Developing the descriptive system for a new preference-based quality of life measure with older people receiving aged care services at home

by

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THESIS SUMMARY

Australia’s population is ageing rapidly and by 2045 demographic projections indicate that one in four Australians will be older (aged 65 years or more) and nearly one in ten will be 80 years or over. This demographic transformation is replicated internationally and poses major challenges for health and aged care systems. As older people are living longer, they often experience frailty and other health conditions and require care and support to maximise their quality of life. Many older people prefer to age in place, resulting in increased demand and pressure on aged care services, in particular support within the home. Government expenditure on aged care is increasing and this trend is projected to continue, therefore it is important that limited resources are allocated efficiently to maximise older people’s quality of life as they age.

Economic evaluation offers a rigorous and systematic framework to compare new and existing services to ensure resources are allocated efficiently and effectively. Currently, no preference-based measure exists that focuses specifically on older people accessing aged care, incorporating their values and preferences into the measurement and valuation of quality of life for quality assessment and economic evaluation. Additionally, there have been limited economic evaluations conducted in the aged care sector despite the widespread potential benefits of this approach in guiding the allocation of limited resources to maximise the quality of life of older people.

This research addresses this gap by developing the descriptive system for the first preference-based quality of life measure to be developed from its inception with older people accessing aged care: Quality of Life – Aged Care Consumers (QOL-ACC). Developing a descriptive system is the first crucial stage in the development of a preference-based measure and this research adopts a unique approach by incorporating older people’s views and values of quality of life in its development.

An innovative mixed method approach was adopted to develop the QOL-ACC descriptive system consisting of several rigorous stages of development. Stage one comprised a series of in-depth semi-structured interviews with older people accessing aged care services in their own homes. Five salient characteristics were identified that were important to older people to experience a good quality of life: independence, mobility, social connections, emotional wellbeing, and activities. Stage two developed draft items for the descriptive system based on the five quality of life characteristics identified, in partnership with a research team and my Project Advisory Group (including aged care consumers and service provider representatives). Stage three tested the draft items for face validity with older people and the results confirmed that the items were measuring what they intended. The draft items were then subject to robust psychometric assessments during stage four, and it was demonstrated the items had excellent psychometric properties and met the necessary psychometric standards. Stage five developed a final item for each dimension of the QOL-ACC descriptive system by combining quantitative and qualitative evidence from the previous stages using an approach based on a traffic light pictorial format with a team of researchers and a panel of experts. The final stage assessed further psychometric properties of the QOL-ACC measure. Strong evidence of construct (convergent and known group) validity was provided indicating that the QOL-ACC descriptive system is a robust and valid measure of quality of life for older people in receipt of aged care services.

The QOL-ACC makes an important contribution to aged care research, policy, and practice. The QOL-ACC can be applied in routine application of quality assessments by aged care providers to measure the impact of existing and new services and outcomes against the new aged care quality standards. It can also be used to monitor older people’s quality of life over time, to compare interventions and to highlight service needs. Future research will develop a scoring algorithm for the measure which will enable the QOL-ACC to assess the cost-effectiveness of new aged care interventions and to make comparisons between existing services to ensure the quality of life of older Australians is maximised. The development of this new measure makes a significant contribution, providing an important mechanism for measuring and ultimately positively impacting the quality of life of older people.

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. A professional editor has not been used in the preparation of this thesis.

Signed:

Date: 21.01.2022

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LIST OF PUBLICATIONS AND PRESENTATIONS ARISING FROM THIS THESIS

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I was the lead author for this publication. I led the writing of the manuscript from initial drafting to final revisions and had final ownership of submission. I contributed to 90% of the research design, 95% of the data collection and analysis and 90% of the writing and editing of the manuscript.

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ABBREVIATIONS

ABS	Australian Bureau of Statistics
ACAT	Aged Care Assessment Team
AIHW	Australian Institute of Health and Welfare
AQoL	Assessment of Quality of Life
ASCOT	The Adult Social Care Outcomes Toolkit
BWS	Best-worst Scaling
CADTH	Canadian Agency for Drugs and Technology in Health
CALD	Culturally and Linguistically Diverse
CDC	Consumer Directed Care
CHSP	Commonwealth Home Support Programme
CUA	Cost-Utility Analysis
DCE	Discrete Choice Experiment
EQ-5D-3L	EuroQol - 5 Dimensions 3 Levels
EQ-5D-5L	EuroQol - 5 Dimensions 5 Levels
HCP	Home Care Package
HUI	Health Utilities Index
HRQoL	Health-related quality of life
ICECAP-O	Investigating Choice Experiments Capability Measure for Older People
MSAC	Medical Services Advisory Committee
NICE	The National Institute for Health and Care Excellence
PBAC	Pharmaceutical Benefits Advisory Committee
PROM	Patient-reported outcome measure
QALY	Quality-adjusted life-year
QCE-ACC	Quality of Care Experience – Aged Care Consumers

QoL	Quality of life
QOL-ACC	Quality of Life – Aged Care Consumers
QWB	Quality of Well Being scale
SCRQoL	Social care-related quality of life
SF-6D	Short-Form-6 Dimensions
SG	Standard Gamble
TTO	Time Trade-Off
VAS	Visual Analogue Scale
15D	15 Dimensions

1. INTRODUCTION

1.1 OVERVIEW

The world's population is changing as people are living longer. Nearly every country is experiencing a growth and there are now 723 million people aged 65 years and over in the world (United Nations Department of Economic and Social Affairs, 2020). This figure is expected to double by 2050 with one in six people aged 65 years and over (United Nations Department of Economic and Social Affairs, 2020). Currently, world life expectancy at birth is 72.3 years; it is highest in Europe and North America (78.5 years) and lowest in Africa (60.5 years) (United Nations Department of Economic and Social Affairs, 2020). Increased longevity is largely due to better healthcare and advances in medical technologies, better working environments, improved living conditions, reduced fertility rates and a decrease in infant mortality (especially in low income countries) (United Nations Department of Economic and Social Affairs, 2019).

In 2020, one in six people living in Australia were older (65 years and over) making up 16% of the total population (4.1 million) and by 2055 it is expected that 23% of Australia's total population will be aged 65 years and over. There has also been an increase in the numbers of individuals classified as the 'oldest old' (85 years and over) from 503,100 in 1999 to 517,000 in 2020 (Australian Department of Health, 2020b). This growth is projected to continue, and it is predicted that by 2058 there will be 1.5 million people aged over 85 years making up 3.7% of Australia's total population (Australian Bureau of Statistics [ABS], 2019). Consequently, more Australians will require support from aged care services at some point in their lives. With government expenditure on aged care services predicted to increase markedly in the coming decades (Aged Care Financing Authority, 2021; Australian Institute of Health and Welfare [AIHW], 2021), it is important to ensure that the resources allocated to aged care are used efficiently whilst also ensuring that the quality of life (QoL) and wellbeing benefits to older Australians are maximised (Royal Commission into Aged Care Quality and Safety, 2021).

At the time of this research being conducted Australia's aged care sector was the subject of a Royal Commission as a consequence of several high-profile cases of abuse and neglect reported by the Australian media. The final report, released in 2021, highlighted the shortfalls of the system and recommended significant policy reform (Royal Commission into Aged Care Quality and Safety, 2021). The Royal Commission acknowledged the lack of research and evaluation undertaken in the aged care sector which has prevented the introduction of new and better care practices. The final report stated the central aim of the aged care system should be for older people to experience a good QoL and recommended more research was needed to ensure that older Australians could access good quality care and be treated with respect and dignity, ultimately leading to a good QoL. Indeed, a key recommendation of the report was for aged care providers to routinely collect QoL data as part of quality care assessments by July 2023 (Royal Commission into Aged Care Quality and Safety, 2021).

This thesis outlines the development and psychometric testing of the descriptive system for a new aged care specific QoL measure for older people in receipt of aged care services at home that will be amenable for preference-based scoring, meaning it can be used in economic evaluation. Economic evaluation offers a systematic and robust framework to compare new and existing services to ensure resources are allocated effectively. Economic evaluations require the use of preference-based measures to value QoL. Currently, no preference-based measure exists in Australia or internationally that has been developed from its inception with older people in receipt of aged care services (Bulamu et al., 2015; Bulamu et al., 2018; Cleland et al., 2019; Makai et al., 2014).

This thesis documents the stages of development of the descriptive system for the Quality of Life – Aged Care Consumers (QOL-ACC) measure; the first preference-based measure to be developed from its inception with older Australians accessing aged care services in the community. Traditionally, most preference-based QoL measures have been developed using a top-down approach based on existing literature or experts in the field (Stevens, 2016). For example, the widely used EuroQoL - 5 dimensions 3 Levels (EQ-5D-3L) measure was developed by researchers who reviewed existing QoL measures and used their expertise to determine the domains to include in the measure they believed to best represent patient's preferences (Gudex, 2005). However, a bottom-up approach, involving the population of interest has recently been encouraged in the development of measures (U.S Department of Health and Human Services, 2009). This approach has recently been incorporated in the development of a new preference-based QoL measure for paediatric populations (Stevens, 2010), and was utilised in the development of the ICECAP suite of measures for assessing capabilities in adult and older populations (Al-Janabi et al., 2012; Grewal et al., 2006). The development of the QOL-ACC uses a bottom-up approach in its development by involving older people at all stages of development from its inception to understand what QoL means to them. This approach ensures the measure will have appropriate language and content, thereby increasing its content validity and relevance to the population. The QOL-ACC will have wide applicability in the aged care sector as part of aged care quality assessments and in economic evaluations, ultimately improving the QoL and wellbeing of older Australians.

1.2 AGED CARE SECTOR

With increases in longevity, many older people become frail and more dependent often requiring support from aged care services to provide care to ensure they have the best possible QoL. The Australian aged care system provides support to older people in their own home, in the community or in residential care. This support is provided by not for profit providers, government providers and for profit private companies. Aged care services are financed by the Commonwealth Government, state, and territory Governments and by personal contributions (means-tested fees and co-payments) from the individuals receiving care. It is estimated that older Australians contributed $5.6

billion to their care in 2018-19 (Royal Commission into Aged Care Quality and Safety, 2021). The Commonwealth Government is responsible for the aged care system in Australia and is required to fund and regulate the sector. Government expenditure in this sector has risen from $17 billion in 2015-16 to $21.5 billion in 2019-20 and this upward trend is predicted to continue (AIHW, 2021a). A large proportion of total expenditure on aged care is allocated to residential care. In the period 2019-20, just over two thirds ($13.6 billion) were spent on residential support compared to $6.7 billion on aged care support in the home (AIHW, 2021a). However, commensurate with recent policy initiatives and the overwhelming preference of the vast majority of Australians to remain cared for and supported in their own homes for as long as possible as they age (Kendig et al., 2014; Kendig et al., 2017; Ratcliffe et al., 2020), the Commonwealth Government's expenditure on home care has increased at a greater rate than expenditure on residential care. Home care expenditure was 47% higher in the period 2019-20 than during the period 2015-16 compared to an 18% increase in expenditures for residential aged care services during the same time period (AIHW, 2021a). Aged care support in the home is now the fastest growing sector for Australia's aged care system. In the ten year period of 2009-2019, the proportion of older people receiving aged care support in the home increased by 142% compared to 15% in residential care (AIHW, 2021a). In 2020, 159,339 older people were receiving home care, and this is projected to increase to 250,000 by 2050 (Australian Department of Health, 2021a; Deloitte Access Economics, 2020).

1.3 AGED CARE SUPPORT IN THE HOME

In Australia, there are two main support programmes for older people to receive care at home: Commonwealth Home Support Programme (CHSP) or a Home Care Package (HCP). CHSP and HCPs enable older people to live safely and independently at home and provide a range of services such as:

- Support with everyday living such as cleaning, shopping, cooking, social activities

- Provision of equipment and home modifications such as handrails, walking frames, bed hoists
- Support with personal care such as dressing, washing, and eating
- Provision of healthcare such as nursing and allied health services
- Provision of accommodation either short-term or long-term

(Australian Department of Health, 2020a).

CHSP provides low-level support and typically provides help with one or two basic tasks for an average of two hours per week or less (Australian Department of Health, 2020c). A higher level of care is provided through HCPs that offer more hours of support for older people for assistance with more complex needs, such as personal care and nursing on a more structured basis. There are four levels of HCPs: level 1 (basic needs), level 2 (low needs), level 3 (intermediate needs) and level 4 (high needs). Care and support are provided for approximately two hours per week for level 1, three to four hours per week for level 2, seven to nine hours per week for level 3 and ten to thirteen hours per week for level 4 (COTA Australia, 2021).

The gateway to access aged care services at home in Australia is through an assessment for aged care services undertaken by an Aged Care Assessment Team (ACAT) funded by the Commonwealth Government. An older person can be referred by their general practitioner or a clinician for an assessment, apply online or by telephoning My Aged Care. ACATs consist of a team of medical and allied health professionals based in the community or within hospitals who conduct individual free face-to-face assessments at the older person’s home to identify any physical, medical, cultural, psychological, and social needs of the individuals. The ACAT team member discusses available care options with the older person and develops a support plan to help find care and services that best suits their needs (Australian Department of Health, 2020b). In 2019-20, 186,891 ACAT assessments were undertaken in Australia (Australian Department of Health, 2020b).

Once assessed for an aged care package, the individual is placed on the National Prioritisation list and provided a package when one becomes available. HCPs are assigned depending on the date of referral and the urgency of the care required. As of 31st December 2020, there were 96,859 older people waiting for a HCP at their approved level. The average wait time in 2020 for a level 1 HCP was between three and six months and for a level 2, 3, or 4 HCP the wait time was at least 12 months. Just under half of people on the waiting list are offered a lower level care package as an interim service (Australian Department of Health, 2021a). However, home care packages are not always accepted and receiving support at a lower level than an individual's assessed care needs can lead to deteriorations in health, premature entry into residential care and in some cases, devastating consequences such as death (Australian Department of Health, 2021a).

The final report by the Royal Commission into Aged Care Quality and Safety identified major shortfalls in the provision of HCPs as a key concern for Australia's aged care system (Royal Commission into Aged Care Quality and Safety, 2021). The unacceptable wait times were highlighted as putting older people at risk of declining function, increased hospitalisation, entering residential care earlier than needed and, in severe cases, dying whilst waiting (Royal Commission into Aged Care Quality and Safety, 2021). Previous research conducted by Visvanathan and colleagues examining wait times for HCPs found that older Australians had a higher risk of entering residential care and mortality if they were waiting longer than six months to receive a HCP (Visvanathan et al., 2019). A key recommendation of the final Royal Commission report was to increase the number of HCPs available immediately. Additionally, they recommended that all older Australians on the waiting list be allocated an appropriate level of HCP by December 2021 and that the wait time for all levels of HCPS be reduced to a maximum of one month by 2024 (Royal Commission into Aged Care Quality and Safety, 2021).

Once an individual is allocated a HCP, it is expected to be delivered with a consumer directed care (CDC) approach. CDC was introduced in July 2015 and was a major policy change for Australia's home care sector for the delivery of care and services from aged care providers (Australian Department of Health and Ageing, 2012). In contrast to the traditional provider directed philosophy which had operated previously, the CDC approach provides choice and control to the older person about the type of care and services they receive with the aim of enhancing their QoL (Gill et al., 2017). The main intent of CDC was to provide older people with increased independence by allowing older people the freedom to exercise choice and control over the care and services they receive within their own HCP, and in partnership with their aged care provider, to determine how their funding is spent (Australian Department of Health and Ageing, 2012; Gill et al., 2018). CDC was introduced following the Living Longer Living Better aged care reforms in 2012 that recognised the need for older people to have more choice and flexibility about the care they received at home, recognising that older people should have the option to remain living independently at home for as long as possible (Australia Department of Health and Ageing, 2012). CDC is discussed in more detail in Chapter two.

Once individuals have been allocated a HCP and chosen an aged care provider that suits their needs, the Commonwealth Government directly pays a subsidy for the individual to the aged care provider. The funding amount received by the aged care provider for an individual varies depending on the level of HCP. HCP level 1 subsidies are approximately $9026 per year, level 2 subsidies are $15,877 per year, level 3 subsidies are $34,550 per year and level 4 subsidies are $52,377 per year (Australian Department of Health, 2021b). Aged care providers may also be able to access further government supplements for older people with additional needs such as dementia and cognition, oxygen and enteral feeding, and for older people who are veterans, or reside in rural areas (Australian Department of Health, 2021b). Older people are also expected to make co-contributions towards the costs of their HCP if they can afford to. Individual co-contributions consist of three types of fees:

- A basic daily fee that based on the type of aged care package. This can be up to $10.85 per day.
- An income tested care fee which is decided through a formal assessment. This can be up to $31.14 per day depending on an individual's income.
- Additional fees to pay for care and services that are not covered by the HCP (Australian Department of Health, 2021b).

If an individual is eligible to pay an income tested fee, the subsidy provided to the aged care by the government is reduced by the amount the individual contributes. Individuals are also required to pay a HCP management fee which is taken directly from the HCP budget. These fees vary between aged care organisations. The older person liaises with the aged care provide to decide how best to spend their aged care package funding and the aged care provider coordinates and manages the services on the behalf of the individual (Australian Department of Health, 2021b).

1.4 ECONOMIC EVALUATION

Socio-demographic shifts in Australia's population with increasing numbers of older people living longer is placing greater demands on the aged care sector to provide more and higher quality care and services for older Australians to maximise their QoL. As a society we unfortunately do not have infinite amounts of resources available (funding, staff, buildings, equipment) to provide aged care services. This means that difficult choices must be made about how best to expend limited resources to maximise the QoL of older people. It is important to assess the cost effectiveness of new service innovations/ models of care and interventions for older people to ensure they are providing value for money. Economic evaluation is a branch of health economics that generates systematic, robust, and transparent evidence to facilitate these types of decisions. Economic evaluation evidence can be used by aged care policy-makers and practitioners to decide how to best allocate resources by analysing the costs and outcomes of existing and new models of care and new service innovations where QoL from the perspective of older people themselves is utilised as the main measure of outcome (Brazier et al., 2017; Drummond et al., 2005; Ratcliffe et al., 2019).

Cost-utility analysis (CUA) is the most prevalent type of economic evaluation and is widely recommended in health system settings e.g., by the Pharmaceutical Benefits Advisory Committee (PBAC) and Medical Services Advisory Committee (MSAC) in Australia. It is also endorsed by international bodies including the National Institute for Health and Care Excellence (NICE) in the UK for the economic evaluation of health and social care (aged care and disability care) interventions and the Canadian Agency for Drugs and Technologies in Health (CADTH) in Canada (CADTH, 2017; Australian Department of Health, 2016; NICE, 2013).

CUA enables the calculation of the quality adjusted life year (QALY) which is a measure of QoL and quantity of life gains. QALYs are calculated by multiplying the amount of time spent in a given health and/or QoL state by the utility value. A utility value is generated from a preference-based measure and can range from 0 (equivalent to being dead) to 1 (equivalent to full health and/or full QoL) (Brazier et al., 2017).

Preference-based measures are typically completed by the person whose QoL is being assessed and consist of a descriptive system that contains several dimensions that describe a person’s health and/or QoL, for example, mobility, social connections, emotional wellbeing with different response options for each dimension. In some instances, such as when a person has severe cognitive impairment or dementia, a proxy assessor (e.g., a family member or a care worker) may be asked to complete the measure on behalf of the person. A preference-based measure also consists of a scoring algorithm that assigns weights to each QoL dimension (e.g., mobility, self-care, independence) based on values derived from the population of interest e.g., older people receiving aged care services and/or the general population and several different valuation techniques are available for this purpose (Brazier et al., 2017). The final preference weighted scoring algorithm is used alongside the measure to produce the utility values which are used to calculate QALYs (Brazier et al., 2017).

A variety of generic preference-based measures exist, but to date no preference-based measure has been developed specifically with older people receiving aged care services. Most existing preference-based measures have been developed for application in the health system and have therefore tended to focus on health status and health related quality of life (HRQoL) than QoL more broadly (Brazier et al., 2017). This may be argued as entirely appropriate for health system settings where the key outcome is to improve health. However, the aged care sector has broader aims than encompass improvements to maximise the QoL and wellbeing of older Australians. To date, economic evaluation conducted in the aged care sector have tended to adopt preference-based measures such as the EQ-5D which focuses more narrowly on health status (Bulamu et al., 2015; Easton et al., 2017). In addition, measures such as the EQ-5D use scoring algorithms which reflect general population preferences and do not reflect what older people deem important to have a good QoL (Cleland et al., 2019). Research has shown that older peoples' QoL values transcend HRQoL dimensions that current preference-based measures typically reflect. For example, research by Milte et al. (2014) highlighted that older people value attributes that go beyond health such as independence, control, and social relationships. Furthermore, Ratcliffe et al. (2017) compared younger people and older people's preferences of QoL attributes and found their preferences were not the same. Older people valued being independent, physically mobile and having control over their lives as most important, whereas younger people placed more emphasis on social relationships and mental health.

Several reviews conducted to identify QoL measures applied with older people have demonstrated the lack of suitable measures for economic evaluations in the aged care sector that encompass these broader dimensions of QoL. For example, a systematic review conducted by Bulamu and colleagues to identify suitable QoL measures for application in economic evaluations in the aged care sector found there was no existing measure that captured the broader aspects of QoL that older people value (Bulamu et al., 2018). Furthermore, Makai et al. (2014) in their systematic review of QoL measures (preference-based and non-preference based) used for economic evaluations in health and social care for older people highlighted the lack of suitable measures. Both reviews highlight that no preference-based measure exists that incorporates the broader dimensions of QoL that older people value that is suitable to be used in economic evaluation with older people in receipt of aged care services. Correspondingly, there have been limited economic evaluations conducted in the aged care sector to date (Bulamu et al., 2018; Easton et al., 2017). This is concerning because economic evaluation evidence is important to drive quality and efficiency in the aged care sector and ultimately improve the QoL of older Australians.

