective
Physical therapy and occupational therapy (PT/OT) staffing levels: 1:50 vs. 1:200	[28]	+	–	Yes	Increasing nurse staffing in nursing homes demonstrated net reduction in re-hospitalisation, pressure ulcer presence, and urinary tract infections
1.0 FTE occupational therapist vs. usual care	[35]	+	+	No	Enhanced PT and OT services delivered improved functional status and reduced nursing costs Occupational therapy has the potential to reduce secondary care costs including hospitalisation, and may uncover unmet needs for services
Off-hours physician coverage via telemedicine vs. on-call physician	[34]	+	–	Yes	Facilities accessing off-hours physician coverage via telemedicine had fewer resident hospitalisations than those facilities who did not utilise the telemedicine program or those who only had access to an on-call physician
Staffing configurations in specialised models of care					
FTE comparisons in Green House model vs. traditional institutional care	[36]	None	+	No	Green house facilities provide more direct care time to residents compared to traditional units/facilities
Direct care time in Green House vs. traditional skilled nursing facilities	[37]	+	–	No	There is an increase in direct care FTEs, which is offset by a reduction in administration and support staff FTEs
Special care unit (SCU) vs. traditional unit	[23, 38, 44]	±	+	Yes	Costs of care are higher on SCUs and in SCU facilities, than non-SCU facilities
SCUs vs. traditional units in SCU facilities	[24]	None	0	No	Special care units provide more direct care time to residents compared to traditional units/facilities
SCU facilities vs. non-SCU facilities		None	+		
Staff education					
Implementation of an evidence-based education and best practice program vs. usual training	[29]	+	+	Yes	Evidence-based education programs show potential to reduce falls compared to non-evidence-based training The potential for cost savings is highly dependent on the true cost of falls

Effectiveness + intervention provides greater health benefit than comparator; *0* intervention provides equivalent health benefit to comparator; – intervention provides lower health benefit than comparator

Cost + intervention costs are higher than comparator; *0* intervention costs are equal to comparator; – intervention costs are lower than comparator

Quality improvement initiatives

Four studies conducted facility-level interventions aimed at improving the quality of care [25, 26, 33, 43]. Interventions included an advance directive program to educate and assist residents with a written expression of their wishes to guide family and health care workers in their care choices [25], an intervention to reduce acute care transfers through the early identification, assessment, communication, and documentation of changes in resident status [43], a quality improvement intervention involving monthly visits and support by expert nurses [26], and a fracture prevention program for all residents upon admission to a residential care facility [33]. The advance directive program [25], the intervention to reduce acute care transfers [43], and the multifactorial fracture prevention program [33] were all found to reduce hospitalisation rates, resulting in cost savings from a broader health care perspective. The quality intervention with expert nurses was found to improve quality of care (measured with the Observable Indicators of Nursing Home Care Quality (OIQ) instrument.), and reduce the incidence of pressure ulcers and weight loss [26]. In all four studies, the increased costs associated with implementation of the interventions were borne by the aged care facility.

Discussion

In comparison with the health care sector, where economic evaluations are common practice for pharmaceuticals and medical technologies, this review identified a paucity of economic evidence relating to the structures and processes of care in the residential aged care sector. A total of 19 studies were identified by this review: 12 cost analyses, one cost-minimisation analysis, one cost-utility analysis, two cost-effectiveness analyses, and three cost-benefit analyses.

Despite the heterogeneity of interventions and outcome measures, synthesis of study results revealed several common themes. Results from three studies suggest a potential for cost savings to the health care sector by increasing the amount of direct care time provided to each resident [20, 28, 35]. Benefits reported were wide ranging from reductions in the frequency of hospitalisations to improved functional status for the residents. The best means of achieving these outcome improvements is unclear, however, as the included studies focused on a disparate array of staff positions including registered nurses, occupational therapists, and physiotherapists. These positive results highlight an opportunity for future research to explore cost-effective methods of increasing the amount of direct care time to residents, and the optimal skill set and configuration of staff (e.g. nurses, allied health professionals, and other aged care workers) needed to achieve the best outcomes for individual residents.

Interestingly, increased levels of direct care time were found in the small, home-like 'Green House' model, as well as the dementia special care units. While we would expect to see cross-sectoral benefits (beyond the aged care sector and into the health care sector) similar to those reported in the enhanced staffing interventions, none of the studies actually measured costs in the health care sector. Three of the four did not report any effectiveness measures [24, 36, 37], while the fourth found no effect on cognitive or functional abilities [44]. By not including costs from all relevant sectors, these studies may be underestimating the potential value of specialised care settings.

Another aspect of residential care that was shown to create cost savings from a broader health care perspective were quality improvement initiatives, such as activity programs and interventions aimed at reducing health care utilisation and hospitalisations. While quality improvement initiatives tend to come at a cost to the facility in terms of planning and implementation, the flow-on effects of improving care quality is likely to extend to other areas of health services. Many of these initiatives, however, such as the quality improvement projects evaluated by Ouslander and colleagues [43], and Rantz and colleagues [26], along with more than half of included studies in this review, focused cost analyses on intervention and care costs incurred by the facility only.