1.5 QUALITY OF CARE AND QUALITY OF LIFE

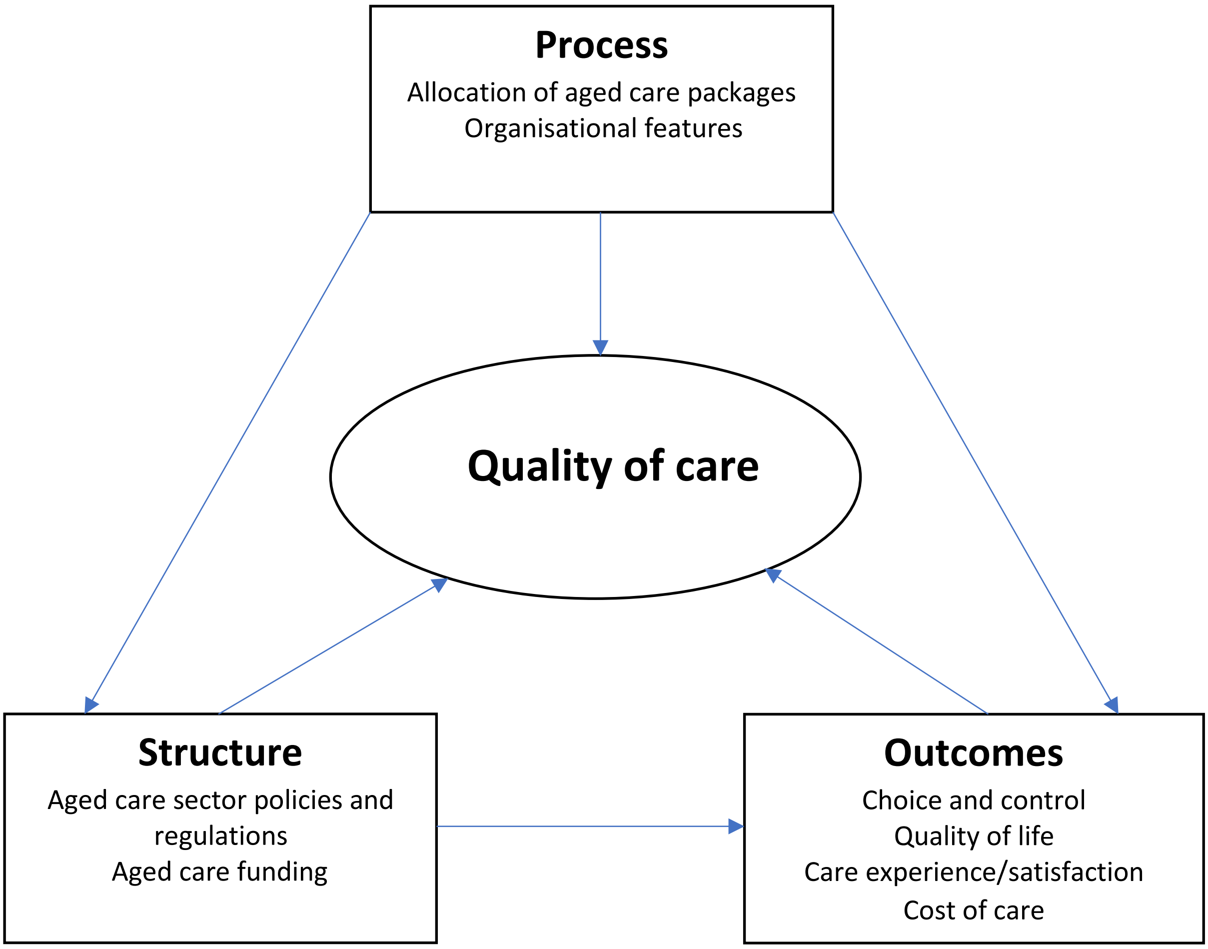
Previous research has recognised the relationship between good quality care leading to improved QoL (Carey et al., 2018; Dyer et al., 2018). Indeed, a recent report commissioned by the Royal Commission into Aged Care Quality and Safety to identify what defines quality of care highlighted the intrinsic link between quality of care and QoL (Ratcliffe et al., 2020). However, despite this link, to date, quality in aged care has tended to focus more specifically on process, organisational outcomes, and clinical indicators of care quality, for example, pressure injuries, use of physical restraints and unplanned weight loss. Whilst these measure important aspects of physical health that can affect an older person’s health and wellbeing, they neglect the wider attributes of quality of care that impact on an older person’s QoL and wellbeing such as independence, control, and dignity (Milte et al., 2018). The use of organisational and process indicators to measure quality of care assumes that better care will be provided but there is no guarantee that this will be the case (Castle & Ferguson, 2010; O’Reilly et al., 2007). Furthermore, the use of clinical indicators to assess quality of care is more relevant to older people receiving care in residential facilities, who tend to be frailer and have higher care needs rather than older people in receipt of aged care services in the community.

The strong inter-connections between care processes and outcomes were first identified in the quality framework developed by Donabedian (1982) who defined good quality of care "as that which yields the greatest expected improvement in health status, health being defined broadly to include physical, physiological and psychological dimensions" (p. 976). The Donabedian framework was originally developed for use in the health care sector but was designed to be a flexible model and is highly relevant to the aged care sector. Donabedian proposed that quality of care can be measured through a theoretical framework that encompasses three components: structures, processes, and outcomes. Structures refer to the organisational features and context of the care and include both physical characteristics (materials, facilities, and equipment) and organisational characteristics (staff, human resources, administrative structures). Processes are the actions taken in care settings by the older person and their families receiving care and the provider delivering the care (diagnosis, treatment, patient education). Outcomes are the effects (negative and/or positive) of the care on the person being cared for and include satisfaction with care, changes in health status, behaviour and QoL, and encompass the costs of gaining these outcomes. Donabedian acknowledges outcomes are the key indicators of good quality care but also recognises that these may be hard to define and measure and can be subject to time delays. The structural and process components are affected by different influences and interact which in turn produces the outcome (Donabedian, 1988).

The Donabedian model (see Figure 1.1) can be applied to the aged care sector to understand quality of care and its intrinsic relationship to QoL outcomes. The organisational features of the model that comprise the structure component are the aged care sector regulations, policies, and funding. The process component relates to the allocation of the aged care packages and the individual organisational features, such as staff levels and skills and the provider's facilities and equipment. The outcome component is the impact on the individual such as increased choice and control, satisfaction with care, improved QoL and cost efficiencies emanating to both the older person and the provider.

Figure 1.1

Quality of care framework for the aged care sector



In July 2019, there was a major shift in the assessment of aged care services through the introduction of eight new aged care quality standards by the Australian Aged Care Quality and Safety Commission (Australian Department of Health, 2019). These new standards acknowledged the link between quality of care and QoL with a key focus on QoL outcomes to help older people and their families make decisions about their care. Aged care providers are expected to provide evidence to demonstrate they are meeting each standard. The eight standards were introduced to ensure aged care services are delivering good quality care centred around the older person's needs, preferences, culture, beliefs, and goals to maximise their health, wellbeing, and QoL. The development of the new Australian aged care quality standards recognises the links between high quality care processes and outcomes typically leading to improved QoL and wellbeing.

1.6 RATIONALE FOR THESIS

As outlined in this chapter, the demand for aged care services is increasing as people are living longer. Government expenditure in the aged care sector is increasing and decision-makers need to be able to allocate limited resources efficiently. Economic evaluation is a useful tool that can assist decision-makers to compare the costs and outcomes of services and programmes to identify the best interventions to maximise the QoL of older Australians. Currently, no preference-based measure exists developed from the perspective of the older person that is designed to be used in health economic evaluation to measure and value QoL of older people receiving aged care services in the community (Bulamu et al., 2018; Cleland et al., 2019; Makai et al., 2014).

This thesis outlines the development of the descriptive system of the QOL-ACC, amenable to preference-based scoring and therefore, suitable to be used in quality assessment and in health economic evaluation in the aged care sector. This new measure will potentially lead to improvements in the aged care sector by monitoring the QoL of older Australians receiving aged care services in the community to understand whether their needs are being met to enhance their QoL. Aged care providers can use the QOL-ACC as part of their quality assessments to identify if they are meeting the aged care quality standards by assessing the impact of their services on the older person's QoL and can be used as a pre and post measure for new interventions and to evaluate QoL over time. The QOL-ACC can also be used to help decision-makers, policy makers and practitioners to generate new economic evaluation evidence to assist in allocating resources efficiently in the aged care sector, maximising the QoL benefits accruing to older people. The development of the QOL-ACC measure has the capacity to change policy and practice, improving the efficiency of the aged care sector and the QoL of older Australians. Ultimately, the development of the QOL-ACC will ensure that the measurement and valuation of older people's QoL, from their perspective, is placed at the front and centre of the aged care system.

1.7 OBJECTIVES AND AIMS

The main aim of this thesis was to develop the descriptive system for the first preference-based older person specific QoL measure in Australia suitable to be used in economic evaluation co-created with older people receiving aged care services at home. The specific objectives to achieve this over-arching aim were:

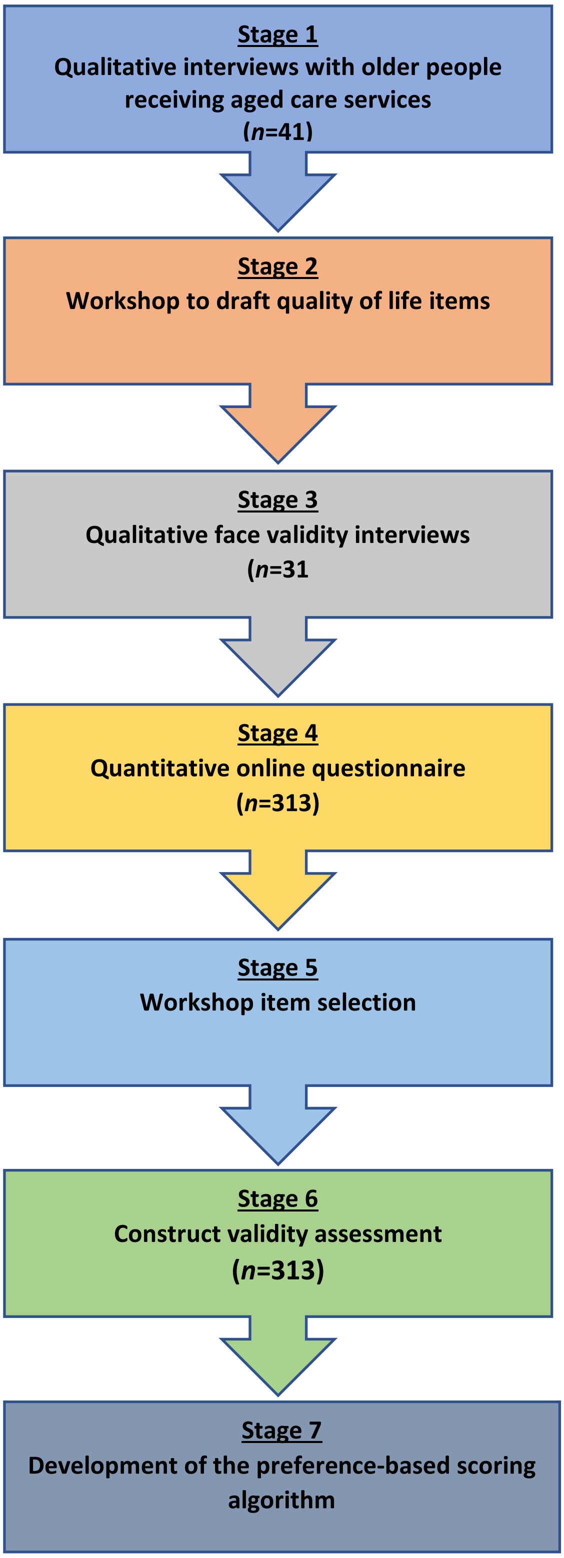
1. To use a qualitative approach comprising in-depth semi-structured face to face interviews to identify the QoL dimensions important to older people in receipt of aged care services in the community.
2. To develop draft items for the descriptive system based on the QoL dimensions identified by older people in receipt of aged care services in the community.
3. To test the face validity of the draft QoL items with older people in receipt of aged care services in the community.
4. To test the psychometric properties of the draft QoL items with older people in receipt of aged care services in the community.
5. To combine the quantitative and qualitative data to select the final items for each QoL dimension to develop the final descriptive system for the QOL-ACC.
6. To test the QOL-ACC descriptive system for construct validity with older people in receipt of aged care services.

1.8 DEVELOPMENT STAGES OF THE QOL-ACC MEASURE

Figure 1.2 outlines the different stages of the development of the QOL-ACC measure. This thesis documents stage one to six of the development of the QOL-ACC. Future research planned to be undertaken by the wider research team (researchers at Flinders University) will address stage seven.

Figure 1.2

The development stages of the QOL-ACC



Stage one of the research involved in-depth semi-structured interviews with older people in receipt of aged care services in the community (*n*=41). The aim of these interviews was to identify what QoL meant to older people and to identify what characteristics they identified as important to experience a good QoL. Stage two of the project was a workshop attended by the project research team and consumer and aged care provider representatives. The aim of the workshop was to review the qualitative data from stage one to develop the draft items for each of the dimensions for the descriptive system.

Stage three (face validity) involved semi-structured interviews with older people in receipt of aged care services in the community to gain feedback on the draft items of the descriptive system and to identify their preferred item for each dimension (*n*=31). The aim of stage three was to reduce the number of items to take forward to stage four. Stage four of the research involved a quantitative online survey with older people in receipt of aged care services to identify the item that performed the best psychometrically for each dimension of the descriptive system based on their psychometric properties.

Stage five was a workshop attended by the research team, aged care providers and consumer representatives to select the final items for each dimension for the descriptive system. The qualitative data from stage three and the quantitative data from stage four was combined and the attendees examined the data to reach a consensus on the best item to represent each dimension of the QOL-ACC descriptive system. Stage six involved a quantitative online survey (*n*=313) with older people in receipt of aged care services in the community to assess the construct (convergent and known group) validity of the QOL-ACC descriptive system.

1.9 STRUCTURE OF THESIS

The thesis consists of 9 chapters:

Chapter 2 provides an overview of the ageing population and the increased demand on aged care services. The chapter explores the recent aged care sector reforms focusing on the introduction and philosophy of consumer directed care and concludes by discussing the importance of person centred quality assessment and economic evaluations in the aged care sector.

Chapter 3 is a comprehensive literature review identifying international grey and peer reviewed literature relating to quality of care and/or person-centred care in aged care.

Chapter 4 provides a background to health economics discussing the different health economic evaluation techniques, health state valuation techniques and QALYS. The chapter provides a review of the development and application of preference-based measures that have been used within the older population and discusses the issues pertaining to their use.

Chapter 5 provides an overview of the theoretical framework for the empirical components of this thesis outlining the research paradigm, methodology and methods adopted.

Chapter 6 presents the results of the qualitative interviews that were undertaken with older people in receipt of aged care services to identify the salient QoL characteristics.

Chapter 7 presents the results from the face validity interviews and the online panel survey and integrates the findings to select the final items for the QOL-ACC descriptive system.

Chapter 8 presents the results from the construct validity (convergent and known group) assessment of the QOL-ACC.

Chapter 9 discusses and concludes the key findings from the research. A summary of the main findings is presented, and limitations and implications of the research is discussed. The chapter concludes by outlining future research.

2. AUSTRALIA'S OLDER POPULATION, THE AGED CARE SECTOR AND RECENT REFORMS

2.1 INTRODUCTION

This chapter provides an overview of Australia's ageing population and the increased demand on aged care services. It explores the recent aged care sector reforms focusing on the introduction and philosophy of CDC and recent evaluations of the CDC approach to aged care service delivery in Australia. The chapter concludes by highlighting the importance of measuring QoL from the perspective of older Australians in receipt of aged care services as the key outcome measure for economic evaluations conducted in aged care.

2.2 THE OLDER POPULATION

2.2.1 An 'older person'

The term 'older person' has different meanings across countries and societies. Internationally, the United Nations defines an older person as an individual aged 60 or 65 years and over (United Nations, 2019). The World Health Organization (WHO) (2004) describes an older person as "a person who has reached a certain age that varies among countries but is often associated with the age of normal retirement" (p. 42). For example, in their research on old age in Africa, the WHO categorised an older person as an individual aged 50 and over as this age better reflected older people in a developing country due to relatively low life expectancy and no formal age of retirement. This classification was adopted by WHO for this research instead of the widely utilised age category of 60-65 years, which reflects the age of benefit entitlements in most developed countries (WHO, 2004).

Scherbov and Sanderson (2016) offer an alternative viewpoint of an older person by replacing the notion of a fixed chronological age by a measure of future life expectancy that they term prospective aging. They argue that using chronological age to define an older person (the number of years an individual has lived) should be replaced with the notion of prospective aging that defines an older person by how many years they have remaining. This approach considers an individual's characteristics at a given age may vary and also that prospective ages amongst the population are constantly changing. Scherbov and Sanderson (2016) claim this approach is more beneficial for demographic estimates as combining prospective years with other health metrics provides a better understanding of health in old age and patterns of survival which can be used to inform policy.

In Australia, 65 years and over is typically adopted as the age threshold to define an individual as an older person. This age threshold is used by ABS (ABS, 2019) and AIHW (AIHW, 2018). ABS and AIHW recognise that the Australian population is diverse, and the Australian Indigenous older population are defined as indigenous people who are 50 years and over, reflecting the lower life expectancy of Indigenous Australians compared to non-Indigenous Australians (AIHW, 2018). However, it is possible that these age classifications may change in the future to reflect changes in pensionable age. The age of pensionable benefits in Australia has gradually been increasing by 6 months every two years from 65 years to reach 67 years by 2023 for both non-Indigenous and Indigenous Australians (Australian Department of Social Services, 2019).

2.2.2 Australia's diverse older population

As highlighted in the previous introductory chapter to this thesis (Chapter one), the world's population is ageing with life expectancy at birth increasing in many countries. Both across countries and within countries, older populations are typically diverse with different socio-economic characteristics including gender, place of birth, language spoken at home, health, education and living arrangements, impacting upon how an individual ages physically, psychologically, and socially, all of which may affect the type and amount of care they require.

Worldwide, women generally have a longer life expectancy than men and Australia is no exception with a higher proportion of older females than older males in the population. An Australian female born in 2020 can expect to live to 85.0 years compared to 80.9 years for an Australian male (ABS, 2020). However, this life expectancy gap is gradually decreasing as male life expectancy has increased at a greater rate (1.6 years) than female life expectancy (1.1 years) in the last 10 years (ABS, 2020).

In 2018, there were 798,400 Aboriginal and Torres Strait Islander people living in Australia representing 3.3% of the total Australian population. Indigenous Australians have a lower life expectancy than non-Indigenous Australians. Only 4.3% of the total Indigenous Australian population are aged over 65 years compared to 15% of the total population of non-Indigenous Australians aged 65 years and over. Indigenous Australians aged 50 years and over (the age category adopted by AIHW for Indigenous older Australians) represent 17% of the total Indigenous population reflecting the lower life expectancy of Indigenous Australians compared to non-Indigenous Australians (AIHW, 2018). However, like the non-Indigenous Australian population, female life expectancy is longer for an Indigenous female (75.6 years) than an Indigenous male (71.6 years) (AIHW, 2020a). The difference in life expectancy between Indigenous and non-Indigenous Australians can be attributed to poorer health of Indigenous people and lower levels of access to health and social services for those living in remote communities. Nearly ninety percent of Indigenous people aged 65 years and over have at least one long-term health condition and are at increased risk of respiratory diseases, chronic kidney disease, mental health problems, diabetes, cancer, and cardiovascular disease (ABS, 2018a).

Australia’s older population are culturally and linguistically diverse (CALD) with just over one-third of older people born overseas, with three-quarters originating from Europe. One-fifth of people aged 65 years and over were born in a non-English speaking country and 18% of older people speak a language other than English at home. The most common languages spoken at home are Italian, Greek, and Chinese. AIHW estimates indicate that approximately six percent of older people living in Australia cannot speak any English or speak English poorly (AIHW, 2018). The diversity of the Australian older population in terms of ethnicity and language is a result of Australia introducing multiple immigration programmes to increase the population since the second World War, resulting in significant waves of migration from multiple countries (Thomson, 2014).

Geographical diversity is also prevalent with two-thirds of people aged 65 years and over living in major cities, just under one-third living in inner regional and outer regional areas and only 1% living in remote areas (AIHW, 2018). Some older Australians continue to be engaged in paid employment and others contribute to society by volunteering in their community. The number of people that continue to be in paid work after the age of 65 has increased over the years. In 2018, 12% of people aged 65 years and over were employed in some capacity compared to 8% in 2006. This growth can be attributed to the increase in pensionable age, better flexible work options and the global financial crisis resulting in the erosion of retirement savings. Unpaid work is also common with one in five people aged 65 years and over volunteering in the community (AIHW, 2018). All these socio-demographic differences create a diverse older Australian population and highlight that there is no ‘typical older Australian’.

2.2.3 Older Populations Health

Global policies on ageing advocate for older people to experience a good QoL for as long as possible through community engagement and leading a healthy lifestyle (WHO, 2002). However, despite major advances in living standards, technological innovations and the development of health and aged care systems, there is evidence to suggest that older people are not necessarily living with better health, wellbeing and QoL than previous generations (AIHW, 2018; WHO; 2015; WHO, 2018).

The older population in Australia experience varying levels of health and wellbeing which impacts upon their QoL and affects the type of care and support required. According to the ABS National Health Survey (2018), 72% of older adults are overweight or obese and only two-fifths of older adults are sufficiently partaking in the recommended Australian physical activity guidelines of 30 minutes or more of physical activity per day. Around one-third of older adults have smoked in their lifetime and 16% of older adults drink more than the recommended amount of two standards alcoholic drinks per day. Only 8% of people aged 65 years and over are meeting the nutritional guidelines of fruit and vegetable intake and just over half have experienced some form of stress in the last year, often related to serious illnesses and the death of loved ones (ABS, 2018b).

These poor lifestyle choices are linked to an increased risk of developing health issues such as type 2 diabetes, cardiovascular disease, certain types of cancer, kidney disease, anxiety, depression, and high blood pressure (NICE, 2018). Nearly 90% of older Australians have at least one long-term health condition and the likelihood of having a long-term health condition increases with age (ABS, 2018b). The most common health conditions experienced by older people are back pain, hypertension, arthritis, diabetes, and high cholesterol levels (ABS, 2018b).

Disability amongst older people is widespread. In 2018, approximately one in two older Australians (49.6%) reported as living with a disability, and this was more prevalent in older people aged 85 years and over (AIHW, 2018). Just over one-third (35%) of people aged 65 years and over reported they had profound or severe activity core limitation, indicating they experience severe difficulty and/or always need help with completing everyday tasks and activities (AIHW, 2018). One and a half million older Australians need assistance with day to day activities including attending healthcare visits, property maintenance and household chores, with older females needing more assistance with tasks such as property maintenance, mobility, and household chores than older males (AIHW, 2018).

Dementia and cognitive disorders are common in older people. In 2021, 472,000 people were living with dementia in Australia, and this is expected to increase to over one million by 2058 (Dementia Australia, 2021). Currently, one in ten people aged 65 years and over and three in ten people aged 85 years and over are living with the condition (Dementia Australia, 2021). The chance of developing dementia after the age of 65 years increases by 50% every five years (Dementia Australia, 2021). Dementia is the second highest cause of death and the main cause of disability amongst older people in Australia (ABS, 2020). Dementia is often diagnosed later than when symptoms appear, and in some cases, it goes completely undiagnosed, therefore, it is believed that dementia incidences are more prolific than the reported statistics (Commonwealth of Australia, 2013). Undiagnosed dementia cases can be attributed to healthcare professionals' misunderstandings of symptoms and lack of knowledge, the stigmatising affects associated with diagnosis, lack of assessment tools and poor communication and refusal by the individual to be assessed and/or treated (Bradford et al., 2009; Lang et al., 2017).

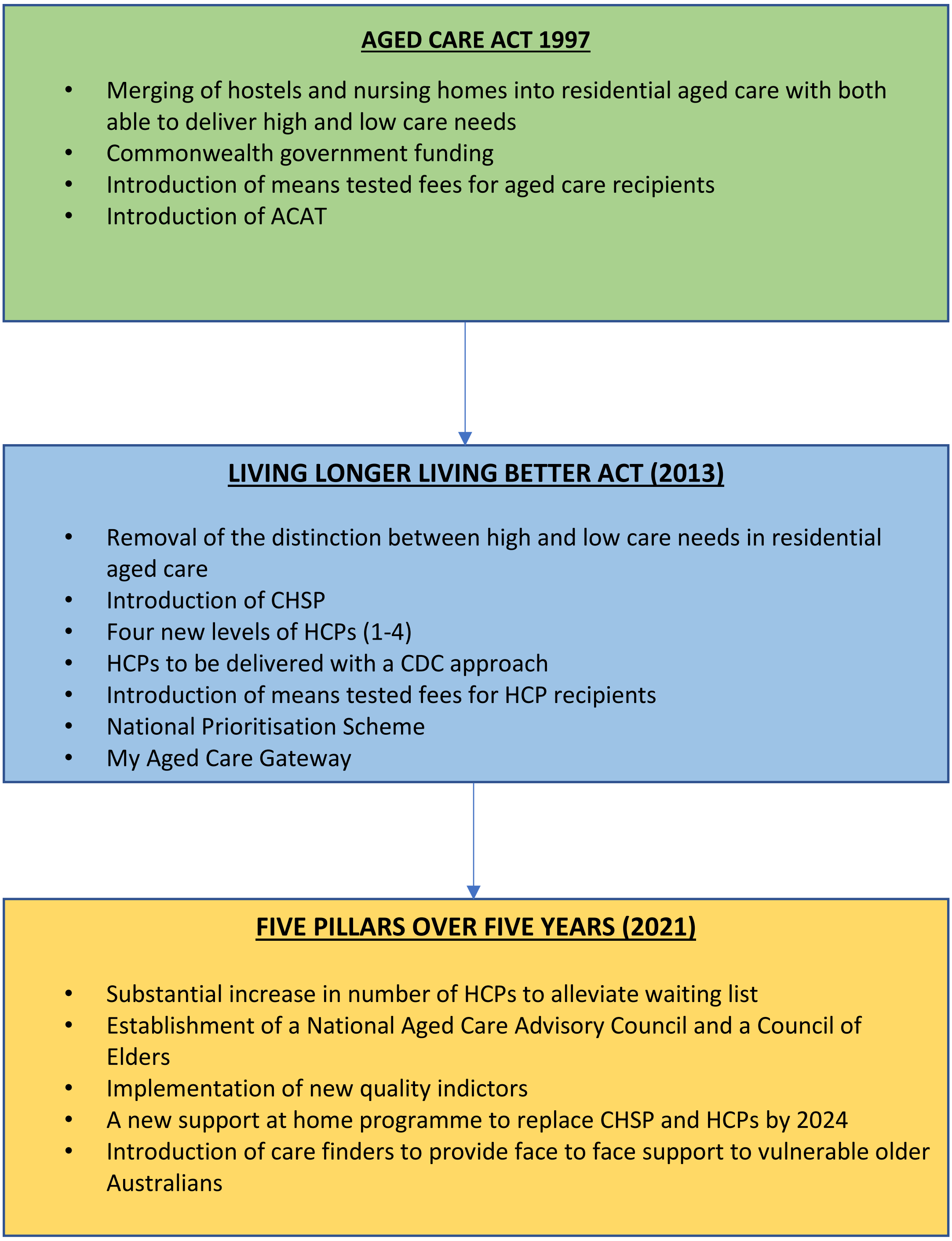
The COVID-19 pandemic has had a disproportionate adverse impact on older people's health and quality of life. Older people with long-term health conditions are more likely to contract the virus (Dawes et al., 2020), and the number of deaths as a result of COVID-19 are higher in the older age groups than the younger age groups (AIHW, 2021b). Up until the age of 59 years, the fatality rates from contracting COVID-19 are lower than 1%. However, this rate increases to 8.7% for people aged between 70-79 and 30% for people aged between 80-89 years (AIHW, 2021b). The risks of complications and long-term effects of COVID-19 also increases with age (AIHW, 2021b; Australian Department of Health, 2021e). Therefore, for older people that survive COVID-19, it is likely that the virus may impact upon their long-term health resulting in increased demand on aged care services to support their needs. Recommendations by the Australian Government are for older people to stay at home where possible and maintain social distancing (Australian Department of Health, 2021e) which has created social isolation among this population. A recent study by Siette et al. (2021) highlighted although older people had maintained social contact with family and friends throughout the pandemic, this was not always face to face, and older people's quality of life had significantly decreased since the pandemic. Furthermore, it has been suggested that social isolation as a result of the COVID-19 pandemic has increased depression and anxiety amongst the older population negatively impacting upon older people's health and quality of life (Chen & Olsen, 2022).

2.3 AGED CARE REFORMS

Chapter one highlighted the increased demand for aged care support in the home. It is well documented that the vast majority of older people prefer to age in place and be cared for in their own homes (Kendig et al., 2017; Ratcliffe et al., 2020). This preference coupled with an increase in life expectancy of older adults (and the associated increase in the numbers of older people living with a variety of co-morbidities and health conditions), has attributed to this increased demand for community-based services. In the last ten years, the number of people receiving aged care support in the home has tripled. In 2021, 183,376 older people were in receipt of a HCP with a further 829,193 older people accessing entry support through the CHSP (Australian Department of Health, 2021a; Productivity Commission, 2021). As of March 2021, 55,483 older people were waiting for a HCP at their approved level (Australian Department of Health, 2021a). This increased demand has resulted in several recent policy reforms enacted by the Commonwealth Government to overhaul the ways in which community aged care services are managed and delivered in Australia. An outline of the key aged care reforms is summarised in Figure 2.1.

Figure 2.1

Aged care reforms



AGED CARE ACT 1997

- Merging of hostels and nursing homes into residential aged care with both able to deliver high and low care needs
- Commonwealth government funding
- Introduction of means tested fees for aged care recipients
- Introduction of ACAT

LIVING LONGER LIVING BETTER ACT (2013)

- Removal of the distinction between high and low care needs in residential aged care
- Introduction of CHSP
- Four new levels of HCPs (1-4)
- HCPs to be delivered with a CDC approach
- Introduction of means tested fees for HCP recipients
- National Prioritisation Scheme
- My Aged Care Gateway

FIVE PILLARS OVER FIVE YEARS (2021)

- Substantial increase in number of HCPs to alleviate waiting list
- Establishment of a National Aged Care Advisory Council and a Council of Elders
- Implementation of new quality indictors
- A new support at home programme to replace CHSP and HCPs by 2024
- Introduction of care finders to provide face to face support to vulnerable older Australians

2.3.1 The Aged Care Act 1997

The Aged Care Act was introduced in 1997 and represents the main government legislation overseeing aged care services in Australia. The Aged Care Act was introduced to streamline previous acts into one main legislative framework with the aim to facilitate older people to age in place. The legislation followed a 1990's review that found gaps in the standards of the quality of care being provided and highlighted the need for the structure of the aged care system to be overhauled (Productivity Commission, 2003).

The overarching aim of the Aged Care Act 1997 was to enable older people to age in place by connecting care services and providing flexible residential and home care services to meet the needs of the older person. The Act changed the structure of existing residential care by allowing hostels (low level needs) and nursing homes (high level needs) to provide both low and high levels of care meaning older people were not forced to move facilities if their care needs increased. Aged care is mainly the responsibility of the Commonwealth Government, and the Act outlined the means-tested financial support provided by the Commonwealth Government for individuals seeking access to residential and home care services. New aged care regulation standards were introduced for aged care providers to monitor the quality of care being provided, to increase staff training and development, and to improve the physical structure of residential care buildings (Australian Government, 1997).

2.3.2 The Living Longer Living Better Act 2013

In 2011, the Commonwealth Government commissioned an extensive review into the aged care sector to identify if the changes to aged care provision introduced following the Aged Care Act in 1997 were meeting the needs and demands of the ageing population. The review conducted by the Productivity Commission (2011) involved consultation with aged care consumers (older people and their families), aged care providers and government organisations. The review acknowledged that aged care services had improved since the Aged Care Act was introduced but highlighted many weaknesses in the existing structure of the sector. Consumers found aged care services to be very confusing to understand and navigate and multiple inconsistencies in delivery and pricing were prevalent. The choice and quality of services available were found to be highly variable across service providers with some good services, but most were generally poor (Productivity Commission, 2011). Furthermore, the review found varying skill levels amongst care workers which was attributed to the low wages of this profession. The Productivity Commission (2011) recommended these weaknesses be addressed by improving the quality of aged care services to enhance older people's QoL and wellbeing through providing increased choice, independence, and community engagement.

Following the review by the Productivity Commission (2011), the Commonwealth Government responded by introducing new aged care reforms in 2012 which were then subsequently legislated in 2013 as the Aged Care (Living Longer, Living Better) Act 2013. This reform represented the most significant policy change in the Australian aged care sector in its history and signalled a period of mass structural and philosophical change to aged care services in Australia. The overarching concept of the act was to ensure older Australians were able to live in their own home and remain in their community for as long as possible by increasing choice and independence with the goal of maximising older people's QoL and wellbeing.

Home care

The Living Longer Living Better Act of 2013 introduced CHSP. CHSP was introduced to streamline the existing basic care services - the Commonwealth Home and Community Care (HACC) program, the National Respite for Carers Program (NRCP), the Day Therapy Centres (DTC) program, and the Assistance with Care and Housing for the Aged program (ACHA) - into one main programme. CHSP provides entry level support to enable an older person to continue living at home independently. Support is typically provided to assist the older person with one or two tasks such as domestic assistance, transport, social support, personal support, meal preparation, home modifications, nursing, and allied health for an average of two hours per week or less (Australian Department of Health, 2020e).

The reforms included an overhaul to the existing structure of HCPs. Prior to the reforms, aged care packages consisted of Community Aged Care Packages (CACPs), Extended Aged Care at Home (EACH) and Extended Aged Care at Home Dementia (EACHD) packages. CACPS provided low level support such as basic personal care, social support, transport, cleaning, meals, and gardening. Both EACH and EACHD packages provided higher levels of support similar to the support provided by CACPs, but also included nursing, allied health, and aids and equipment. EACHD packages had an additional dementia and cognition top up supplement applied to the package (Australian Department of Health and Ageing, 2013).

Four new levels of HCPs were introduced: level 1 (basic needs), level two (low needs), level three (intermediate needs) and level four (high needs). Previously, older people had to change providers as their level of care needs changed but the reforms allowed aged care providers to offer all levels of HCPs enabling older people to remain cared for and supported by a single aged care provider, should they choose to do so, as their care needs increased (Australian Department of Health, 2012).

Prior to the Living Longer Living Better Act 2013, HCP applications continually out-stripped supply and one-third of older people experienced at least a three-month wait to receive a package (Australian Department of Health, 2012). An individual would join an aged care provider waiting list once approved but there was no prioritisation protocol in place. Aged care providers applied for places through the Aged Care Approval rounds and were allocated places once a year to assign to older people. The new reforms increased the number of HCPs from 60,000 to 99,669 to immediately alleviate this unmet demand and introduced a ‘national prioritisation system’ in 2017 to ensure individuals that needed care the most received it first. The national prioritisation system prioritised the allocation of HCPs to older people based upon their assessed care needs determined through an ACAT assessment and by the date of their assessment (Australian Department of Health, 2012).

ACAT assessments are conducted face-to-face in an individual's home under the Aged Care Act 1997 to assess an older person's care needs. During the assessment, the assessor identifies and discusses what support the individual may need based upon their health, lifestyle, ability to complete daily tasks, cognition, personal safety, and considers what support they may already receive. During the assessment recommendations are made for suitable services and a support plan is developed with the individual tailored to their needs. Following the assessment an older person is notified within 14 days of their eligibility for a HCP and what services they can receive and are placed onto the waiting list. Depending on the individual's circumstances, a lower level of HCP may be offered whilst the individual waits for a HCP on their assessed level (Australian Government, 2021).

Residential Care

The Commonwealth Government pledged to increase funding to build new residential care homes to accommodate more older people with high level care needs and to refurbish care homes in need of repair. The main change to residential care was that residential places became permanent allocations and the distinction between low care needs and high care needs was removed. This change simplified the residential care system and meant an older person could remain in one residential facility as their care needs increased allowing them to age in place (Australian Department of Health and Ageing, 2012). The reforms also made financial changes by offering more consumer flexibility, choices for care payments and the introduction of a more consistent means-tested fee structure alongside annual fee caps and lifetime fee caps (Australian Department of Health 2012).

CDC

One of the main changes legislated by the Living Longer, Living Better Act 2013 was the introduction of CDC. CDC was introduced to provide more choice and control to older people placing them at the heart of their care to maximise their QoL and wellbeing. CDC has six main principles:

- Choice and control over care for the consumer
- Respecting the rights of the individual
- Respectful partnership between the consumer and the aged care provider
- Participation in management of care if the consumer wishes
- Aged care provider to assist with the wellness and reablement of an individual in their care.
- Full transparency of allocated funding and services to the consumer

(Australian Department of Health and Ageing, 2013).

These six principles underpin the delivery and management of HCPs by supporting older people to live as independently as possible. The philosophy of CDC encourages older people to identify and set their own goals through individualised care plans developed with aged care providers. The approach supports individuals to choose who delivers their care and what type of services they receive to suit their needs within their allocated resources. CDC also places an emphasis on control and flexibility and encourages older people to maintain regular contact with their provider to ensure services are meeting their changing needs (Australian Department of Health and Ageing, 2013).

Care delivered with a CDC approach requires the consumer and the aged care provider to develop an individualised budget to pay for services. This includes the contribution of the Commonwealth Government subsidy, the home care fees payable by the older person and a detailed breakdown of the cost of the services and care the older person will receive. The aged care provider is required to develop the budget once the services are agreed and ensure that the older person is aware of the details of their budget. The aged care provider is also expected to provide the older person with a monthly statement of their available funds and expenditure (Australian Department of Health and Ageing, 2013).

Delivering homecare support on a CDC basis was introduced to encourage older people to work in partnership with their service providers to ensure they receive the care and services they need to maximise their QoL and wellbeing, thereby allowing them to remain in their own home in the community for as long as possible. Research has suggested that this is an overwhelming preference for a large majority of the older population and is key to an individual's wellbeing and QoL (Kendig et al., 2014; Kendig et al., 2017; Olsberg & Winters, 2005; Ratcliffe et al., 2017). The Productivity Commission (2015), in their research on older Australians' housing decisions, found that 83% of older people would choose to remain in their own home as they get older. Indeed, a recent report for the Royal Commission into Aged Care Quality and Safety, to which I contributed, assessed the public's preferences for quality of care and future funding of aged care. The report highlighted that a large majority of the general public (72%) would be willing to pay a co-contribution of $184 per week on average to receive care and support at home and avoid entering residential care (Ratcliffe et al., 2020). Research has shown that older people who remain in their own homes for longer time periods experience improved mental and physical health as a result of tighter social and community networks in comparison to those who live in less permanent dwellings (Freilich et al., 2014). Likewise, Bowers et al. (2009) found older people experienced a good QoL when they had control and feelings of empowerment which were strongly associated with individuals remaining in their own homes.

CDC was initially piloted in 2010/11 with 1,000 places allocated to existing or new consumers as part of the Commonwealth Government funded care packages programme and was then introduced into the 2012 reforms due to its success (Australian Department of Health, 2012). From August 2013, all new HCPs were required to be delivered on a CDC basis and from July 1st 2015 all HCP (new and existing) had to be delivered with this approach. CDC underwent further changes in 2017 with funding going directly to the older person rather than the aged care provider, meaning older people could change their service provider more easily and take their package with them if they wished to change their provider (Australian Department of Health, 2020b).

Financial Changes

The Productivity Commission (2011) review recommended a financial overhaul to aged care services to provide transparency in costs of services and availability of services to enable older people to make better and more informed choices for their care. As a result, The Living Longer Living Better Act 2013 introduced changes to the structure of HCP fees. A new means tested fee was introduced for older people based on their income, in addition to the basic daily fees (set at a maximum of 17.5% of the basic single age pension), with a cap of $60,000 over their lifetime. Individuals with a yearly income of over $43,186 were required to pay a care fee of up to a maximum of $10,000 per year. Full time pensioners were not required to pay any care fees and part-time pensioners contribution were capped at $5,000 per year. No older person receiving care contributed more than the total cost of the care they were receiving, and the individual’s home and other assets were not included in assessing an individual’s contributions to their care. Furthermore, the Commonwealth Government introduced a dementia supplement of 10% on top of the basic Commonwealth Government funding for aged care packages to enable more people living with dementia to be cared for at home (Australian department of Health and Ageing, 2012).

National Carer strategy

Following the Productivity Commission review (2011), the National Carer Strategy (2012) was introduced by the Commonwealth Government to support and recognise the vital work that informal carers provide within the community. The strategy consisted of six key areas that the Government pledged to prioritise so informal carers were better valued and supported:

- recognition and respect
- information and access
- economic security
- services for carers
- education and training
- health and wellbeing

Through this strategy, the Commonwealth Government increased additional support services and respite for informal carers and increased funding for informal carer counselling. Respite funding arrangements were streamlined, and informal carers were provided with more choice and flexibility of services. These changes were designed to increase carer's rights and choices to enable them to participate economically and socially in their community and improve their health, wellbeing, and QoL (Australian Department of Social Services, 2012; Australian Department of Health and Ageing, 2012).

Aged Care Workforce

The Productivity Commission (2011) reported that the growing number of older Australians in need of care and support necessitated expansions in the aged care workforce. In 2010, there were 304,000 aged care workers and this was predicted to increase to 872,100 by 2050. Aged care staff turnover was relatively high leading to reduced productivity and increased expenditures on attracting and training new workers into the aged care industry (Productivity Commission, 2011). As part of the Living Longer Living Better Act 2013, the Commonwealth Government pledged to promote aged care as a career and to provide aged care providers more funding to improve the terms and conditions of their employees to help retain their workforce. Higher wages, better career structure, more training opportunities, career development and an improved work environment were amongst the key changes that the Government intended to implement to create a more skilled and dedicated workforce (Australian Department of Health and Ageing, 2012).

My Aged Care

The Productivity Commission (2011) highlighted in their review that the existing aged care system was extremely complicated for older people, their families, and carers to understand and did not support older people to make informed decisions about their care. Therefore, My Aged Care was introduced as a single access point to the aged care system to provide a clear and consistent means of information about aged care for older people and their families outlining options for care, assessments, and financial arrangements (Australian Department of Health and Ageing, 2012).

My Aged Care initially consisted of a website and a telephone contact centre to provide a single entry point for older people and their family carers to access aged care services, introduced in July 2013. In July 2015, it expanded to include a centre for client records, an assessment service for approval of care and web portals for clients, assessors, and providers (Australian Department of Health, 2018). The Commonwealth Government wanted older people and their families to be able to access information about the quality and ratings of aged care providers to make better choices about their care to fulfill their needs.

However, a report conducted by National Seniors found that less than 20% of older people had accessed the My Aged Care gateway and accessing the website was less common amongst those aged 75 years and over compared to older people aged 65-74 years. Additionally, lower satisfaction rates amongst consumers using the website to access information were experienced compared to those consumers accessing the contact centre (McCallum & Rees, 2017). These findings are not surprising considering the relatively low proportion of older people (65 years and over) accessing the internet (61.6% in 2018) (ABS, 2021). This highlights the need for improved access and knowledge of digital literacy for older people in the future if My Aged Care is going to achieve its ultimate aim to facilitate older people and their families in accessing relevant and timely information about aged care services in an easy and accessible format.

2.3.3 Further reforms

Since the Living Longer Living Better Act 2013, the Commonwealth Government have continued to introduce further reforms to improve the aged care sector. Following from the introduction of a CDC approach to the design and delivery of HCPs, the Commonwealth Government introduced the Increasing Choice in Homecare Reforms in 2017 to assist older Australians to have more choice and control over the care and services they receive. This key reform meant that aged care providers delivering home care support no longer had to apply for aged care packages through approval rounds as HCPs were allocated directly to older Australians. This change enabled individuals to choose which aged care provider they gave their package funding to and allowed any remaining funds to be transferred if they changed aged care providers (Australian Department of Health, 2021b).

Since July 2019, it has become compulsory for aged care providers to publish their pricing structure on the My Aged Care website and to provide their fees to individuals receiving their services. This new transparency in costs was introduced to enable older Australians to make comparisons between aged care providers to help them make decisions about their care (Australian Department of Health, 2021b). However, a recent report identifying the barriers for older people and their families accessing HCPs highlighted most older people struggle to navigate the system and find the information difficult to understand. Only 6.8% of older people had accessed the My Aged Care portal to compare providers and approximately two-fifths of older people reported they did not understand their aged care provider’s fees and charges. Two-fifths of older people did not have a care plan outlining who will deliver their care services and when the services will be delivered. Furthermore, a large majority (90%) of individuals stated they needed clearer information when making decisions about their care and would prefer to receive this information face-to-face or via the telephone rather than using the My Aged Care website. Information such as the quality and reputation of the organisation was imperative to individuals when choosing aged care organisations. However, for homecare recipients this information is not really known until the individual is experiencing the care being delivered from the organisation, making it difficult for individuals to know about the quality of care prior to choosing an organisation. Therefore, individuals are choosing aged care organisations based on recommendations from other health professionals and family and friends (Consumer Policy Research Centre, 2020).

Aged Care Quality and Safety Commission

In 2019, the Commonwealth Government created the Aged Care Quality and Safety Commission which combined the roles of the former Australian Aged Care Quality Agency and the Aged Care Complaints Commissioner. The Aged Care Quality and Safety Commission was introduced as the regulator of the aged care sector to monitor the quality and safety of aged care services to ensure older people’s health, wellbeing, and QoL was maximised. The Aged Care Quality and Safety Commission is responsible for approving and regulating aged care providers, conducting quality reviews, enforcing sanctions, and dealing with complaints. The Aged Care Quality and Safety Commission introduced eight new aged care quality care standards, which all aged care providers were expected to adhere to and be assessed against, to ensure aged care providers were providing good quality care that meets the needs of older Australians (Australian Department of Health, 2019). These standards are discussed in more detail in Chapter three of the thesis.

Royal Commission into Aged Care Quality and Safety

In October 2018, The Royal Commission into Aged Care Quality and Safety was established by the Governor-General, Commonwealth of Australia with the final report being released in February 2021. Royal Commissions in Australia are independent of the Commonwealth Government and conduct the highest level of investigations into public matters by holding public hearings and calling witnesses for evidence. The Royal Commission makes recommendations to the Commonwealth Government on what needs to change and outlines these recommendations in a final report (Royal Commission into Aged Care Quality and Safety, 2021).

The Royal Commission into Aged Care Quality and Safety was established following ongoing problems and challenges with the current aged care system. The ageing population and subsequent demand for aged care services was putting pressure on a system that was failing to meet the needs of older Australians. The system did not support older people's QoL, consisted of a complicated navigation system, long waiting lists, unskilled aged care workers and a poor assessment system to measure the quality of aged care providers. Poor care, widespread abuse, mistreatment, and neglect were also prevalent (Royal Commission into Aged Care Quality and Safety, 2021). In the two years of the inquiry, the Royal Commission commissioned independent organisations to undertake detailed research on aged care services and conducted 23 hearings and workshops across Australia in regional and metro areas where witnesses gave evidence about their knowledge and experience of the aged care system (Royal Commission into Aged Care Quality and Safety, 2021).