The remaining studies are difficult to generalize, largely due to differing implementation methods. In terms of caring for individuals with dementia, recent research into person-centred care suggests its potential to reduce agitation and aggression [31, 39], though this was not a unanimous conclusion [30]. Despite the sound methodological quality of these three studies, disparate implementation methods render it difficult to draw any definitive conclusions. For instance, of the two studies that considered dementia care mapping, one study had two experienced, accredited researchers as well as two care staff from each facility to conduct the mapping [31] while the second study used two care staff from each facility but no researchers [30]. These disparities raise questions about the conclusions drawn, as the two studies described reported higher costs and cost-neutrality respectively.

The concept of integrated care is not well-defined, and is therefore difficult to generalize. Two studies identified by this review defined integrated care in terms of integration between staff and residents [21], and integration across disciplines [22]. Both integrated care interventions reported limited cost-saving potential, however further research in this area is needed which links costs to outcomes. The study of integrated care between staff

Table 4 Summary of results pertaining to processes of care

Intervention	Source	Effectiveness	Cost	Randomised design	Key findings
Dementia-specific care					
Person-centred care (PCC) vs. usual care (UC)	[39]	+	+	Yes	Person-centred care has the potential to reduce agitation and aggression in residents living with dementia
Person-centred environment (PCE) vs. UC		+	+		
Both (PCC + PCE) vs. UC		Unclear	+		Disparate implementation methods and mixed findings suggest a need for future research to examine the cost-effectiveness of person-centred care as well as different methods for assessing clinically-relevant quality of life
PCC vs. UC	[31, 32]	+	+	Yes	
Dementia-care mapping (DCM) vs. UC		+	+		
Dementia-care mapping (DCM) vs. usual care	[30]	0	0	Yes	
A.G.E. dementia care program (activities, medication guidelines, educational rounds) vs. usual care	[27]	+	+	Yes	For an additional cost, activity programs and psychiatric care can reduce behavioural symptoms, antipsychotic medications, and restraints, as well as increase activity participation rates for residents with dementia
Integrated care					
Multidisciplinary Integrated Care model vs. UC	[22]	Unclear	+	Yes	There is limited cost-saving potential for integrated care in nursing homes
Integrated care vs. traditional care	[21]	NA	+	No	If there was unmet care, a multidisciplinary integrated model could address this gap; however a trade-off must be made as to whether the additional benefit is worth the additional cost
Quality improvement initiatives					
Advance Directive program vs. usual care	[25]	0	–	Yes	Activity programs aimed at reducing health care utilisation and hospitalisations have the potential to create cost savings from a broader health care perspective
INTERACT II tools (interventions to reduce acute care transfers)	[43]	+	+	No	
Multifactorial fracture prevention program provided by a multidisciplinary team vs. no prevention in newly admitted nursing home residents	[33]	+	+	No	
Multilevel intervention with expert nurses vs. monthly info packs on ageing and physical assessment	[26]	+	+	Yes	It is possible for facilities in need of quality of care improvements to build the organisational capacity to improve while not increasing staffing or costs of care

Effectiveness + intervention provides greater health benefit than comparator; *0* intervention provides equivalent health benefit to comparator; − intervention provides lower health benefit than comparator

Cost + intervention costs are higher than comparator; *0* intervention costs are equal to comparator; − intervention costs are lower than comparator and residents [21] considered only the costs of care, with no attempt to measure outcomes. The multidisciplinary integrated care method, which conducted full cost-effectiveness analyses, found that for resident-related quality of care, the probability that the intervention was cost-effective compared to usual care was 0.95 or more for ceiling ratios greater than €129, while the same intervention was not cost-effective in terms of functional health or quality adjusted life years.

Another issue affecting the generalizability of findings is the geographic concentration of research in the United States. Research conducted outside of the United States is sparse. More than half of the included studies were conducted in the United States, while the remaining third were split between the Netherlands, Germany, Canada, Australia, and the United Kingdom. While these findings are consistent with a recent systematic review of randomised controlled trials in care homes, which reported that 50% of the randomised controlled trials undertaken in care homes were from the United States [45], they do highlight a need for research in a wider array of countries and health systems to increase transferability of results.