The final report released in 2021 highlighted several areas of concern with the Australian aged care sector and made 148 recommendations for improvement, placing a key emphasis on improving quality of care to enhance older people's QoL. Commissioners called for a new rights based Aged Care Act (Recommendation 1) to be introduced focusing on the needs of the consumers rather than the funding requirements of aged care providers. This new act would focus on older people's rights to access good quality care to enhance their social participation, dignity, self-determination and ensure they were free from neglect and harm. The report recommended the establishment of a new National Cabinet reform Committee on Ageing and Older Australians to develop an integrated national approach to ageing for the long-term support and care of older Australians. The cabinet would be expected to work directly with older people and develop a ten year strategy plan for the aged care sector (recommendation 4) (Royal Commission into Aged Care Quality and Safety, 2021).

The Royal Commission recommended better access and support to aged care services for older Australians. A key recommendation made was to clear the HCP waiting list by December 2021 and to approve HCPs within a month from 2022-2024 (recommendation 39) (Royal Commission into Aged Care Quality and Safety, 2021). As previously highlighted in Chapter one, the average waiting time for a level 1 HCP is between three and six months and for a level 2, 3, or 4 HCP the wait time is at least 12 months with nearly 30,000 individuals dying in the last two years whilst waiting for a HCP (Australian Department of Health, 2021a).

The Report recommended ‘care finders’ be established who would act as case managers to provide guidance and support to older people and their families to help them make informed decisions and choices about their care (recommendation 29). Increased respite, training, and support for informal carers would be introduced by identifying informal carers during assessments of older people and better links between My Aged Care and the carer Gateway (a service that provides advice, support, and services to carers) (recommendation 42) (Royal Commission into Aged Care Quality and Safety, 2021).

Recommendations were also made to attract, retain, and upskill the aged care workforce to meet the increasing demand of aged care services through a revision of aged care sector wages (recommendation 84, 85), the establishment of better career pathways (recommendation 76), the introduction of certificate three as the minimum qualification level required (recommendation 77, 78), and increased training and funding for teaching aged care programmes (recommendation 83). Furthermore, a review of certificate-based courses for aged care including the consideration of modules relating to quality of life was also recommended (recommendation 79) (Royal Commission into Aged Care Quality and Safety, 2021).

The Royal Commission into Aged Care Quality and Safety’s recommendations have an overarching concept of improving the QoL of older Australians through the provision of good quality care. Indeed, the Royal Commission stated, “quality of life should be the constant and predominant aim of the aged care system” (Royal Commission into Aged Care Quality and Safety, 2021, p. 79). The focus on quality of life was demonstrated through the recommendations made. For example, recommendation 105 highlighted the need for the Aged Care Quality and Safety Commission to provide information on the effectiveness of the system in relation to safeguarding the quality of life and quality of care provided to older people. Furthermore, the ICT Architecture and investment in technology and infrastructure recommendation (109) proposed an increased investment in technology and information and communication systems for the aged care system with an emphasis on all technology supporting the quality of life of older people.

A full review of the Aged Care Quality standards was recommended to take place by July 2022 to ensure aged care services were focusing on the QoL of care recipients (recommendation 21). Additionally, the Aged Care Quality and Safety Commission were advised to routinely report on the effectiveness of the aged care system in providing good quality care that enhances older people’s QoL (recommendation 105). The report also recommends that by July 2023, quality indicators should be introduced and implemented for aged care services at home. These quality indicators would include a QoL assessment tool to be routinely applied to measure the QoL of older Australians receiving care as it was highlighted that quality of life is an outcome of good quality care and has been shown to have a positive impact on clinical outcomes (Royal Commission into Aged Care Quality and Safety, 2021). In the past, quality indicators have not included a QoL tool for routine assessment of aged care quality services and this inclusion highlights the central importance of QoL as a key quality indicator for older people accessing aged care (recommendation 22). The new home care quality indicators would enable benchmarking in which providers can compare their performance against expectations of care delivery. The indicators would also allow for performance to be monitored across aged care services provided to older people in the home (Royal Commission into Aged Care Quality and Safety, 2021).

Five pillars over five years

In response to the Royal Commission into Aged Care Quality and Safety, the Commonwealth Government declared aged care reform as a priority of the 2021/22 budget and introduced the ‘five pillars over five years’, supported by $17.7 billion government funding. The ‘five pillars over five years’ aims to overhaul the aged care system by making changes in home care services, residential care, the aged care workforce and governance with a key focus on ensuring good quality care to enhance the QoL of older Australians (Australian Department of Health, 2021c). As mentioned previously, the implementation of new quality indicators to assess aged care services (including QoL assessment alongside existing clinical care measures e.g., pressure injuries, unplanned weight loss and physical restraints) were agreed to be implemented. The quality indicators will be used to benchmark aged care providers against one another to promote continuous improvement in the sector. Providers will be given star ratings based on the quality indicators which can be used by older people and their families to make decisions and choices about which aged care providers and services they wish to access (Australian Department of Health, 2021c).

The Commonwealth Government recognised the increase in older Australians choosing to remain at home to receive care, and therefore $7.5 billion was allocated to support homecare services for those who choose to age in place. The government pledged to release an additional 40,000 HCPs in 2021 with a further 40,000 in 2022 making a total 275,598 packages available by 2023 to help clear the waiting list. Other homecare reforms included improved access for older Australians to more assistance and information about aged care through multiple aged care service centres and increased support for informal carers. By 2023, 500 care finders would be introduced to act as case workers by providing face to face support to vulnerable older Australians. A new support at home programme is also planned to replace the existing CHSP and HCPs by 2024. This single in-home care programme intends to be easier to navigate, and better equipped to meet the needs of older Australians by providing high quality care that places the individual at the centre of their care. The new Support at Home Program will replace the existing assessment and delivery of home care with individualised support plans to provide more tailored and unique care based on individual’s circumstances rather than being placed into a broad HCP level. The new program will have a strong focus on independence by providing older Australians with increased guidance and support to make individual choices about their care (Australian Department of Health, 2022; Australian Department of Health, 2021c).

$652 million of the budget was allocated to grow the aged care workforce and upskill the workers in this sector. A single assessment workforce will be created to conduct all assessments for home care, thus simplifying the system by 2022. The government intend to increase the number of aged care workers over the next five years to meet the needs of the growing demand for aged care services and provide additional training for the aged care workforce (Australian Department of Health, 2021c).

The Government pledged $698 million to make improvements to the governance of the aged care sector by placing older Australians at the centre of the aged care system to ensure they receive good quality care that meets their needs and are treated with respect and dignity. Amongst the governance reforms were the establishment of a National Aged Care Advisory Council and a Council of Elders to provide advice to the government to be introduced in 2021. Improved access to aged care services for older people with special needs, Indigenous Australians and older people living in remote and rural areas will be achieved by increasing funding in these areas. By 2022, the government aims to introduce a First Nations Workforce to help older First Nations people understand and navigate aged care services. By mid-2023, a new values-based Aged Care Act will replace the Aged Care Act 1997 outlining all the key reforms (Australian Department of Health, 2021c).

COVID-19 Pandemic

During 2020 and 2021, the COVID pandemic has created significant challenges in the aged care sector. As mentioned in section 2.2.3, the COVID-19 pandemic has had a disproportionate adverse impact on older people's health and quality of life. As a result, the Commonwealth Government has worked with the aged care sector to reduce transmission, manage COVID-19 cases, and put in place infection control measures. The Commonwealth Government recognised the challenges that aged care workers faced caring for older Australians during this period and pledged $850 billion to support the aged care sector though this pandemic. The funding includes extra training for the aged care workforce about the pandemic, retention bonuses for aged care workers, delivery of food supplies to older Australians and additional workers to support the increased enquiries through My Aged Care (Australian Department of Health, 2020b).

2.4 THE IMPORTANCE OF MEASURING QOL IN AGED CARE

As highlighted in Chapter one, government expenditure on aged care is costly and resource intensive, therefore it is important to assess if new policy initiatives such as CDC are improving the QoL of older Australians to ensure the effective use of limited resources in this sector. Economic evaluation is a useful tool that can assist decision-makers to compare the costs and outcomes of services and programmes to identify the best interventions to maximise the QoL of older Australians (Drummond et al., 2015).

Despite the growing importance of economic evaluations in aged care, it has been documented that economic evaluations in aged care are sparse in comparison with those undertaken in the health sector (Ratcliffe et al., 2012). A recent systematic review of economic evaluations in community aged care only found 11 studies reporting economic evaluations, the majority of which were conducted in Europe (Bulamu et al., 2018). The 11 studies heavily focused on aged care structure and processes such as the value of preventative home visits, re-ablement programmes following a hospital stay, analysis of integrated multidisciplinary care in comparison to GP visits, comparisons of assessment of aged care service models, and the value of case management for outreach services. Furthermore, only five of the 11 studies had used CUA allowing comparison across the interventions with the common outcome measure of the QALY (Bulamu et al., 2018). Similar results were documented in a systematic review in residential care that only found fourteen studies with an economic component, and none of the identified 14 studies had carried out a full economic evaluation using CUA with quality of life as the main measure of outcome (Easton et al., 2017). This systematic review highlights the scarcity of economic evaluations that have taken place across other services in the aged care sector, and not just in community aged care.

As mentioned previously in this chapter, a major shift in the delivery of HCPs took place when the Living Longer Living Better Act 2013 introduced CDC. CDC was introduced to provide older Australians with more choice and control about the care they receive to enhance their QoL. To date, limited CDC evaluations have been conducted in Australia with most research being undertaken prior to the legislation of CDC.

One of the first CDC trials was the People at Centre Stage (PACS) funded by the Commonwealth Government and co-developed by care recipients and aged care providers in Victoria. The pilot generated mostly positive outcomes for care recipients. For example, the care recipients reported they felt empowered, enjoyed the flexibility of the care services, had better control, changed their outlook on what they could achieve, felt less lonely, and increased their capacity to do other tasks such as paying bills, paperwork and making their own meals. However, a small amount of care recipients highlighted they struggled to manage the paid care workers and missed the support that case workers usually provided (Ottmann et al., 2012).

An evaluation of CDC was also undertaken in 2014-15 by the Brotherhood of St Laurence, a non-Government, community-based organisation that provide services to disadvantaged individuals in Victoria. The Brotherhood of St Laurence had been part of the PACs trial and had involved their consumers in developing a CDC approach for the delivery of HCPs following this trial. The evaluation reported the consumers found CDC complex, confusing, and struggled to manage their own care. However, once consumers were supported, they grew in confidence and most learnt how to manage their own funds and care. This CDC evaluation highlights that additional practical support may be required for older people from disadvantaged backgrounds to manage their own care successfully (Simons et al., 2016).

Research conducted by Gill et al. (2017) identifying the problems and challenges of implementing CDC approaches highlighted consumers welcomed the choice of services available but limited information about CDC prevented them from fully engaging in the approach. Other research has produced similar results recognising many aged care employees and consumers did not fully understand CDC highlighting the need for further CDC information and support to be provided to aged care providers and their consumers (Day et al., 2018; Gill et al. 2018). Ottmann and Mohebbi (2014) support these findings and suggest capacity building approaches such as CDC can improve older people's satisfaction with care and QoL through providing greater choice and independence but acknowledge these positive outcomes can only be achieved through providing support and information to the individual.

More recently, research undertaken by Bulamu et al. (2017) aimed to evaluate if CDC had improved older Australian's QoL using standardised QoL measures. The research compared the QoL of older people receiving community aged care on a CDC basis to those receiving community care on a non-CDC basis using the Investigating Choice Experiments Capability Measure for Older People (ICECAP-O), an older person specific QoL measure anchored on a capability scale (Al-Janabi et al., 2012; Coast et al., 2008) and the EQ-5D-5L (a generic preference-based QoL measure) (Herdman et al., 2011). Despite the study reporting no significant difference in QoL between the two groups identified, older people receiving community care support with the CDC approach reported increased choice and control which could potentially lead to a better QoL in the future.

The largest CDC evaluation in Australia to date was conducted in 2012 during the pilot phase of CDC. This evaluation was led by a consulting company (KPMG) in 2012 evaluated 700 HCPs delivered using a CDC approach. The evaluation found inconsistencies in the way CDC was delivered by aged care providers such as the range and flexibility of services provided and that allocated package amounts did not always reflect the needs of the participants. However, most older people were satisfied with their involvement in care planning, and most were receiving services representing their needs. Overall, individuals believed they had enough knowledge and information to make informed choices, although many preferred to only be involved in the basics of budget planning. Older people's QoL was assessed using the ICECAP-O measure, a validated non-aged care specific measure of capability for older people, and through a series of semi-structured interviews. The evaluation found older people reported overall improved QoL since the introduction of CDC, highlighting increased independence, increased participation in social and community activities, better relationships with family and friends and improvements in their health, wellbeing, and QoL (KPMG, 2012).

Whilst these evaluations are important to understand how CDC has been implemented and its level of success, CDC was introduced to empower older adults by providing them with more choice and independence about their care ultimately leading to a better QoL. However, except for the KPMG (2012) study which used the ICECAP-O to measure QoL, and the small-scale study by Bulamu et al. (2017) that used the ICECAP-O and the EQ-5D-5L, none of the other evaluations used a standardised QoL measure to evaluate older Australian's QoL as part of their evaluation. Furthermore, not one of the studies conducted a full economic evaluation of the interventions. Indeed, KPMG (2012) in their evaluation report recommended a full economic evaluation of CDC approaches within the community should be undertaken in the future using a validated measure appropriate for older people that can calculate QALYs in order for comparisons between interventions and programmes to be made (KPMG, 2012).

The importance of measuring QoL of older Australians has been highlighted by the introduction of the new Australian aged care quality standards in 2019 by the Aged Care Quality and Safety Commission that focus on quality of care with a key emphasis placed upon QoL outcomes. Aged care providers are now expected to adhere to the standards and provide evidence to show they are meeting these standards (Australian Department of Health, 2019).

Furthermore, in their final report, The Royal Commission into Aged Care Quality and Safety acknowledged that the central aim of the aged care system should be to ensure older Australians have a good QoL through the provision of good quality care. The report highlighted the lack of attention paid to monitoring the QoL of older people receiving care and therefore, a key recommendation was to introduce a QoL assessment tool to be used in aged care to measure and monitor the QoL of older Australians in receipt of aged care services (Royal Commission into Aged Care Quality and Safety, 2021). However, as mentioned previously in Chapter one, no preference-based measure exists developed from the perspective of the older person, incorporating broader dimensions of QoL, designed to be used in health economic evaluation to measure and value the QoL of older Australians receiving aged care services in the community (Bulamu et al., 2015; Cleland et al., 2019; Makai et al., 2014). Therefore, it is imperative that a new measure is developed to measure and value older people's QoL that can be applied in economic evaluations in the aged care sector to fill this gap.

Following on from the Royal Commission's final report acknowledging an intrinsic link between quality of care and QoL, Chapter three will focus on what defines quality of care for older people and the relationship between quality of care and QoL. Chapter four will discuss the use of existing QoL measures that have been applied with older people in receipt of aged care services in the community and the issues pertaining to their use with this population in more detail.

3. WHAT DEFINES QUALITY OF CARE FOR PEOPLE IN AGED CARE?

This chapter contains material from:

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3.1 INTRODUCTION

This chapter focuses on older people's experiences of care to examine what constitutes quality of care and person-centred care and the relationships of these constructs to QoL. The quality of care and services provided in Australia's aged care system is a matter of concern, not only to older people and their families currently engaged with aged care, but also for potential future consumers, members of the public as taxpayers, and society more generally.

As highlighted in the preceding Chapters, at the time of this research being conducted, the quality of the aged care system was the subject of a Royal Commission as a result of ongoing problems and challenges in the system and several cases of abuse, neglect and mistreatment documented in the Australian media (Royal Commission into Aged Care Quality and Safety, 2021). In its interim report, the Royal Commission for Aged Care Quality and Safety (2019) highlighted that the quality of care provided in Australia's aged care system "fails to meet the needs of our older, often very vulnerable, citizens. It does not deliver uniformly safe and quality care for older people. It is unkind and uncaring towards them. In too many instances, it simply neglects them" (p. 1).

3.1.1 What is quality of care?

Whilst it is evident that the provision of good quality care is imperative, in practice, quality of care is difficult to define and measure due to the term having a multitude of different meanings. In health systems, quality of care is often understood as the extent to which services meet individuals' needs to improve their health outcomes (World Health Organization [WHO], 2019). The WHO (2019) asserts that high quality care should be safe (minimises risks and harm), effective (provides services based on evidence-based guidelines), timely (reduces delays), efficient (uses resources to provide the greatest benefit and lowest waste), equitable (high quality care should be available despite the individual's personal characteristics e.g. gender, ethnicity) and person-centred (taking into account the unique preferences, values and needs of the individuals accessing it).

Person-centred care is becoming increasingly recognised as an integral component of good quality aged care and the two terms (person-centred and quality of care) are often used interchangeably (Slater, 2006). In pioneering research focused on people with dementia, Kitwood (1997) used the term person-centred care to describe care that moves away from purely focusing on the physical and medical aspects of care towards more individualised care focusing on the person with dementia as a whole person, and meeting all of their individual's needs. More recently, the definition of person-centred care has been extended to encompass the unique preferences, values and needs of the individuals accessing it (Koren, 2010).

3.1.2 The relationship between quality of care and quality of life

Within aged care, quality of care is intrinsically linked to QoL. The quality of the care provided in aged care is likely to impact upon an individual's QoL due to the ongoing nature of the care provided, with better quality of care associated with a better perceived QoL (Bulamu et al., 2017; Batchelor et al., 2020; Royal Commission into Aged Care Quality and Safety, 2021). Quality of care relates to the structure and processes of care such as the environment in which care is delivered, staff skills, staffing levels and type of care and focuses on factors external to the individual. QoL is a broader concept, is multi-dimensional and has different meanings to different people as it is inherently personal and grounded in the individual's experience. Jenkinson (2020) indicates that QoL encompasses emotional, social, physical, and material wellbeing and can relate to both an individual's satisfaction of life and their level of capabilities in life, for example, levels of mobility, ability to engage with their role in society, extent to which they have desired independence. A study conducted in Canadian aged care that examined quality of care highlighted that quality of care was synonymous with QoL for older people and found older people valued socio-psychological aspects of care, such as social relationships and personhood more than clinical aspects of care (Coughlan & Ward, 2007). A recent review on the National Aged Care Quality Regulatory processes in residential care in Australia claimed good quality care delivery should focus on improving QoL outcomes for older people. The review argued aged care providers should be measured against QoL standards as QoL is an imperative indicator of quality of care (Carnell & Patterson, 2017). However, this is not currently occurring in practice, with the predominant current quality of care indicators focused around organisational and clinical measures with an absence of the use of measures from the perception of the care recipient themselves (Australian Department of Health, 2021d). Indeed, the recent recommendations outlined by the Royal Commission into Aged Care Quality and Safety in their final report have an overarching concept of improving QoL for older people by ensuring aged care providers are delivering good quality care. A key recommendation was to introduce a QoL assessment tool to be used in aged care to measure and monitor the QoL of older Australians in receipt of aged care services as part of quality of care assessments highlighting the intrinsic link between quality of care and QoL (Royal Commission into Aged Care Quality and Safety, 2021).

3.1.3 Measuring quality of care

As discussed in Chapter two, the Productivity Commission (2011) highlighted the need for significant reform in aged care services with a key focus on improving the quality of care provided. As a result of this review, the Living Longer Living Better reforms (2012) were introduced that advocated for better quality services to be achieved through improved consumer choice and control, recognition of diversity, increased support for carers, more options for care to be delivered at home and additional residential care places. As part of these reforms, CDC was introduced to improve the quality of care by providing increased choice and control to older Australians to make decisions about their care to enhance their QoL. However, it is currently unclear whether these reforms are achieving their aim to improve the quality of care provided to older adults, not least because what constitutes good quality care and how quality of care should be measured continues to be debated. Measuring quality of care is imperative to ensure the needs of consumers are being met and to ensure that scarce funds are being used efficiently to provide the best outcomes for older Australians to understand whether costly reforms to the aged care sector are achieving their aims.

As highlighted in Chapter one, to date, the quality of Australia's aged care system has tended to be measured using organisational and process indicators, and more recently clinical indicators of care quality for older people (e.g., pressure injuries, use of physical restraints, unplanned weight loss, falls and major injuries, medication management) (Australian Department of Health, 2021d). Whilst these indicators measure important aspects of quality of care that can affect an older person's health and wellbeing, they neglect the wider attributes of quality of care such as independence, control and dignity that impact on an older person's QoL and wellbeing (Milte et al., 2018). These types of clinical indicators are also potentially less relevant to older people in receipt of aged care services in the home, compared to older people in residential care who often require higher levels of care as they tend to be frailer and have reduced mobility. Furthermore, the use of these types of clinical indicators as measures of the quality of care assume that better quality care is being provided where the frequency of these indicators are lower which may not necessarily be the case, and therefore, relying on these indicators to measure an older person's quality of care is not ideal (Castle & Ferguson., 2010; Inacio et al., 2020; O'Reilly et al., 2007).

A major change in how quality of care is assessed in the Australian aged care sector took place in July 2019 with the introduction of the new aged care quality standards. The new standards are far more wide-reaching than the previous quality indicators with a broader focus on person-centred care, consumer experience and consumer outcomes and apply to both aged care in the community and residential care. The standards were developed following consultations with older people and their families, aged care providers and the wider community with the intent of developing a high quality aged care model. The new standards place a strong emphasis on ensuring older people are treated with respect and dignity and receive individualised care to improve the quality of care experience. The quality standards are made up of eight individual standards and were introduced to provide a framework of core requirements for quality and safety and to make it easier for consumers and their families to make decisions about the quality of care (Australian Department of Health, 2019). The new quality standards are described below.

1. ***Consumer dignity and choice***

   Standard 1 is focused around older people being treated with dignity and respect, maintaining their identity, and making informed choices about their care with the overarching aim of achieving social inclusion and improved health and wellbeing. The standard recommends aged care providers adopt a socially inclusive environment, treat older people with respect, support them to be independent and make their own choices, including taking risks, to enable them to live the best life they can and to provide a safe and private environment.

2. ***Ongoing assessment and planning with consumers***

   Standard 2 aims to involve older people and their families in the ongoing assessment and planning of their care to improve their health and wellbeing. The standard encourages providers to plan and regularly review all stages of care directly with the individual to ensure the older person’s needs, goals and choices are being met.

3. ***Personal and clinical care***

   Standard 3 aims for older people to receive safe and high quality personal and clinical care to meet their needs to enhance health and wellbeing. Providers are required to deliver good quality personal and clinical care considering the older person's needs and ensuring care is delivered safely and respectfully.

4. ***Services and supports for daily living***

   Standard 4 requires individuals to receive services that support their daily living to enhance their health and wellbeing through providers implementing safe and effective services that meet the needs and preferences of the older person. Services should also support the individual's engagement with the community and be of interest to the older person.

5. ***The integrity of the provider's service environment***

   Standard 5 requires the providers to ensure older people feel safe and welcome in the care environment to encourage independence and enjoyment. This can be achieved through the provision of a safe and comfortable environment that promotes access to all spaces.

6. ***An effective system of feedback and complaints***

   Standard 6 is about ensuring individuals feel comfortable to raise any issues or concerns they may have and for them to be resolved promptly and efficiently. The aged care provider should be continuingly seeking feedback from older people and their families in order to improve their services.

7. ***Human Resources***

   Standard 7 aims for older people to receive good quality care from knowledgeable and skilled staff. Aged care providers should ensure they employ adequate numbers of employees to provide services and they should also ensure they employ highly trained individuals who are able to deliver good quality care efficiently.

8. ***Organisational governance***

Standard 8 aims for older people to feel confident in the ability of the care provider to provide them with high quality care. Aged care providers should involve individuals in the delivery and evaluation of services, be highly organised and ensure efficient governance, risk management and clinical governance polices are in place and are adhered to.

The new quality standards recognise and acknowledge that strong interdependencies exist between processes and outcomes, with high quality care processes theoretically associated with better QoL outcomes. The relationship between processes and outcomes was first identified by Donabedian (1982) who claimed quality of care can be measured through a theoretical framework that encompasses three components: structures, processes, and outcomes. This model was designed to be used in the clinical sector but is also appropriate to be adapted to the aged care sector (see Chapter One for further details on the Donabedian model). The new aged care quality standards mirror Donabedian's model by placing emphasis on the older person and the aged care organisation and its workforce attaining high quality of care outcomes enhancing older Australian's QoL and wellbeing (Australian Department of Health, 2019).

Despite the Commonwealth Government emphasising the importance of good quality care for older Australians through the introduction of CDC, the new aged care quality standards, and the inquiry by the Royal Commission into aged care quality and safety, it is unclear what quality of care means to older Australians and what constitutes good quality care. This chapter outlines a comprehensive review of the literature relating to quality of care and/or person-centred care to understand what defines quality of care for older people in receipt of aged care services and its relationship to QoL.

3.2 METHODS

3.2.1 Search Strategy

The overall aim of the review was to understand what defines quality of care for older people in receipt of aged care services and its relationship to QoL. Therefore, a comprehensive literature review was undertaken to identify and examine the literature on quality of care and/or person-centred care in aged care from June 2009 to July 2021. This time period was selected to reflect the dates of changing policies in aged care of the movement towards consumer led care and an emphasis on quality of care from the consumer's perspective in Australia and internationally. The review involved a two-stage process. In stage one, grey literature published in Australia was identified through an online search focusing on recently published government reports and other relevant research and policy documents on government websites.

In stage two, SCOPUS and PubMed were searched for Australian and international articles using the following terms: 'quality of care', 'person-centred care', 'aged care', 'residential care', 'nursing home' using Boolean operators. Although this thesis has a primary focus on aged care in the community, this search also includes residential care because there has been limited research undertaken about the quality of care in aged care in the community, and it was expected that the principles of quality of care could be appropriate to both settings.

3.2.2 Screening Strategy

The titles and abstracts of all articles were assessed for inclusion/exclusion by myself with a second individual (CH) screening 20% of the articles. Duplicate articles were removed and then articles were firstly excluded based on their title and abstract and then further excluded by reading the full article text using the inclusions and exclusion criteria. The titles and abstracts identified by the literature searches for eligibility to be included in the review were based upon the following criteria:

Inclusion criteria

- Published in English language
- Quantitative and/or qualitative design
- Published from 2009 onwards
- Study sample of people aged 65 years and over
- Addressed quality of care and/or person-centred care within aged care
- Addressed quality of care and/or person-centred care from the perspective of the older person or a suitable proxy

Exclusion criteria

- Not published in English language
- Majority of the study sample were not adults aged 65 years and over
- Addressed quality of care and/or person-centred care by individuals other than the older person or a suitable proxy
- Staff training interventions focusing on quality of care and/or person-centred care

3.2.3 Analysis

A thematic approach was adopted to analyse the sources to identify the main themes relating to quality of care experience to produce a comprehensive narrative. This approach consisted of four separate stages. The first stage involved reading the articles and reports to become familiar with the content. The second stage involved extracting the main characteristics of each source (the purpose of the study, sample size, methodology, country of origin and main findings) and charting these characteristics into a table. This stage involved analysing the results/findings/discussion section of each source to extract the relevant findings relating to quality of care and/or person-centred care to include in the main findings section for the table. The third stage involved examining the main findings from each source to group the initial findings and to identify any emerging quality of care themes. The initial quality of care themes identified from the studies were then analysed and reviewed to finalise the themes of the review (stage four).

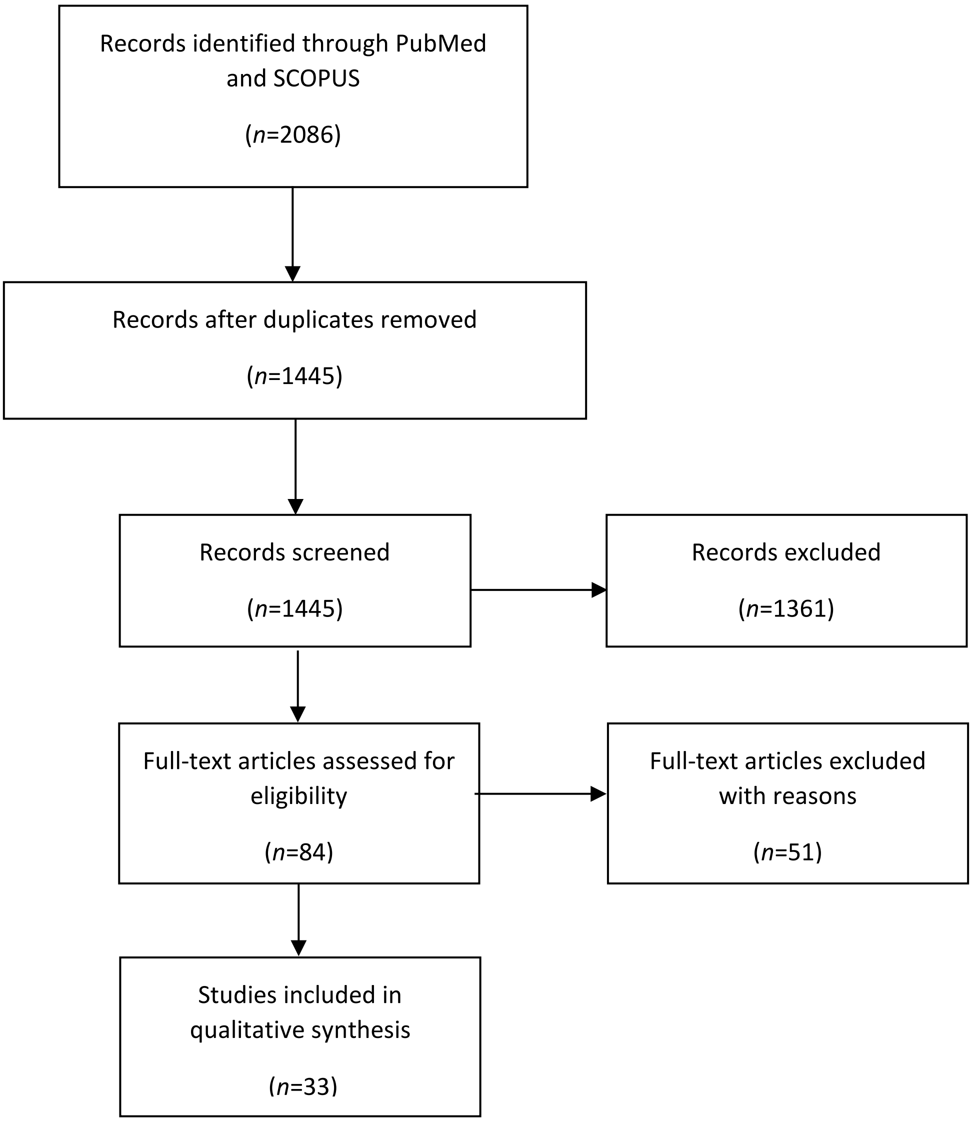
3.3 RESULTS

3.3.1 Data extraction

Five grey literature sources and 33 peer-reviewed articles were found to be relevant to be included in the review (see Figure 3.1). Of the 33 peer-reviewed articles, 26 articles examined quality of care in residential care and 7 articles examined quality of care in both residential care and home care. Of the five grey literature sources, two sources examined quality of care in home care, one examined quality of care in residential care and two sources examined quality of care in both residential care and home care. Appendix 1 provides a detailed description of the sources included in the review.

Figure 3.1

Flow chart of study identification process for quality of care



3.3.2 Data synthesis

Nine key themes were identified from the analysis of the sources which are shown in Table 3.1.

Table 3.1

Quality of care themes

Theme	**Subthemes**
Respect and dignity	Staff attitude and communication Privacy Independence, autonomy, and choice
Spiritual, cultural, religious, and sexual identity	Knowledge of an individual's identity Supporting an individual's identity
Aged care staff skills	Skill levels of staff members Training of staff member
Relationships with aged care staff	Friendliness and respectful staff Staff having adequate time Close and meaningful relationships
Informed choices	Ability to make choices about care Making decisions about everyday care Access to information to make choices
Social relationships and the community	Aged care services facilitating social relationships Barriers to social relationships Remaining part of the community
Supporting older people's health and wellbeing	Provision of meaningful activities Engagement in meaningful activities
Safety and comfort	Physical safety Emotional safety
Ability to make complaints and provide feedback	Ability to make complaints Outcome of complaints

Respect and dignity

Older people have a right to be respected and treated with dignity and recent studies have indicated that this is important to older people receiving aged care services. Dignity can encompass a range of attributes, but mainly involves being treated with respect and being valued by others. To older people this can include a variety of dimensions such as ‘identity’, ‘human-rights’ and ‘autonomy’ (Woolhead et al., 2004). Bangerter et al. (2016) identified staff attitude, etiquette, and communication as key factors of respect that older people living in residential care value.

A recent study by COTA Australia (2018) highlighted the importance of respect and dignity in both residential and home care settings through a survey and focus group with consumers and aged care providers to measure quality and consumer choice in aged care. The report found older Australians ranked being treated with respect and dignity as the most important characteristic that they would look for when choosing an aged care provider. Participants identified carers supporting them with dignity and respect, and them being trained to do so, as central to their definition of quality care. Family members also stressed the value of respect for the older person including understanding the older persons’ past, their preferences, and their identity (COTA Australia, 2018).

In residential care facilities, older people rely on carers to provide them with daily care. A recent review identifying the key domains for choice of residential care facility in Australia highlighted the importance of respect and dignity. The review found it was imperative for good quality care to encompass residents being treated by carers with respect and dignity through respecting their privacy and possessions, enabling them to feel valued and useful and being involved in decision making (Jeon & Forsyth, 2016). Research by Hall et al. (2014) in the United Kingdom supports these findings by highlighting the need for independence, autonomy, choice, control, and privacy as ways of facilitating dignity for residents of nursing homes. Furthermore, Abbott et al. (2018c) identified that staff treating older people with respect was the most important preference for individuals living in American residential care. Being treated with respect and dignity has also been identified as important for older people with cognitive impairment and dementia. For example, Milte et al. (2016) found that family members and close friends of people with dementia in residential care in Australia believed it was of paramount importance that they were treated with respect and dignity, and not stigmatised in their quality of care.

Several studies have revealed that older people receiving aged care in their own home and in the community feel they are treated with respect and dignity. A recent report conducted by National Seniors Australia (2018) to understand the experiences of consumers receiving aged care in the community and home found that most older people believe that care workers treat them with respect (McCallum et al., 2018). Studies in residential care have also revealed older people feel they are treated with respect and dignity (Australian Aged Care Quality Agency, 2019; Poey et al., 2017).

Spiritual, cultural, religious, and sexual identity

Knowledge of consumers' identity, culture and personal preferences has been identified by several key Australian studies as an important aspect of providing good quality care (COTA Australia 2018; Edvardsson et al., 2010; Jeon & Forsyth, 2016). COTA Australia (2018) found that 90% of consumers receiving aged care services in the home and in residential facilities believed good quality care involved the provider maintaining and supporting their spiritual, cultural, sexual, and religious identity. Furthermore, Jeon and Forsyth's (2016) review of the experiences of older people in residential aged care, found the ability of residential care staff to support, respect and value individuals' identity, including their personal preferences and needs, as a key domain of good quality care.

A study identifying the key elements of person-centred care in a residential setting caring for older people with dementia found it was imperative that care workers knew and understood the history and interests of the individuals to enable them to provide high quality care (Edvardsson et al., 2010). Similarly, a large-scale study in the USA to assess the relationships between person centred care and satisfaction with quality of care found that older people living in residential care facilities that had actively implemented a person-centred care approach, reported higher levels of satisfaction with staff having a stronger understanding of the person and being better able to meet their religious and spiritual needs compared to those settings who had not adopted person-centred care (Poey et al., 2017).

Aged care staff skills

It is well documented that quality of care can vary depending on the aged care staff member's skills and training, and therefore, it is important for aged care staff to be adequately trained and possess appropriate skills (Australian Aged Care Quality Agency, 2019; McCallum et al., 2018). Research has shown professional skills and training of staff members are key predictors of good quality aged care in the home and in residential facilities (Hasson et al., 2011; Jeon & Forsyth, 2016). A cross-sectional study conducted in Sweden with older people receiving both residential and home care found that a significant factor of individuals rating care highly was based on their confidence in the staff member's skills and how staff behaved towards them (Hasson et al., 2011).

Furthermore, it has been found that older people believe carer's level of skills are an important factor when choosing care. The recent study on measuring quality and consumer choice in aged care undertaken by COTA Australia found that consumers would prefer to know the qualifications and skills of staff when choosing aged care providers for care at home. Furthermore, the report found that low staff ratios in organisations in residential facilities impedes effective delivery of services that enhance older people's QoL (COTA Australia, 2018).

It has been suggested that overall aged care workers are adequately trained and deliver appropriate care (Australian Aged Care Quality Agency, 2019; McCallum et al., 2018). Nearly three-quarters of older people surveyed about consumers experiences of aged care services in the home and the community agreed that carers know what they are doing and are well trained. However, this is not always the case with poor training for staff in dementia care highlighted as an issue (McCallum et al., 2018).

Relationships with aged care staff

Positive staff attitudes and interactions with older people receiving care at home and residential care are valued as integral elements of good quality care and are fundamental to QoL (COTA Australia, 2018; Jeon & Forsyth, 2016). Older people receiving care rely on carers to provide support with everyday activities. Positive carer relationships consisting of mutual respect and friendliness can provide meaningful relationships for older people and have been found to impact positively upon QoL and wellbeing of Norwegian and American older adults living in residential facilities (Drageset et al., 2017; Roberts, 2018). Moreover, COTA Australia (2018) has also highlighted the importance of staff friendliness to an individual’s QoL when choosing residential facilities and aged care services in the home.

Carers having enough time to interact with older people and deliver personal care in line with the preferences of the individuals has also been identified as important for the provision of quality care in residential facilities (Jeon & Forsyth, 2016). Carers who helped older people to feel comfortable, spent additional time with them and brought them items they requested, facilitated positive carer-resident relationships in a USA study (Roberts, 2018). However, despite individuals placing great importance on meaningful relationships, only some older people reported close friendships with carers, and many did not experience a meaningful relationship. However, not all older people preferred close relationships with their carers, and some deliberately avoided forming close bonds to maintain the professional relationship believing this would enable them to receive better quality care. Similarly, research on aged care services at home has shown that individuals prefer to receive care from friendly, sensitive, and kind carers who they are able to develop rapport and relationships with (Wells et al., 2018).

Research by Karlsson et al. (2013) examining satisfaction with aged care services found that older people receiving care at home were more satisfied with their quality of care compared to older people living in residential care facilities. The findings suggested individuals receiving care at home believed staff members had more time, were more respectful and they had better personal relationships with staff members than individuals in residential care.

Informed choices

Recent aged care reforms have stressed the importance of older people exercising choice and having control over their care (Productivity Commission, 2011). Enabling older people receiving care at home and living in residential facilities to make choices about their aged care supports them to be independent and enables increased control over their life leading to empowerment (COTA, Australia 2018; Ottmann et al., 2013). For older people to make informed decisions they need to be equipped with the necessary information and supported in their decision-making processes.

COTA Australia (2018) examined the processes adopted by older people when making choices about residential care and aged care services at home, and found older people valued QoL and experiences of consumers care highly and placed less importance on clinical care measures. For example, over two-thirds of older people receiving aged care services at home and just under three-quarters of older people living in residential care wanted to know how the services impacted on QoL, such as choices available to the individuals about food and activities. Furthermore, older people identified independence and having control over their daily life as key features to enable a good QoL when receiving care in residential facilities and at home.

Most older people living in residential facilities and receiving aged care services at home would choose to be actively involved in decisions about their care (Abbott et al., 2018b; Wells et al., 2018). Wells et al. (2018) suggested consumers receiving aged care services at home prefer flexible care that meets their changing needs and preferences and stressed the importance of individuals being able to make their own choices about care. Research has also indicated the importance of decision-making for older people living in residential care for everyday choices such as daily routines and choice of food (Abbott et al., 2018b; Cooney et al., 2014; Jeon & Forsyth, 2016; Milte et al., 2016). For example, Milte et al. (2016) found that nursing home residents valued independence, autonomy and flexibility and wanted their care to meet their individual needs and preferences to enable good outcomes. Likewise, Jeon and Forsyth (2016) highlighted maintaining independence and autonomy through being able to make choices as a crucial characteristic of good quality residential homes.

Having access to information is imperative to be able to make informed choices about care. Jeon and Forsyth (2016) identified choice, respect and dignity, physical environment, social environment, functional environment, staff actions and interactions, organisational environment and resources and clinical and personal care as the key characteristics that older people needed information about prior to choosing residential care facilities. However, it has been suggested that consumers lack information when choosing aged care providers. For example, COTA Australia (2018) found many aged care providers delivering services in the home did not make the fees they charged readily available and did not provide other information about their services, such as languages they may service, religious and cultural needs they cater for, specialised services, and levels of care packages. This lack of information often led to older people choosing aged care providers based on recommendations from friends and family and healthcare professionals.

Indeed, much of the literature suggests that older people living in residential facilities and receiving aged care services at home have limited control in making decisions about their care (Bangerter et al., 2017; Jeon & Forsyth, 2016; Karlsson et al., 2013). Karlsson et al's (2013) research on older people receiving care at home in Sweden highlighted the insufficient input into decisions by older people about their care. Furthermore, Bangerter et al. (2017) in their study on perceptions of choice in residential care found that residents lacked choice over everyday activities. The research suggested that individuals experienced limited autonomy and choice due to care and activities being predetermined as part of the residential settings care structure.

An everyday activity that is often pre-determined as part of a residential setting, and sometimes within the community is food and mealtimes. Information about food satisfaction was rated highly as a key characteristic that consumers would like to know information about when choosing an aged care provider (COTA Australia, 2018). Regarding this topic, Grondahl et al. (2016) examined experiences of food and mealtimes in residential settings in Norway and found that older people had limited involvement in food choices. The individuals interviewed expressed that they were not involved in choosing what to eat, when they wanted to eat or who they wanted to eat with. Indeed, other research in this area has highlighted the negative impact that the lack of involvement in meal and nutrition choices has on quality of care (Reimer et al., 2009).

However, research has suggested that levels of decision-making can vary depending on the type of aged care service. For example, a study by Gnanamanickam et al. (2018) comparing quality of care amongst older people living in standard residential facilities and homelike clustered settings found variations in the levels of choice experienced. The individuals living in homelike clustered care settings had greater flexibility in care choices than those living in standard residential care facilities resulting in better levels of care. It was suggested that these differences were due to the physical structure of the facilities, such as the group living style and staffing levels (Gnanamanickam et al., 2018). Furthermore, research examining the impact of person-centred care on QoL and quality of care in residential settings found higher satisfaction in settings that had fully implemented person-centred care (Poey et al., 2017). Edvardsson et al. (2010) stress the importance of good quality care in residential facilities being person-centred and focusing on the individual needs rather than staff needs and the structure of the facility. These findings are supported by Roberts et al. (2018) who argue person-centred care should involve the individual making choices about their care in residential facilities to ensure a good quality of care is received.

Social relationships and the community

Social relationships can positively impact on an individual's health and wellbeing and can improve an older person's QoL living in residential care (Abbott et al., 2018a; Cooney et al., 2014). Cooney et al's (2014) review exploring the meanings of social relationships in residential care found that relationships were positively linked to QoL. The feelings of connectedness experienced through social interactions between older people reduced feelings of loneliness, enhanced feelings of belonging and improved QoL. Research has also highlighted the importance that older people receiving care place on maintaining social relationships. For example, COTA Australia (2018) found that a large majority of individuals valued maintaining social relationships and contact with the community as important for a good QoL and were interested in how aged care providers' services in the home and in residential care facilitate social connections to improve the QoL of consumers.

Abbott et al. (2018a) argue person-centred care should incorporate the social preferences of older people but found a multitude of barriers preventing these preferences being fulfilled within residential settings. Lack of personal resources was highlighted as the main barrier which focused around limited social networks being available, particularly as individuals approach the later stages of their life, as social networks diminish due to friends passing away. Cognition can also be a barrier to older people as declining cognitive ability can hamper communication and meaningful relationships affecting QoL (Abbott et al., 2018a; Cho et al., 2017). Similarly, research in an Australian residential unit by Casey et al. (2016) illustrated how residents had limited friendships, and in cases where friendships did exist, they were not always friendships of their own choosing due to the lack of freedom they experienced. Social connections were difficult to create due to the characteristic of other residents, independence, and social opportunities available. Other studies have also highlighted limited social connections amongst older people in both residential care and home care, despite the importance that individuals place on friendships (Cho et al., 2017; Hasson et al., 2010; Roberts, 2018).

Therefore, it is evident that many older people have fewer social connections than they would like. Various research studies have attempted to offer explanations for this. For example, a study conducted in the Netherlands by De Boer (2017) compared the quality of care and QoL of residents living in small-scale home-like facilities with residents in nursing homes. The findings suggested that not only did the individuals in the small-scale home-like facilities have a better QoL, but they also took part in more activities and had more social relationships than the individuals in the nursing homes. This research may suggest smaller home-like facilities provide more opportunities to establish friendships, and potentially this may be achieved through organised activities (De Boer, 2017). Having access to activities is important to older people receiving care at home and living in residential care to establish friendships and to experience good quality care and a good QoL (Casey et al., 2016; Jeon & Forsyth, 2016; Milte et al., 2016). For example, Milte et al. (2016) found that having access to meaningful activities provided within residential care settings is highly valued by residents and should be an essential component of good quality care, illustrating that quality of care goes beyond meeting the physical needs of the resident but also encompasses their wider emotional and social needs. However, research has suggested that residential care facilities are better at delivering physical care rather than care that impacts upon the social wellbeing of residents, such as social connections (Li et al., 2013; Netten et al., 2012b).

Older people have also expressed their desire to remain and feel part of the community. Maintaining contact with friends and family was highlighted as important for individuals living in residential facilities and losing contact with family and friends is seen as a major concern (Milte et al., 2016). It has been suggested that visits from family and friends whilst in residential care allow for family bonds and connections to the outside to continue which can positively impact on the QoL of individuals (Cooney, 2009; Drageset et al., 2017; Milte et al., 2016).

The findings suggest that although social relationships are important to older people, lack of opportunities and resources often prevent older people fulfilling their social preferences. It has been argued that this could be overcome by carers understanding older people's needs and preferences for social contact and activities and facilitating these relationships both in the home and in residential settings by providing more opportunities (Andrew et al., 2018; Hasson et al., 2011; Roberts, 2018).