Another important factor to facilitate transferability of findings in residential aged care, and particularly dementia-specific models of care, is the question of the most appropriate primary outcome measure to use in economic evaluation. All of the dementia-specific studies into person-centred interventions used agitation as the primary outcome, and some small but significant decreases were detected for person-centred care and person-centred environments [31, 39]. Agitation is an outcome measure that is specific to dementia interventions, and therefore comparisons across a broader set of service configurations cannot be made. Given finite resources and a limited budget devoted to aged care, additional investment in one program will likely require a reduction or de-investment in another program in order to free up the necessary resources. A broader outcome measure such as a quality of care and/or a quality of life instrument, which is designed to combine a range of outcomes into a single composite outcome, applicable to all aged care residents, would allow decision makers to make comparisons across differing programs. Each of the three studies focused on person-centred interventions incorporated quality of life instruments as secondary outcome measures. Five different instruments were used: QUALID [31], DEMQOL [39], DEMQOL-proxy [39], EQ-5D [30], and Qualidem [30]. However none of the instruments were able to show significant group differences between the intervention and control groups with the exception of the DEMQOL-proxy, which is completed by a family member or carer on behalf of the person with dementia. Further research is needed to identify appropriate and meaningful quality of care and quality of life instruments for residents of residential care homes, particularly those living with dementia or cognitive decline, which allows comparisons to be made at a service planning level.

Acknowledging that the economic evidence of program features which directly relate to how care is provided in terms of the workforce and its operations (structures of care) and the services provided (processes of care) is limited, we have selected a number of recommendations for change based on the best evidence available. Firstly, increasing the amount of direct care time provided to each resident appears to have wide-ranging benefits at both an institutional and health care level. While further research is needed, additional direct care time provided by nurses, allied health professionals, and other aged care workers all appear to provide benefit. Secondly, benefits arising from initiatives such as increased direct care time or quality improvement initiatives are likely to occur in the health care sector rather than the aged care sector. Future research and policy decisions surrounding residential care initiatives should strive to include health care costs and benefits when considering resource allocation decisions.

In terms of methodological recommendations, our primary suggestion is improved transparency in reporting study methods and results. Future economic evaluations in this area should strive to meet the quality standard for reporting economic evaluation as specified in the Consolidated Health Economic Evaluation Reporting Standards (CHEERS) statement [46] including the quantities of resources used in addition to costs and incorporating the measurement and valuation of service outcomes and quality of life. Disclosures should also be included to indicate the timing of cash flows and the sources of cost data. Secondly, we would strongly encourage future economic research in this area to evaluate both costs and effectiveness in the form of a full economic evaluation. The usefulness of studies containing only partial economic evaluations is limited for policy and decision makers, in that they do not present the case on whether the costs of a course of action is worthwhile in terms of benefits provided to improve quality of care. Finally, we recommend that, where possible, future studies incorporate a societal perspective (especially in considering benefits that may occur in the healthcare sector offsetting costs accrued in the provision of social care) in order to better inform decision makers of the true benefit of an intervention.

This systematic review has several limitations. Firstly, the search strategy was restricted to English-language publications, which may have resulted in some relevant international research being excluded. Secondly, due to the large number of results retrieved when searching the multidisciplinary database ProQuest, limits to source type were applied that were not part of the original search strategy. The ProQuest search was limited to scholarly journals, reports, dissertations and theses, conference papers and proceedings, and working papers. Newspapers, trade journals, wire feeds, magazines, other sources, books, and encyclopedias and reference works were excluded. While this may have resulted in some relevant research being missed, this limitation was justified to maintain the feasibility of abstract screening within the given time constraints. Finally, due to the broad scope of this review, the synthesis and analysis of results was limited by the heterogeneity of included studies.

Conclusions

This review provides the first comprehensive summary of the existing economic evidence pertaining to workforce structures and care processes in residential care, and highlights an urgent need for robust economic evaluations to inform future service development in this area. In order to fully capture the impact of an intervention or model of care in a residential aged care setting, it is important to take a societal perspective when conducting economic evaluations. The inclusion of broader health care costs in economic evaluations of interventions in residential care, in particular the use of hospitals, is critical for ensuring the value of the intervention is not underestimated. Furthermore, the practical application and transferability of findings would benefit from identifying appropriate and meaningful outcome measures that can be used at a service planning level.

This review also brings to light the potential value of direct care time for residents in care homes. Future research should explore cost-effective methods for increasing the amount of direct care time to residents, and identification of the most appropriate skill mix (with comparison between nurses, allied health professionals, and other aged care workers) for the provision of care according to the care needs of the individual.

Economic evidence is essential to the promotion of efficiency, facilitating future policy directions within the aged care sector and will assist in identifying and quantifying the cross-sectoral impacts of new innovations in the structures and processes of care in terms of both the costs and benefits provided.

Abbreviations

CMAI: Cohen Mansfield Agitation Inventory; DEMQOL: dementia health-related quality of life; EQ-5D: EuroQol-5 dimensions; PRISMA: preferred reporting items for systematic reviews and meta-analyses; QUALID: quality of life in late-stage dementia; SCU: special care units; SF-6D: short form 6 dimensions.

Authors' contributions

TE, RM, MC and JM contributed to the conception, design, analysis and interpretation of data, as well as critical revisions of the manuscript. TE was responsible for the acquisition of the data and drafting the manuscript. All authors read and approved the final manuscript.

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Competing interests

The authors declare that they have no competing interests.

Availability of data and materials

Details of the review protocol and full search strategy are available on PROSPERO (http://www.crd.york.ac.uk/PROSPERO; registration number CRD42015015977).

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