Supporting older peoples' health and wellbeing

The provision of meaningful activities for older people living in residential care facilities is an important aspect of person-centred care and can support an individuals' health and wellbeing and QoL (Edvardsson et al., 2010; Edvardsson et al., 2014; Roberts et al., 2018). Roberts et al. (2018) assessed preferences that were important to older people in residential care to effectively deliver person-centred care and found engagement in meaningful activities was an important preference. Likewise, Edvardsson et al. (2010) found that the provision of meaningful activities to older people with dementia living in residential care was a crucial element of person-centred care. Meaningful activities were found to support individual's self-esteem and provide feelings of contentment. Other research has also illustrated the benefits of participating in activities to older people's QoL (Cooney et al., 2009; Drageset et al., 2017; Edvardsson et al., 2014). For example, Edvardsson et al. (2014) explored the participation and outcomes of activities amongst older people in Swedish residential care. The findings identified that individuals had a significantly higher QoL if they had taken part in everyday activities such as walks, church visits and excursions than if they had not participated in any activities.

Safety and comfort

Feeling safe and comfortable is an important aspect to fulfil a good QoL and older people have a right to feel safe in their surroundings. Older people that move into residential care homes can often experience physical and psychological comfort by releasing the burden of doing everyday activities such as preparing meals, cleaning, and managing medication (Cho et al., 2017). Older people living in residential care place great value on feeling safe and the safety and security of a residential home, and this is a key feature that older people look for when choosing a suitable aged care provider (Jeon & Forsyth, 2016). Kajonius and Kazemi (2016b) found that satisfaction in Swedish care homes was highly correlated with how safe individuals felt and higher feelings of safety were often related to higher staff ratios. The research also showed that safety as a characteristic of quality of care was more important to individuals living in residential care than those receiving care in the home. In their recent audit, the Australian Aged Care Quality Agency (2019) found that a large majority of older people living in residential homes felt safe.

Research has also shown that older people value feeling safe in their home and community, both emotionally and physically (COTA Australia, 2018; Jeon & Forsyth 2016; Wells et al., 2018). For example, COTA Australia (2018) found that for older people to feel emotionally safe, they needed to be heard and respected by others and to feel physically safe involved aspects such as being able to lock doors and to be able to move around freely in a safe and secure environment. The Australian Aged Care Quality Agency report (2018) identified characteristics that were important to older people when choosing home-based aged care providers and looked at older people’s experiences of quality of care. The report recognised older people wanted to feel protected and safe in their home and community as a key characteristic of good quality care (Wells et al. 2018). Similarly, COTA Australia (2018) found feeling safe was ranked as the third most important feature (respect and dignity and staff friendliness were the first and second most important features) when choosing an aged care provider.

Feedback and Complaints

Having a responsive complaints procedure is an important part of providing quality services so that improvements can be made to processes and services. It is important for older people to feel comfortable and safe when raising concerns about their care to their aged care provider and be assured it will not affect the care they receive. The Australian Aged Care Quality and Safety Commission advises consumers to firstly raise concerns directly with their provider and to work together to solve any issues. However, if the issue is not resolved or they do not feel comfortable raising the concern directly with the provider, the consumer is advised to contact the Aged Care Quality and Safety Commission who will liaise with them and the provider to resolve any issues (Australian Government Aged Care Quality and Safety Commission, 2019).

A report compiled by COTA Australia (2018) found that 85% of aged care providers claimed they measured the quality of their services, mainly through the completion of questionnaires. Despite this high percentage, measurement of quality was largely focused on satisfaction with services and staff and not on individual care experiences. The findings highlighted that older people rank being supported and being able to raise concerns highly when choosing residential and home aged care providers. Furthermore, just under two-thirds of older people would like the opportunity to review any complaints that have already been made when choosing their aged care provider. Although COTA Australia (2018) identified that being able to make complaints was a key indicator of quality care, many older people and their families were concerned about raising complaints due to the potential impact it may have on the care they receive.

Similarly, Jeon and Forsyth’s (2016) review of the quality of residential care illustrated the importance of consumers being able to raise any concerns with their aged care provider, but they also highlighted the need to do this without any consequences to their care. However, research by

The Australian Aged Care Quality Agency (2019) found that most individuals in residential care were happy with the way in which staff followed up on any concerns that were raised.

3.4 DISCUSSION

This chapter has identified and synthesized international literature relating to the quality of care in aged care. It is apparent from the review that research in this area has predominantly focused on residential aged care rather than aged care provided in the home and community. However, it is evident that the key themes emerging from the literature relating to the quality of care experience for older people are equally relevant for aged care provided in the home and community.

This chapter has identified nine key themes encapsulating quality of care in aged care. The review identifies that older people have a strong preference for person-centred care that is reflective of their spiritual, cultural, sexual, and religious background and where they are treated with respect and dignity by trained and skilled aged care staff. Social connections and participation in meaningful activities are of great importance to older people for a good QoL, but close relationships, particularly in residential care are not always established and nor are meaningful activities always available. Neither do older people often report close bonds and relationships with aged care staff which is an important aspect of good quality care that was highlighted. Most older people value safety and feel safe in their surroundings. A key issue within aged care is the gaps in knowledge surrounding the choice and control available to older people to promote their autonomy in making decisions about their care and services. As discussed in Chapter two, older people having choices and making decisions about their care is a central tenet of CDC introduced as part of the aged care reforms in 2015 (McCallum & Rees, 2017). Without the necessary information and support to older people in both home and residential care settings it is unlikely that they will be able to make informed choices about their care and services they receive.

Overall, the study findings demonstrate that high quality care in aged care goes beyond the clinical aspects of care to encompass the broader aspects of care that impact on the QoL and wellbeing of individuals. Traditionally, quality in aged care systems has tended to be measured by focussing on organisational and process indicators, and more recently, clinical indicators of care quality for older people. Measuring quality of care with organisational and process indicators is not ideal because it is assumed to result in better care provided, but there is no evidence that this occurs in practice (Castle et al., 2010; O'Reilly et al., 2007). Furthermore, whilst clinical indicators measure important aspects of the quality of care that can affect an older person's health and wellbeing, they are generally more applicable for aged care residents who tend to be frailer, less mobile and have a higher level of care needs than home care recipients. However, even in residential care, the prevalence of these clinical indicators is low and are not relevant to the majority of residents (Inacio et al., 2020). Clinical indicators also tend to neglect the wider attributes of the quality of care experience that impact on an older person's QoL and wellbeing (Milte et al., 2018).

The themes from the literature review closely align with the new Australian Aged Care Quality Standards (Australian Department of Health, 2019). This is not unexpected as the introduction of the aged care standards aim to ensure that all older Australians in need receive safe quality care that is underpinned by their preferences, needs and goals. One theme that emerged from the review was the importance of developing good relationships with aged care staff which is not specifically included in the standards. However, the aged care quality standards acknowledge the importance of skilled and trained staff providing care and the importance of personal relationships which could include relationships with staff. The similarities between the themes found in the review and the aged care quality standards demonstrate the importance of the introduction of these new standards in Australia in promoting quality of care; going beyond clinical indicators of care quality to include person-centred aspects that impact upon the QoL of older people.

It is important to recognise the limitations to this review. Whilst the inclusion of grey literature is a strength of the study, due to practical and resource constraints only Australian grey literature could be included. Another limitation is that most of the identified literature focused on residential care with a limited number of studies in aged care in home and community settings which is the focus of the thesis. However, this is not surprising as residential care has been a major focus of research in the aged care sector to date.

Therefore, it is important to recognise that some of the key themes identified may not be equally important to both home care and residential care recipients. For example, the review highlighted access to social relationships as a key characteristic of good quality care. Whilst social relationships may be of equal importance to older people, increased barriers exist for older people in residential care compared to older people receiving care at home, such as fewer social opportunities available, decreased independence, less social opportunities and lack of freedom (Abbott et al., 2018a; Casey et al., 2016). Therefore, opportunities for establishing social relationships for older people in residential care are less than for older people in receipt of aged care services at home. Likewise, safety was highlighted as important to both individuals in residential aged care and individuals receiving aged care services at home. However, research suggests older people in residential care place greater emphasis on safety and security and is a key feature that older people and their families look for when choosing a residential facility (Jeon & Forsyth, 2016). Furthermore, feeling safe was linked to higher rates of satisfaction by aged care residents and it was highlighted that safety as a characteristic of good quality care was more important to individuals living in residential care than those receiving care in the home (Kajonuis & Kazemi 2016b).

This review recognises the limited amount of research that has been undertake in aged care in the home and community and highlights the need for further research to investigate what constitutes quality of care and its link to QoL in this sector, especially with the growing demand for aged care services in the home.

3.5 Conclusion

Overall, these findings highlight the central importance of person-centred care and care experience as fundamental tenets of the quality of aged care service delivery in Australia and internationally. This review emphasises the importance of measuring quality of care in a way that is meaningful to older people that goes beyond the clinical aspects of care to ensure services are meeting individual's needs and enhancing their QoL. It is important to recognise that this review formed the foundational underpinnings for the development of a subsequent quality of care measure developed for the Royal Commission (Ratcliffe et al., 2020; Khadka et al., 2020). It is evident from this review that quality of care is intrinsically linked to QoL and therefore, QoL needs to be assessed to ensure aged care providers are delivering services that are maximising older people's QoL. As highlighted at the beginning of this chapter, the recent final report by the Royal Commission into Aged Care Quality and Safety highlighted the importance of good quality care improving the QoL of older Australians. A key recommendation was for the introduction of a QoL measure to be introduced to assess the QoL of older people in receipt of aged care services (Royal Commission into Aged Care Quality and Safety, 2021). However, as documented in Chapters one and two, currently no preference-based QoL measure currently exists that has been developed exclusively from its inception with older people receiving aged care services in Australia for application in this context. The following chapter will discuss in more detail the existing preference-based QoL measures that have been applied in Australia and internationally to date with older people in receipt of aged care services in the community and key issues pertaining to their application with this population.

4. INTRODUCTION TO HEALTH ECONOMICS AND A REVIEW OF THE DEVELOPMENT AND APPLICATION OF PREFERENCE-BASED MEASURES WITH THE OLDER POPULATION

This chapter contains material from:

Cleland, J., Hutchinson, C., Khadka, J., Milte, R., & Ratcliffe, J. (2019). A Review of the Development and Application of Generic Preference-Based Instruments with the Older Population. *Applied Health Economics and Health Policy, 17*(6), 781-801.

4.1 HEALTH ECONOMICS

The discipline of economics more broadly examines how society allocates resources in different ways to maximise benefits to ensure efficient use. Health economics is a sub-discipline of economics that focuses on how best to allocate scarce resources (e.g., staff, equipment, consumables, land, buildings) in the health, public health, and social care sectors (disability and aged care). Ideally, the supply of treatments, services and supports available to patients in our health system, members of the general community in our public health system and consumers in our social care sector (aged care and disability care) would match the demand but this is not the case as resources are often scarce, and therefore, decisions need to be made about how to allocate resources appropriately. When making these decisions it is imperative that resources are maximised to ensure efficiency or value for money. The application of health economics principles can help decision-makers to understand what treatments, services and supports should be made available, how to produce them and who should receive them. Although health economics to date has predominately been applied in health system settings and not been widely applied in social care, the principles of health economics are particularly relevant to the aged care sector. Australia's population is ageing rapidly, and therefore the demand for aged care services and supports is increasing (see Chapter One and Chapter two for more detail) resulting in decisions needing to be made about which services and supports to provide and to whom (Ratcliffe et al., 2010).

Economic evaluation is an integral component of health economics and can be defined as “the comparative analysis of alternative courses of action in terms of both their costs and consequences” (Drummond et al., 2015, p. 4). The aim of economic evaluation is to provide a robust framework to assist policy makers and other key stakeholders when making difficult decisions about how best to allocate scarce resources. It involves identifying the inputs (the costs) and the outputs (the benefits) of different interventions e.g., health care treatments technology devices, public health care programmes, disability care services and supports and aged care services and supports. Application of an economic evaluation framework allows competing interventions to be compared to assess their incremental costs and benefits (where benefits are typically measured in terms of health and/or QoL benefits to patients or consumers) to make informed decisions about the costs and consequences of alternative courses of action.

Since the first introduction of the approach in the early 1970’s (Torrance et al., 1972) there has been a rapid increase in the development and application of economic evaluation in the healthcare sector to inform healthcare decisions (Drummond et al., 2015). In 1993, the Commonwealth of Australia instructed the use of economic evaluation in pharmaceutical submissions to PBAC (Brazier et al., 2017; Department of Health, 2016). In 1998, MSAC was established to provide the Commonwealth Government with evidence on the cost-effectiveness of new medical technologies and procedures to inform funding decisions (Australian Department of Health, 2020d). Many other countries also request economic analyses for pharmaceuticals such as CADTH in Canada (CADTH, 2017), and the Scottish Medicines Consortium (SMC) (SMC, 2021). In the United Kingdom, NICE requires economic analyses for healthcare, social care, and public health interventions to inform their recommendations about their routine introduction into the National Health Service (NHS) (NICE, 2018).

Although it has been far less widely applied in the aged care sector to date, economic evaluation has particular relevance to aged care due to the increasing older population placing more demand on this sector combined with a move towards choice and autonomy (Australian Department of Health, 2019). Funding decisions about what services and supports to provide and to whom need to be made on the best available courses of action. Economic evaluation can assist in this process by quantifying the cost and consequences of alternative courses of action with the aim of maximising older people's overall health, QoL and wellbeing (Ratcliffe et al., 2010).

4.2 WHAT IS HEALTH AND QUALITY OF LIFE?

There have been multiple definitions of health given but one of the most commonly used definition is the one that is provided by WHO (1948) that defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (p. 100). This is a broad definition and encompasses physical, mental, and social domains. However, in modern society this definition is less relevant as it focuses on the medical aspect of health and because people are living longer, often with illness, disease, and cognitive impairment, it is not appropriate to assume individuals would be free of disease (Huber et al., 2011). Whilst the social aspect of the definition provided by the WHO can be related to QoL it can be argued that social wellbeing is a part of QoL that is determined by health (Brazier et al., 2017).

More recently, there has been the recognition that measuring health should move beyond the traditional concept of health and focus on aspects that go beyond health that impact upon an individuals' QoL (WHO, 1991). QoL is both different to health, and similar to health, and can focus more on physical health or be broader to include psychosocial aspects of QoL. Multiple definitions of QoL have been provided but a common definition is the one by WHO (2022) that defines QoL as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns". QoL is a broad multi-dimensional concept and can mean different things to different people as it is subjective and can change over time (Lawton, 1991). Research by Bowling et al. (2012) recognised that QoL is subjective and can be affected by an individuals' personal circumstances and their environment. In their research they found that older people living in the community valued wellbeing, good health, social relationships, access to activities, living in a good neighbourhood, independence, and financial stability as key dimensions of a good QoL. HRQoL is the aspect of QoL that relates to the ability and function of an individual to maximise their experience of daily life. Aspects that may affect an individuals' HRQoL are factors such as disease, impairment, injuries.

It has been recognised that QoL/health/HRQoL should be measured, where possible, from the perspective of individual's themselves because these concepts consist of dimensions which cannot be measured externally. The varying definitions of health, QoL and HRQoL have resulted in the development of measures covering a wide variety of dimensions, with some measures addressing physical health whilst other measures focus more on QoL and wellbeing. The dimensions of different measures will be discussed further in section 4.6.9. Firstly, it is important to understand the different techniques used in health economics to measure outcomes such as health and QoL.

4.3 TECHNIQUES IN HEALTH ECONOMIC EVALUATION

A variety of different economic evaluation techniques exist. All of the techniques involve the measurement and valuation of costs. The main difference between the techniques is the extent to which they consider, quantify, and present the benefits from the different courses of action. Health and/or QoL outcomes are often the main unit used for measuring the benefits, however, this is not always the case. The different techniques shall now be discussed.

4.3.1 Cost-minimisation analysis

Cost-minimisation analysis compares the costs associated with alternative courses of action (e.g., alternative treatment pathways for patients in the health system, alternative bundles of services and supports for HCP consumers in the aged care sector) to examine which action is the least costly. This technique assumes the outcomes of alternative courses of action to be identical as the aim is to compare the costs of the two approaches to identify which one is better value for money. However, cost-minimisation analysis has been criticised for its use in health economics mainly based on the argument that two different courses of action would be unlikely to produce the same outcomes (Briggs & Brian, 2001; Drummond et al., 2015). Briggs and O’Brien (2001) argue that because both costs and outcomes are uncertain and since outcomes are not often known definitively prior to the analysis, this technique is rarely suitable in practice which is why it is rarely applied in economic evaluations. Furthermore, it has been argued that a comprehensive health economics analysis should focus on comparing both costs and outcomes, not just the costs, of interventions for a full economic evaluation to be undertaken (Drummond et al., 2015; Gray et al., 2011).

4.3.2 Cost-consequence analysis

Cost consequence analysis collates and presents all the costs and outcomes of the competing interventions under consideration but rather than combining the outcomes into one unit (i.e., an incremental cost-effectiveness ratio (ICER)), they remain in their original units. Decision-makers can use the information by assigning their own weights to the costs and outcomes, which are presented in a table or graph to make decisions about different courses of action as to which are the most important and whether they represent good value for money. Cost-consequence analysis is used less often in health economics than other techniques as it has several limitations. Firstly, the approach depends on an individual analysing the data reliably and requires decision-makers to assign appropriate weights to the outcomes which may be very difficult to do when a series of potentially very different outcomes are presented simultaneously. Also, if a particular course of action results in some positive outcomes but also some negative outcomes it may be difficult to decide on whether that course of action results in a positive net benefit or a net loss overall where different units of measurement have been applied for the presented outcomes (Coast, 2004; Gray et al., 2011). As an attempt to overcome this problem, multi-criteria decision-analysis (MCDA) has been recently suggested as a comprehensive and structured method to help decision-makers understand the different consequences of a decision in a thorough and transparent manner (Thokala & Duenas, 2012). Decisions are made by identifying and comparing the numerical scores for each criterion which are developed individually and then weighted using explicit techniques. The different options are scored against each criterion resulting in numerical scores to be used for comparisons. The approach recognises that decision-makers use multiple criteria when making decisions and therefore enables wider objectives (health and non-health) to be incorporated extending the cost-effectiveness analysis (Jit, 2018).

4.3.3 Cost-benefit analysis

Cost-benefit analysis examines both the costs and the outcomes of different courses of action by assigning a monetary value to the inputs (costs) and the outcomes (benefits). Decisions on the cost-benefit of new interventions are made by comparing the incremental benefits measured in monetary terms relative to the incremental costs associated with the new intervention relative to existing intervention/s to produce the cost benefit ratio, or alternatively by comparing the net monetary loss/gain associated with the new intervention. In principle, because outcomes are measured and valued in monetary terms this method can be used to compare the value for money of interventions across a variety of sectors e.g., education, transport, health, aged care, and the environment (Brazier et al., 2017; Drummond et al., 2015) in addition to within sectors e.g., health or aged care.

Monetary values placed on inputs and outputs are assigned using either the human capital approach or the willingness to pay (WTP) technique. The human capital approach involves valuing a health improvement based on the value of an individual's expected earnings to estimate the improved productivity of the individual in the marketplace. WTP involves asking individuals how much they would be willing to pay to achieve a particular outcome or a series of outcomes. Here, individuals are presented with hypothetical scenarios and asked what they would be willing to pay to avoid illness or to gain a benefit (Drummond et al., 2015). However, the human capital approach has not often been used to develop monetary values for health due to its irrelevance when measuring interventions that are aimed at older people or children. The approach values a lifetime based on a person's wages and therefore, discriminates against individuals who are not in the workforce such as older people who have retired from paid work (Huter et al., 2016). It has also been criticised for offering a limited understanding of what constitutes health and QoL (Brazier et al., 2017; Drummond et al., 2015). WTP has also been used less frequently in health economic evaluations relative to other approaches for valuing benefits as the extent to which individuals are willing to pay for outcomes is strongly related to their actual ability to pay and the distribution of income in society which for many countries is highly inequitable (Brazier et al., 2017). The technique also creates problems when evaluating health interventions with fixed budgets as the decision rule must be adjusted to analyse the costs and benefits of each health intervention for suitable comparisons between the health interventions to be made (Brazier et al., 2017).

4.3.4 Cost-effectiveness analysis

Cost-effectiveness analysis examines both the costs and outcomes of two or more alternative approaches by calculating the incremental differences in costs and outcomes to provide a cost per unit of outcome. The outcome unit must be the same for each intervention and only one outcome unit can be used for each analysis. Outcomes are 'natural', for example, life years, number of falls prevented and health functions (Brazier et al., 2017: Drummond et al., 2015). Cost-effectiveness analysis enables decision-makers to identify which approach is less costly per unit of outcome by calculating the differences in the costs and the differences in the outcomes which are then combined to produce the ICER (Gray et al., 2011). This technique is often used when there is a fixed budget and decisions need to be made between limited alternative courses of action (Drummond et al., 2015). However, cost-effectiveness analysis has several limitations. The main limitation is that the technique is unable to measure more than one single-dimensional unit of outcome, and therefore, is not suitable to make comparisons between interventions that generate different outcomes (Brazier et al., 2017).

4.3.5 Cost-utility analysis

CUA is the most prevalent form of economic evaluation in a healthcare setting and compares interventions using a common unit of outcome, the QALY. This approach is recommended by many regulatory authorities including PBAC and MSAC in Australia (Australian Department of Health, 2016), and is mandated by NICE in the UK (NICE, 2018). QALYs allows for both QoL and quantity of life to be measured simultaneously within a single outcome. QALYs are typically calculated through the application of preference-based measures which consist of two main components; a descriptive system to describe a person's health and/or QoL and a scoring algorithm which reflects the relative values or weights attached to different health and/or QoL states defined by the descriptive system on the 0-1 (being dead to full health) QALY scale. Valuation techniques are discussed further in section 4.7. This approach enables interventions that may affect more than one aspect of health and/or QoL to be analysed as the respective dimensions of health and/or QoL e.g., mobility, pain, anxiety, and depression are combined into one measurement. It also allows for the comparison of interventions that have the same aims but may impact upon different health and/or QoL dimensions to be compared (Brazier et al., 2017). However, it is recognised that using different techniques to assign values to health and/or QoL states can occasionally lead to different results (Joore et al., 2010).

4.4 QUALITY-ADJUSTED LIFE YEARS

To make comparisons about the value for money of different courses of action e.g., health care treatments technology devices, public health care programmes, disability care services and supports and aged care services and supports interventions, a common outcome unit is ideally required. CUA analysis produces QALYs which can be used to compare the outcomes associated with alternative interventions. A QALY combines information about the extra years gained and quality of those years lived into a single number. The quality of those years lived are usually expressed as health states which are assigned a utility value from 0 (being dead) to 1 (full health) and in some cases negative values can be produced which equate to a state being considered as worse than being dead. A health state refers to an individual's state of health (and/or broader QoL) which can change over time due to disease, impairment, treatment, and injuries. The utility values are typically generated from large general population samples and are based on an aggregation of the values individuals place on a specific health state on the 0-1 QALY scale (Section 4.7 discusses the different methods used to elicit health states from the population). QALYs gained are calculated by multiplying the utility value assigned to a health state by the amount of time an individual spends in that state. For example, 1 QALY would represent an individual who lives a full year in full health and/or QoL (1 utility x 1 life year), whereas an individual who lives one half of the year in full health and/or QoL would be equal to 0.5 QALYs (1 utility x 0.5 years) (Brazier et al., 2017; Drummond et al., 2015).

QALYs are advantageous in health economics because they allow outcomes to be transformed into one single generic measure of outcome enabling interventions to be compared directly in terms of their costs and effectiveness. Interventions that produce several different QoL outcomes can be assessed by combining the outcomes into one common outcome measure. Comparisons can also be made across interventions targeting the same condition even when producing different effects, and for interventions targeting different conditions and producing different effects as they can be transformed into a single unit of outcome reflecting the QALYs gained (Brazier et al., 2017).

However, it has been argued that QALYs are ageist with those with greater life expectancy being favoured (Evans, 1997; Harris, 1987). This is because the length of lifetime to be gained is inherent to how QALYs are calculated with the more life years gained, the more effective the intervention or service. Adopting this approach favours individuals with greater life expectancy, which is typically the younger population. If QALYs are used to choose who receive services or interventions, then it is likely that those with shorter life expectancy (such as older people) will be given lower priority. This argument is less relevant in the context of this thesis as the QOL-ACC is older person specific and when used in economic evaluations in the future it will only be applied with older people. However, this argument is important to highlight because it is a potential concern in the health system when there are competing priorities, for example, when comparing interventions for children versus interventions for older people, as children will be given a greater weight when calculating QALYs with a lifetime perspective because their life expectancy is greater than an older person.

4.5 PATIENT REPORTED OUTCOME MEASURES

Recently, in health system settings, there has been a movement towards patient-reported outcome measures (PROMs) to capture single or multi-dimensional aspects of an individual's health/QoL through a self-reported measure (Australian Commission on Safety and Quality in Health Care, 2019; Thompson et al., 2016; Williams et al., 2016). The benefit of using PROMs to measure an individual's health/QoL is that the individual is reporting on their health/QoL themselves, and therefore providing an understanding of how they experience health/QoL from their own perspective (Lavallee et al., 2016; Williams et al., 2016). Where the person is unable to respond on their own behalf e.g., due to significant cognitive impairment and dementia PROMs may be completed by proxy assessors e.g., a family carer or close family member (Ayton et al., 2021; Smith et al., 2018). PROMs consist of a descriptive system that contains different dimensions (a component of a health state that ranges in severity) for example, mobility, independence, self-care, that have different response options. Measures vary in length consisting of different numbers of items for each dimension and response options. There are two types of PROMs; preference-based measures and non-preference-based measures which are distinguished from each other by their scoring method. Non-preference-based measures typically produce simple summative scores in which the dimensions' individual scores are added together to produce one single score. Non-preference-based measures assess and describe health/QoL. However, they are unable to value health/QoL as unlike preference-based measures they do not include a weighted scoring algorithm reflecting the values attached to different dimensions of QoL to convert the responses into a utility score, which is required to conduct economic evaluations (Brazier et al., 2017).

Preference-based measures typically apply an off the shelf scoring algorithm unique to each measure and often country specific based on the values that have been previously elicited from general population samples in which individuals assign values for different combinations of health states using valuation techniques and are anchored on a scale suitable to generate QALYs. (Brazier et al., 2017). A description of the different valuation techniques is provided in section 4.7.

There are several reasons why non-preference-based measures are not suitable to be used in health economics. Health economists argue non-preference-based measures that produce summative scores are not appropriate because the intervals between the response options may not be equally valued by individuals. For example, previous research by Brazier et al. (1998; 2002) using the valuation methods of Standard Gamble (SG) and Visual Analogue Scale (VAS) to value the 36-Item Short Form Survey (SF-36) identified that individuals did not value the intervals between the response categories equally. Furthermore, individuals may not place the same value on each dimension in the measure, and using summative scores assumes the dimensions have equal value because each dimension is not weighted according to the value individuals may place on each dimension (Brazier et al., 2002). For example, valuation studies of the EQ-5D and the Health Utility Index 3 (HUI3) have both shown that the intervals between the response categories are not equal and dimensions are not weighted equally (Dolan, 1997; Feeny et al., 2003; Le Gales et al., 2002; Mulhern et al., 2014). Preference-based measures account for these differences by allowing dimensions to be weighted differently and are therefore suitable for application in economic evaluation. The use of preference-based measures is the main way to generate QALYs for economic evaluation to enable the benefits of interventions to be compared using a common outcome metric.

Preference-based measures can be generic or condition-specific. Generic preference-based measures of health cover a wide range of aspects of health and/or QoL and are in principle relevant to all health conditions and populations. Generic preference-based measures vary significantly in terms of how they describe health/QoL, how they value health/QoL, the number of dimensions and the number of response levels for each dimension. As mentioned previously, the health state for an individual is calculated by using a scoring algorithm that has been generated using values from the general population. Several preference-based measures have been developed to be used specifically with children and adolescents, but most are designed to be used with adults. The Adult Social Care Outcomes Toolkit (ASCOT) (Netten et al., 2012a) is an example of a population specific measure that is designed to be used specifically within a social care setting with adults. Measures have also been developed to go beyond the traditional concept of health to measure wellbeing such as the ICECAP-O (Al-Janabi et al., 2012; Coast et al., 2008) which is based on Sen's theory of capability (Sen, 1993). The ICECAP-O is the only preference-based measure to date that has been developed from its inception to be used with older people. The following section provides details of preference-based measures that are typically applied with the older population.

4.6 PREFERENCE-BASED MEASURES

4.6.1 EQ-5D

The EQ-5D is a widely applied generic preference-based measure consisting of five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The EQ-5D-3L was the first version to be developed in 1990 and comprises three levels for each dimension (The EuroQol Group, 1990). The EQ-5D-5L was later developed in 2009 as a 5-level version to improve reliability and sensitivity of the measure and to increase the number of health states generated (Van Reenen et al., 2015).

4.6.2 HUI (1,2,3)

There are three versions of the HUI: HUI1, HUI2 and HUI3. The HUI1 was originally developed in the 1970s to evaluate HRQoL in low birthweight babies in neonatal intensive care (Torrance, 1982); the HUI2 was developed in the early 1990s to be used in childhood cancer research, but more recently has also been widely applied within the general adult population; and the HUI3 was developed in the early 2000s for application within the general adult population. The measure consists of eight dimensions (vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain), with five to six levels of disability/functional ability for each dimension (Feeny et al., 2002).

4.6.3 Short-Form-6 Dimensions (SF-6D)

The SF-6D was developed in the late 1990s from the Short Form 36 Health Survey (SF-36). The SF-36 is a generic tool comprising eight dimensions (physical health, physical role functioning, social role functioning, emotional role functioning, mental health, pain, vitality, and general health perceptions) but it is unable to be used in economic evaluation in its original form as it lacks a preference-based scoring system. The SF-6D scoring algorithm was developed from the SF-36 to enable the measure to be used in CUA. There are two versions: one version created from the 12-item SF-12 and one version created from the 36-item SF-36. Recently, the SF-6D version 2 was developed with a new scoring system to increase the utility score range (Mulhern et al., 2015).

4.6.4 Assessment of Quality of Life 6 Dimensions (AQoL-6D)/ Assessment of Quality of Life 8 Dimensions (AQoL-8D)

Four AQoL measures have been developed to measure HRQoL: AQoL-4D, AQoL-6D, AQol-7D and AQoL-8D. The original AQoL-6D was developed in the early 2000s and consists of 20 items that cover six dimensions: independent living, relationships, mental health, coping, pain and senses. The AQoL-8D is the most recent measure and was developed in 2011. It builds upon the previous AQoL measures by adding two further psychosocial dimensions to the previous six outlined above: happiness and self-worth. Each item has four to six response levels (Richardson et al., 2014a).

4.6.5 Quality of Wellbeing (QWB)

The QWB scale measures status and wellbeing and was developed in the 1970s to be used in health policy for the allocation of resources (Patrick et al., 1973). The QWB scale required a trained interviewer to administer the measure to the participant. The QWB Scale-Self-Administered (QWB-SA) was introduced in 1996 for ease of use and is a self-complete version of the QWB. The measure consists of four sections: chronic symptoms, physical symptoms, mental health symptoms, and behaviours, and has three dimensions (mobility, physical activity, and social activity) (Kaplan et al., 1997).

4.6.6. 15 Dimensions (15D)

The 15D was developed in Finland in the early 1990s to measure HRQoL and comprises a self-administered tool consisting of 15 dimensions: mobility, vision, hearing, breathing, sleeping, eating, speech, usual activities, elimination, mental function, discomfort and symptoms, depression, distress, vitality, and sexual activity. Each dimension has five levels, and the measure defines billions of health states (Sintonen et al., 1993).

4.6.7 ASCOT

The ASCOT was developed in 2010 and evaluates the impact of social services on an individual's QoL (referred to as Social Care-Related Quality of Life [SCRQoL]). The toolkit consists of eight dimensions: control over daily life, personal cleanliness and comfort, food and drink, personal safety, social participation and involvement, occupation, accommodation cleanliness and comfort, and dignity. Each dimension comprises of four levels (ideal, no unmet needs, some unmet needs, high unmet needs) devised from Sen's theory of capabilities (Netten et al., 2012a). However, its developers suggest it is used alongside other broader generic preference-based measures as it does not capture specific items relating to QoL such as physical health and emotional wellbeing (Van Reenen et al., 2019).

4.6.8 ICECAP-O

The ICECAP-O is a relatively new measure, designed from its inception for application with older people, that focuses on capabilities with respect to broader QoL and wellbeing rather than just health. The measure is based on Sen's capability theory (Sen, 1993), which is reflected in the ICECAP-O measure with the items using 'able to' or 'can'; for example, 'I can have all', 'I can have a lot', 'I can have a little', 'I cannot have any'. The measure has five dimensions (attachment, security, role, enjoyment, and control), with four levels for each dimension. The measure produces capability values ranging from 0 (no capability) to 1 (full capability). Currently, the ICECAP-O is the only older-person-specific preference-based measure in existence. The ICECAP for Adults (ICECAP-A) was developed later for application with the general adult population rather than specifically with the older population. However, it is not possible to calculate QALYs using the ICECAP-O and consequently, some commentators have raised concerns about the measure's applicability for application in CUA, where QALYs are typically the main outcome measure. The ICECAP-O measure developers have indicated that the ICECAP-O may be used within the framework of economic evaluation using a capability scale for the assessment of outcomes (Coast et al., 2008).

4.6.9 Comparison of preference-based measures

Table 4.1 presents a comparison of the preference-based measures identifying the different characteristics of each measure. As shown in the table, most measures adopt ‘present’ as the recall period, except for the QWB-SA, which uses a 3-day recall period; the AQoL-6D and AQoL-8D, which use ‘past week’ as the recall period; and the SF-6D (emanating from responses to the SF-36 and SF-12), which uses a standard recall period of 4 weeks. However, the HUI1 and HUI2 have three other standard options in addition to the present recall period: ‘past 1 week’, ‘past 2 weeks’ and ‘past 4 weeks’. The measures vary in the number of dimensions, items, and response levels. The EQ-5D-3L and EQ-5D-5L have the least number of dimensions (five) compared with the 15D, which comprises 15 dimensions. The number of dimensions does not always directly correlate to the number of items in a measure. For example, the EQ- 5D-3L and EQ-5D-5L both comprise five items that produce five dimensions, but the AQoL-8D, for example, consists of 35 items that form eight dimensions. The response options for each measure’s items range between two and six levels. The different number of dimensions, items and response levels produce varying numbers of health states. The 15D and the AQoL-8D define the most health states, while the EQ-5D-3L defines the least.

Table 4.1

Preference-based measures descriptive systems

Characteristics	ASCOT	AQoL-6D	AQoL-8D	EQ-5D-3L	EQ-5D-5L	HUI2	HUI3	ICECAP-O	QWB-SA	SF-6D	SF-6D (V2)	15D
Country of origin	UK	Australia	Australia	Netherlands, UK, Sweden, Finland, and Norway	Netherlands, UK, Sweden, Finland, and Norway	Canada	Canada	UK	USA	UK	UK	Finland
Population	Adults	Adults	Adults	Adults	Adults	Adults children	Adults	Adults aged 65 and over	Adults	Adults	Adults	Adults
Respondent	Self-completion interviewer administered Proxy	Self-completion	Self-completion	Self-completion interviewer administered proxy	Self-completion Interviewer administered proxy	Self-completion interview administered proxy	Self-completion interviewer administered proxy	Self-completion	Self-completion interview administered proxy	Self-completion	Self-completion	Self-completion
Length of health-status recall period	Present	Past 1 week	Past 1 week	Present (today)	Present (today)	Usual (present), Recall (past 1 week, past 2 weeks, past 4 weeks)	Usual (present), Recall (past 1 week, past 2 weeks, past 4 weeks)	Present	3 days	Present	Present	Present
Primary Focus	Social Care	Health states and psychometric scores	Health states and psychometric scores	Health states	Health states	Health states, health-related quality of life	Health states, health-related quality of life	Capabilities	Health outcomes	Health states	Health states	Health states
Dimensions	8	6	8	5	5	7	8	5	3 (and 58 symptoms)	6	6	15
Items	8	20	35	5	5	7	8	5	76	11 (SF-36) 7 (SF-12)	11	15
Levels	4	4-6	4-6	3	5	3-5	5-6	4	2-4	4-6	4-6	5
Health states		5.4×10^{13}	$2.43\text{x}10^{23}$	243	3,125	24,000	972,000		945	18,000 (taken from SF-36)	18,750	31billion

										7,500 (taken from SF-12)		
Other versions of measures	CH3 (for care homes) CH3-INT-Res (Interview administered within communal living) CH3-INT-FS (completion by family members of participant in communal living) CH3-INT-QUAL (Qualitative interview for participants in residential care) CH3-Obs (Care home observation) CH3-ratings (care home ratings schedule)	AQoL-4D AQoL-7D AQoL-8D	AQoL-4D, AQoL-6D, AQoL-7D	EQ-5D-5L EQ-5D-Y	EQ-5D-3L EQ-5D-Y	HU1, HUI3	HUI1, HUI2	ICECAP-A CES ICECAP-SCM	QWB	SF-6D v2	SF-6D	16D 17D
Website	https://www.pssru.ac.uk/ascot/	https://www.aqol.com.au	https://www.aqol.com.au	https://euroqol.org/	https://euroqol.org/	http://www.healthutilities.com/	http://www.healthutilities.com/	https://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/HE/ICECAP/index.aspx	https://hoap.ucsd.edu/qwb-info/	https://www.sheffield.ac.uk/scharr/sections/heds/mvh/sf-6d	https://www.sheffield.ac.uk/scharr/sections/heds/mvh/sf-6d	http://www.15d-instrument.net/15d/

Preference-based measures include different dimensions and consist of both physical and psychosocial health dimensions to measure health/QoL. Table 4.2 shows the different types of dimensions included in each measure which is based on the classifications used by Richardson et al. (2014b) in their review of preference-based measures. Overall, the physical health dimensions are more prevalent in the measures than the psychosocial health dimensions. The EQ-5D measures, HUI measures, AQoL-6D and 15D consist of predominantly physical health dimensions, whereas the ASCOT, SF-6D, AQoL-8D and ICECAP-O consist mostly of psychosocial health dimensions. QWB-SA focuses more on symptoms and therefore mainly covers physical dimensions. The most widely used dimensions are the physical health dimensions of bodily function/self-care (adopted in all measures apart from the ICECAP-O) and mobility/physical activity (present in all measures except the ASCOT and the ICECAP-O). The physical health dimensions dexterity and fertility are the least adopted dimensions, with only the HUI3 covering dexterity and the HUI2 covering fertility (fertility is an optional dimension that can be excluded if measuring generic health status). The psychosocial health dimensions of meaning/achievement, safety/security and family are the least captured, with only the ICECAP-O covering meaning/achievement and the AQoL-6D and AQoL-8D covering family and intimacy dimensions.

Even when the measures are categorised by physical dimensions and psychosocial dimensions, differences exist in the way that the measures conceptualise health/QoL. For example, the HUI measures describe health by capacity whereas the QWB-SA describes health by behaviour and performance. Furthermore, the inclusion of dimensions relating to symptoms, mental health and social health varies between the measures. Most of the measures include usual activities, work, role, and relationships which are seen as activity and participation aspects of health. However, the HUI measures are different in the fact that they focus on symptoms and impairments, for example speech, vision, hearing and do not include the activities and participation aspect of health.

Table 4.2

Preference-based measures dimensions

Health Dimension	ASCOT	AQoL-6D	AQoL-8D	EQ-5D-3L	EQ-5D-5L	HUI2	HUI3	ICECAP-O	QWB-SA	SF-6D	SF-6D (V2)	15D
Physical												
Mobility /physical activity		3	2	1	1	1	1		7	1	1	1
Bodily function/ self-care	1	2	1	1	1	1	1		13	1	1	3
Dexterity							1					
Coping		1	1									
Pain/ Discomfort		2	2	1	1	1	1		14	1	1	1
Senses		2	2			1	2		5			2
Usual activities /work role related to physical health			4	1	1				12	1	1	1
Communication		1	1			1	1		2			1
Vitality		1	1						1	1	1	1
Fertility						1						
Psychosocial												
Sleeping			1						1			1

Wellbeing/ depression/ anxiety		5	7	1	1	1	1		4	1	1	2
Autonomy/ control/ dignity	1		1					1	1			
Self-esteem/ Identity	1		2									
Meaning /achievement								1				
Safety/ Security	1											
Cognition /memory						1	1		1			1
Usual activities related to psychosocial health	1		4	1	1			1	12	1	1	1
Relationship/social functioning	1	1	6					1	2			
Family		1	1									
Intimacy		1	1						1			

4.7 VALUATION TECHNIQUES

As mentioned previously in this chapter, preference-based measures are able to value health/QoL as they consist of a scoring algorithm based on a survey in which individuals assign values for different combinations of health states. There are two main approaches of valuing health states: direct and indirect. The direct approach involves mapping preferences directly onto a utility scale by eliciting preferences through cardinal techniques such as time trade-off (TTO) and SG. Measuring patients' preferences directly can be time-consuming as it involves asking study participants their preferences each time a study is conducted. Indirect methods can be used as an alternative approach and are less time-consuming as they only involve eliciting preferences once and the utilities can then be used multiple times. The indirect method involves mapping preferences indirectly onto a utility scale using generic preference-based measures with individuals that cover a broad range of health dimensions and is the most common method to generate QALYs (Brazier et al., 2017).

The valuation of health states requires individuals to indicate their preferences for different health states to generate utility values. Cardinal preference measurement is often preferred over ordinal measurement as ordinal techniques involve a simple ranking of health states in order, and therefore do not allow for the strength of preferences to be known. Cardinal methods such as SG and TTO are the main techniques that have been adopted. However, more recently there has been a move towards valuing health through ordinal valuation techniques such as discrete choice experiments (DCE) with survival duration included as an additional attribute to dimensions and/or health and/or wellbeing, and best-worst scaling (BWS), mainly because they are considered more straightforward to administer and are easier for the participant to understand than some of the other methods (Brazier et al., 2017). Both DCE and BWS are ordinal approaches and therefore, they are not anchored onto the QALY scale. However, both approaches can be re-scaled using an established valuation technique such as TTO or SG to be able to produce QALYs (Brazier et al., 2017).

4.7.1 Cardinal methods

Visual Analogue Scale (VAS) is used less frequently than SG and TTO and it is not strictly a cardinal method as it does not require individuals to make choices or trade-offs when choosing their preferences, and instead involves individuals placing their agreement to a statement on a continuous scale (Brazier et al., 2017). A VAS scale is a line (horizontal or vertical) with equal intervals and two end points. When using VAS to value health an individual is asked to place different health state scenarios at points on the line between the two endpoints. This technique requires the two end points to be clear with 0 representing dead and 1 representing full health (Brazier et al., 2003). VAS can also be adapted to measure states worse than death and temporary health states (Brazier et al., 2017). VAS has been widely used due to its simple administration and lower cost than other techniques such as SG and TTO (Brazier et al., 2017). The technique has been used to value health states for the QWB scale (Kaplan et al., 1998), the EQ-5D (Brooks et al., 2003), the 15D (Sintonen, 1994) and the HUI (Feeny et al., 2002). However, VAS has been criticised for not offering choice resulting in lack of confidence in the results generated with individual's choices not necessarily expressing the value of health (Brazier et al., 2003; Nord, 1991; Robinson et al., 2001). Gray et al. (2011) highlight that because VAS does not require individuals to make choices or trade-offs when choosing their preferences there is doubt surrounding the accuracy of preferences indicated, thus it is not usually recommended for economic evaluation as it is not strictly preference-based (Brazier et al., 2017). VAS has also been criticised for its reliability when used to value an individual's own health state (Feng et al., 2014). Other criticisms of VAS to elicit health states is end of scale bias in which individuals avoid placing points at the two ends of the scale (Torrance et al., 2001), and the increased likelihood of individuals placing their choice on a 5 or 10 point mark rather than the points in between. The technique can also be prone to spacing out bias where individuals leave even intervals on the scale between the health state choices (Gray et al., 2011).

Alternative methods such as SG and TTO include an element of risk and require the participant to make trade-offs when making choices which improves reliability of a patient's preferences compared to VAS (Oppe et al., 2016). SG is based on a rational decision-making under uncertainty theory developed by von Neumann and Morgenstern (1944). The technique involves an individual choosing between two different options. Option one is a guaranteed health state for a set number of years compared to choice two which has two different outcomes. Option two involves a risk as one outcome represents full health, and the other outcome represents death. The technique aims to measure the willingness of an individual to accept the outcome of death to avoid the health state in option one. The SG method can be adapted to value different health states (worse than death and temporary health states). Utility weights are gained by altering the best outcome until the individual is indifferent between the guaranteed outcome and the gamble (Brazier et al., 2017). For ease of use individuals are often presented with two cards: one card displaying option one and the other card with a coloured probability wheel illustrating the two outcomes from option two (death and full health) (Torrance, 1986). However, this administration method is not ideal as it requires face to face completion which can be costly (Gray et al., 2011). Furthermore, Gray et al. (2011) suggest individuals using this method may experience difficulties because the probabilities can be hard to comprehend. Concerns have also been raised that individuals' health state valuations do not always represent the valuations generated from the SG approach because it involves an element of risk and gambling in addition to an individual's health (Richardson, 1994).

TTO was initially developed by Torrance (1976) to be used in healthcare as a less complicated alternative to SG. The technique is a simpler alternative to SG as it does not involve the element of probability. The method requires an individual to choose between two alternatives representing a certain outcome. Alternative one is a health state less than full health for a specified amount of time compared to alternative two which is a full health state for a reduced amount of time than alternative one. The technique aims to measure the willingness of an individual to trade-off remaining life expectancy to avoid a less than perfect health state. TTO can be adapted for health states worse than death by alternative one representing death and alternative two representing an amount of time in a health state less than full health followed by an amount of time in a full health state (Brazier et al., 2017). It can also be altered to represent temporary health states by alternative one being an amount of time spent in a specific health state followed by full health with the alternative being a longer amount of time in a specified health state better than the one proposed in alternative one followed by full health (Gray et al., 2011). Similar to the SG method, visual aids such as cards with a sliding health scale have been developed to make the task more understandable to participants (Dolan et al., 1996). One issue with TTO has been the increase in the variants of TTO which has led to problems when comparing interventions if different variants have been used (Arnesen & Trommald, 2005). Further concerns relate to individuals choosing between two certain outcomes when health is known to be uncertain (Mehrez & Gafni, 1991) and that they are willing to trade life expectancy which is not always the case (Robinson et al., 1997). There are also issues relating to time preferences as the method assumes the amount of time an individual will sacrifice to be in a health state is not related to the amount of time they would be in that health state. However, an individual may value health differently depending on the quantity of time they have to spend in a particular health state (Brazier et al., 2017).

4.7.2 Ordinal Methods

More recently, health economists have increasingly adopted ordinal methods to elicit health states such as DCEs, ranking, and BWS due to ease of administration, easier comprehension for individuals and reduced cost (Brazier et al., 2017). Unlike TTO which often requires face-to-face administration, most ordinal approaches can be easily conducted online. For example, Brazier and colleagues (2013) conducted an online study in the UK to elicit societal preference for QALYs in healthcare settings using the DCE approach (Brazier et al., 2013). Furthermore, ordinal methods have the advantage of not being influenced by time preferences or risks as the cardinal methods of TTO and SG (Brazier et al., 2017).

Ranking is an ordinal method that involves an individual placing a set of health states in order from best to worst, or worst to best in an independent ranking activity or during an interview. In an interview setting the interviewer would ask the individual to either place the health states in order one by one or to choose the best health state and the worst health state followed by the middle health states (Brazier et al., 2017). An alternative ordinal approach is BWS which can be used in three different ways. One approach (known as the profile case) is for the individual to choose the best and worst health states from a set with a minimum of three choices with each health state comprising of levels on numerous attributes. The second approach (known as the object case) is similar to the first approach in that the individual chooses the best and worst health states from a set with a minimum of three choices, but the health states have no attribute and level structure. The third approach (known as the multi-profile case), and the one more commonly adopted, is where an individual is shown one health state at a time and decides which is the best and worst by looking at the different levels of the attributes of each health state. As mentioned previously, although BWS is an ordinal approach the BWS estimates can be re-scaled using established valuation techniques to produce values on the QALY scale. BWS multi-profile case was recently used to value the ICECAP-O where individuals were asked to choose the best and worst set from a combination of sets of the ICECAP-O five dimensions with the four different levels (Coast et al., 2008).

DCEs involve presenting individuals with two or more alternative health states consisting of several attributes with different levels. The individual is required to choose their overall preferred health state without having to choose their preferred level for each attribute. Individuals can be presented with several sets of alternatives and the assumption is the best health state would be chosen for each set (Ryan et al., 2008). DCEs have increasingly been used to value health states for preference-based measures. For example, the EQ-5D-3L has mainly been valued using TTO (Szende et al., 2007), but more recently work has been undertaken using DCEs to estimate health state preferences for the EQ-5D-5L (Bansback et al., 2012; Mulhern et al., 2014; Viney et al., 2013). DCEs have also been used to value the SF-6D (Version 2) in the UK using online methods in which individuals were presented with 10 DCE sets (Mulhern et al., 2020).

However, concerns have been raised surrounding the methodology of DCEs such as validity and test-retest reliability. Most DCE sets only present a brief description of attributes, and therefore there can be inconsistencies in how the attributes and levels will be interpreted by different individuals. Furthermore, respondents may concentrate on one or two attributes and overlook other attributes to simplify the task impacting the validity of the activity (Brazier et al., 2017). Test-retest is where a DCE choice scenario is replicated during the same activity, and it is expected that the individual should provide the same response (Drummond et al., 2015). Those responses that do not match are often seen as inconsistencies in the research and are subsequently not included. This approach has been criticised as valid responses may be removed unnecessarily (Drummond et al., 2015). Despite these concerns, DCEs are fast gaining popularity in the area of health economics research, particularly for the valuation of consumer and/or general population preferences for health and quality of life outcomes (Brazier et al., 2017; Drummond et al., 2015).

4.8 WHO SHOULD VALUE HEALTH STATES?

Obtaining values for a health state requires individuals to provide values using the health state valuation techniques discussed above. The choices individuals make are used to indicate the strength of preferences for different aspects of health. Patients, carers, health professionals and the general public have been used to produce health values (Brazier et al., 2017) and there is an ongoing debate about who is most appropriate to value health and/or QoL. The argument for patients valuing their own health state is based on the fact that they have direct experience and knowledge of their own health and are therefore more suitable to value the health state in question (Nord et al., 1999). It is important to recognise that the focus of this thesis is older people in receipt of aged care services, however, the arguments for the use of patient values are relevant to older people receiving aged care services because they have direct experience of their own health state and QoL, in the same way as patients. Using patients to value health states is recommended by organisations such as the Dental and Pharmaceutical Benefits Agency in Sweden (The Dental and Pharmaceutical Benefits Agency, 2017). However, this approach may lead to patients providing higher values to health states with perceived limitations or negative health effects similar to those they experience, because they may have adapted physically and psychologically over time to the given health state, which is particularly relevant to older people who may adapt to their conditions through the gradual ageing process (Brazier et al., 2107). It has also been suggested that patients may provide bias values as they may be due to benefit from the situation (Stamuli, 2011).

An alternative approach is to ask the general public to value an imagined state of health that they have not experienced, often referred to as a hypothetical health state. Recently generic preference-based measures generating QALYs have been based on values elicited from the general population using this type of approach (Brauer et al., 2006; Versteegh & Brouwer, 2016). Organisations such as the Washington Panel on Cost-effectiveness in Health and Medicine in the United States of America recommended using general population values. This argument is based on the concept that the general population funds the healthcare system via taxation, and should therefore, be involved in healthcare decisions (Gold et al., 1996; Helgesson et al., 2020). Other organisations such as NICE in the UK and CADTH in Canada also advocate the use of general population values in their guidelines on new healthcare technologies (CADTH, 2017; NICE, 2013). Gold (1996) argues this approach is preferable as health state valuations should be based on decisions rather than experiences.

Organisations such as NICE in the UK endorse this approach and recommend HRQoL values should be based on the general public's preferences elicited through choice based techniques (NICE, 2018). However, asking the general public to value a health state that they have no experience of raises concerns. The main concern with using the general public is that values are not truly accurate unless they are based on patients' preferences as they are the only individuals that have real experience of the health state and using the general public may lead to biased results (Dolan et al., 2008; Nord et al., 1999). Other concerns are that the general public may be inclined to over emphasise health concerns and not take a person's potential for adaptation into account (Stamuli, 2011). Furthermore, Litva and colleagues (2002) argue that even though the public want to be involved in decision-making, this does not necessarily mean they want to value health states.

It is important to use the correct population when valuing health/QoL because using different population groups can influence the values. Research has suggested health state values generated from patients can lead to higher valuations of health compared to values from the general population (Ratcliffe et al., 2007; Tengs et al., 2000; Ubel et al., 2003). However, other research has indicated that patients providing higher values is not necessarily true for all health conditions. For example, Rowen and colleagues (2014) found that older people with dementia and their carers valued their health state as lower than the general population. Similarly, Pyne et al. (2009) found individuals with depression provided lower valuations of depression than the general population. Further large scale research in this area comparing EQ-5D profiles and VAS data from patients with eight different health conditions with general population data from the EQ-5D value set reported differences in valuations between patients and the general public and these differences were found to be based on the health condition of the patient (Mann et al., 2009). Indeed, a recent systematic review based on published literature consisting of the patient values versus general population values concluded that patients' values were the most accurate source (Helgesson et al., 2020). These findings are also applicable to older people in receipt of aged care services and indicate that older people may be the most accurate source for values for any new preference-based QoL measure in aged care rather than the general population.

It is evident that differences in values exist depending on the population group eliciting the values and therefore it is important to make a considered choice on whose values to use when conducting economic evaluations used for decision-making. This is of particular importance when developing a new preference-based measure as the scoring algorithm should ideally be developed using values from the population it is intended for to accurately reflect the preferences of that population group.

4.9 VALUATION METHODS OF THE PREFERENCE-BASED MEASURES

Table 4.3 shows the valuation methods, source of the population weights, predicted utilities and scoring algorithms for the preference-based measures. VAS is the most common valuation method and has been used with the AQoL-8D, EQ-5D-3L, HUI2, HUI3, QWB SA and 15D. The algorithms for the ASCOT, AQoL-6D, AQoL-8D, and both the EQ-5D-3L and EQ-5D-5L were produced using TTO. Other valuation methods include SG (used with the HUI2, HUI3 and SF-6D), BWS (used with the ASCOT and ICECAP-O) and DCE (used with the EQ- 5D-5L and SF-6D v2). It is notable that more than one valuation method has been used to create utility scores for six of the measures.

Typically, scoring algorithms for preference-based measures have been generated from large general population sample values rather than older person specific values (Brazier et al., 2017). With the exception of the ICECAP-O all the measures in Table 4.3 used adult general population samples to generate scoring algorithms for the measures. The ICECAP-O elicited values from adults aged 65 years and over to create the capability index for the measure, which is not surprising given the ICECAP-O is an older person specific measure. As discussed in section 4.8, it is preferable to elicit values from the population the measure is intended for to accurately reflect the preferences of the population group as values between groups may differ. The preference-based measures, i.e., AQOL-

8D, EQ-5D-3L, EQ-5D-5L, HUI2, HUI3 and SF-6D v2, can produce negative utility scores representing health states considered worse than being dead. The SF-6D v2 is the preference-based measure that generates the lowest (all worst state) utility score (− 0.718).

Table 4.3

Properties of the preference-based scoring algorithms and their predicted utilities

Properties	ASCOT	AQoL-6D	AQoL-8D	EQ-5D-3L	EQ-5D-5L	HUI2	HUI3	ICECAP-O	QWB-SA	SF-6D	SF-6D (V2)	15D
Original source of population weights	General adult population in the UK	General adult population in Australia	Mental health patients and the general adult population in Australia	General adult population in Europe (Finland, Germany, The Netherlands, Spain, Sweden and the UK)	General adult population in the UK	General adult population in Canada	General adult population in Canada	Adults aged 65 and over in the UK	Adults from primary care clinics and college campuses in San Diego, USA	General adult population in the UK	General adult population in the UK	General adult population in Finland
Valuation	BWS TTO	TTO	VAS transformed into TTO	TTO VAS	TTO DCE	VAS SG	VAS transformed into SG	BWS	VAS	SG	DCE	VAS
Best health	1	1	1	1	1	1	1	1	1	1	1	1
Worst health	-0.17	0	-0.04	-0.56	-0.208	-0.03	-0.36	0	0.09	0.301	-0.718	0.11
Scoring algorithms developed in other countries				Several other countries such as Japan, Singapore, USA, Australia, China, Poland	Several other countries such as Australia, France, Philippines, Poland, USA, Singapore	UK	UK, France			Japan, Hong Kong, Portugal, Brazil, Australia, Singapore, Spain	USA, Canada, Australia, Portugal and Brazil	

Note. BWS = Best-Worst Scaling; TTO = Time Trade-Off; VAS = Visual Analogue Scale; DCE = Discrete Choice Experiments; SG = Standard Gamble.

4.10 METHODS

The following sections of this chapter outline a comprehensive review of the application of preference-based measures within the older population to understand the frequency of their use and the different contexts in which they have been applied. An overview of the use of generic preference-based measures with populations of older people is important in order to assess the methodological issues surrounding the applicability and practicality of their use with this specific population.

4.10.1 Search Strategy

A comprehensive literature review was undertaken to search and identify the application of preference-based measures in the older population from January 2014 to June 2021. This time period was selected for pragmatic reasons and with the observation that the two most recently developed generic preference-based measures included in this review (ICECAP-O and ASCOT) would be more likely to have been applied in economic evaluations during this period than in earlier time periods during which they were still in development and undergoing psychometric testing.

The review was conducted by first searching the websites pertaining to each measure to identify published studies. Second, a literature search was conducted using the PubMed and Google Scholar electronic databases. The search terms for the older population included ‘older people’, ‘elderly’, ‘aged’ and ‘geriatric’. These terms were combined with the keywords ASCOT, AQoL-6D, AQoL-8D, EQ-5D, HUI2, HUI3, ICECAP-O, QWB, SF-6D, 15D, preference-based instrument, preference-based measure, multi-attribute utility, health utility and cost utility.

4.10.2 Screening strategy

The search produced 1354 articles. The duplicate articles were removed, and the remaining articles (n = 1253) were screened using the eligibility criteria detailed below. 1004 articles were excluded as they did not meet the eligibility criteria (see Figure 4.1). The full texts of the 249 articles were then screened by myself, followed by two other individuals (CH, JR). The overall agreement (interrater reliability) was calculated using Cohen's kappa. An average kappa statistic of 0.95 was obtained, which indicated almost perfect interrater reliability (Landis & Koch, 1977). Differences were resolved by discussion between myself, CH and JR.

Inclusion criteria

- Published in English language
- Quantitative and/or qualitative design
- Published from 2014 onwards
- Study sample of people aged 65 years and over
- Application of a preference-based measure (ASCOT, AQoL-6D, AQoL-8D, EQ-5D, HUI2, HUI3, ICECAP-O, QWB, SF-6D, 15D) exclusively with people aged 65 years and over

Exclusion criteria

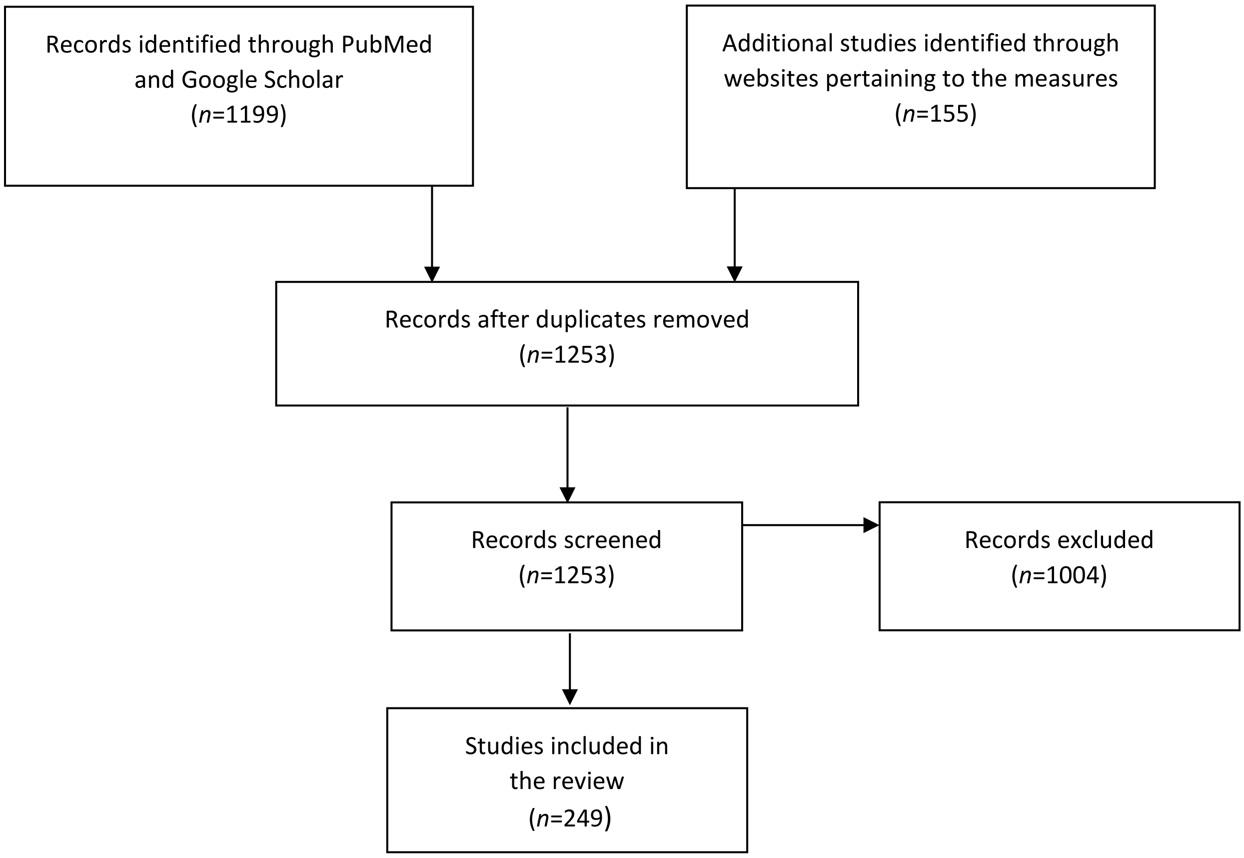
- Not published in English language
- Study sample were not adults aged 65 years and over
- Thesis or conference paper

4.11 RESULTS

In total, 249 peer-reviewed articles were found to be relevant to be included in the review (see Figure 4.1).

Figure 4.1

Flow chart of study identification process for the application of preference-based measures within the older population



4.11.1 Application of the generic preference-based measures in the older population

Table 4.4 presents an overview of the application of the generic preference-based measures within different contexts across the health and aged care sectors in the older adult population. Further details of the identified studies are presented in Appendix 2. Studies were classified using the WHO International Classification of Diseases, Tenth Revision (ICD-10) (WHO, 2016), with extensions into broader areas of social and aged care as dictated by the application areas for the generic preference-based measures identified.

Table 4.4

Number of preference-based measure applications in populations of older people

Context	ASCOT	AQoL-6D	AQoL-8D	EQ-5D-3L	EQ-5D-5L	HUI2	HUI3	ICECAP-O	QWB-SA	SF-6D	SF-6D (V2)	15D
Mental and behavioural disorders				16	3		1	2				2
Musculoskeletal system and connective tissue				13	1							
Genitourinary system				3				1		2		
Endocrine, nutritional and metabolic		1		6	1							
Respiratory system				2								
Neoplasms				5	1							
Circulatory system				6	1							1
Blood and blood-forming organs				1								
Nervous system				1						1		
Muscle Mass				4	2							
Fractures				7	7			1		1		1

Pain		3								
Multi-morbidities		5	1							
Functional Implants		5			1					
Medical procedures		1	2							
Frailty	1	10	5		1	2		1		2
Physical disability		2			1			1		
Falls		15	2			2				
Digestive system		2								
Lifestyle behaviour		12	3			1	1			
Medication		12	2		1					3
General health-related quality of life		18	1			2	1			
Survey development/testing/validation	2	2	6			3				
Aged care services	5	5	1			1				1
Acute Care		3								
Other		1								

The review highlighted the wide variety of settings in which the preference-based measures have been applied. In general, the measures were most frequently applied in studies in the areas of mental and behavioural disorders(n=24), frailty (n=22), falls (n=19) and general HRQoL (n=22). Thirteen studies had applied the preference-based measures specifically in aged care studies. Of these thirteen studies, six studies were based in home care settings, four studies were based in residential settings, two studies were based in both residential care settings and home care settings, and two studies were based in community day centres proving aged care services. The most common preference-based measures to be applied within the aged care settings were the ASCOT (n-=5) and the EQ-5D-3L (n=5). The EQ-5D-5L, ICECAP-O and the 15D had been applied in one study.

The most common measures applied in the older population were the EQ-5D-3L (n=161), followed by the EQ-5D-5L (n=39), which was used in a wide range of health contexts. A recent review also identified the EQ-5D to be the most widely used measure to date, and it has been validated in many countries and across numerous health conditions (Richardson et al., 2014b). One reasonable explanation for this measure's prevalence is that organisations around the world recommend its use in economic evaluations for the measurement and valuation of HRQoL. For example, NICE in the United Kingdom has mandated the EQ-5D as its preferred measure, and it is also recommended by the Australian PBAC and CADTH in Canada, (CADTH, 2017; Australian Department of Health, 2016; NICE, 2013).

The HUI2 and AQoL-8D were not applied in any of the identified studies. The HUI3 (n=5), AQoL-6D (n=1), QWB-SA (n=2), 15D (n=10) and SF-6D (n=6) measures were applied in a relatively small number of studies in comparison with the EQ-5D measures. Despite being a relatively new measure, the ICECAP-O (n=15) had been applied in a variety of areas, including mental and behavioural disorders, genitourinary system, fractures, frailty, falls, lifestyle behaviour, survey development and testing and general HRQoL. The ASCOT, which also represents a relatively new measure designed principally for application in a social care context, had been applied in several studies (n=8), including frailty, the aged care sector and survey development and testing.

4.12 DISCUSSION

The application of generic preference-based measures in the older population raises several key methodological issues. One issue is that the content of the descriptive systems of the generic-preference-based measures are not typically applicable to older people. Within health economics, older peoples' QoL has been assessed using preference-based measures to generate QALYs; however as previously mentioned in Chapter one and Chapter two, QALYs typically measure health status and to date have not tended to focus on the broader dimensions of QoL that are important to older people, particularly within the aged care sector (Coast et al., 2008; Milte et al., 2014; Ratcliffe et al., 2017). For example, dimensions such as independence, control, safety, dignity, and social relationships are imperative to older people's overall QoL and these are not routinely captured in existing measures suitable for economic evaluation (Grewal et al., 2006; Milte et al., 2014; Ratcliffe et al., 2017). Research acknowledging that generic preference-based measures need to go beyond the traditional concept of health has resulted in the development of the ICECAP-O and the ASCOT. The ICECAP-O currently represents the only older-person-specific generic preference-based measure in existence and was developed exclusively from its inception to measure and value older peoples' broader concept of QoL. The items in the descriptive system were elicited from qualitative research with older people that identified the salient QoL attributes for this population group (Grewal et al., 2006). The measure focuses on QoL influenced by an individuals' capabilities (based on Sen's capability theory) (Coast et al., 2008). Therefore, the index scale is not compatible with the QALY scale as it reflects levels of capability, i.e., 1 (full capability) to 0 (no capability) (Sen, 1993).

The ASCOT was designed to be used to evaluate social care and focuses on broader concepts of QoL; however, the measure does not include specific items that relate to physical health and emotional wellbeing. Therefore, the ASCOT developers recommend that it should be used alongside other generic preference-based measures designed to capture these dimensions, e.g., the EQ-5D (Van Reenen et al., 2019). Furthermore, the ASCOT was not designed to be used specifically within the older population, hence it does not reflect the views and preferences relevant to this specific population group.

If interventions aimed at the older population are to be accurately evaluated, older people's QoL preferences need to be incorporated when validating measures to accurately reflect the older populations' preferences (Coast et al., 2008; Ratcliffe et al., 2017; Richardson et al., 2015). However, with the notable exception of the ICECAP-O which was developed from a sample of community-dwelling older people aged 65 years and over, using BWS (Coast et al., 2008), the scoring algorithms pertaining to the preference-based measures were generated based on preferences drawn from the general adult population. As previously mentioned, there is evidence to suggest that older people interpret QoL differently to the general adult population (Coast et al., 2008; Milte et al., 2014; Ratcliffe et al., 2017). Therefore, the preferences elicited across dimensions of QoL to develop the scoring algorithms of the measures are unlikely to accurately represent older peoples' preferences.

Furthermore, the QoL domains included in the preference-based measures are varied and there is very little commonality to the ways in which QoL domains or attributes are described between measures, which makes it hard for the outcomes of different measures to be compared across aged care interventions. For example, both the ASCOT and ICECAP-O have a domain that measures ‘control’; however, the ASCOT measures control by identifying the participants’ ‘control’ over their daily life, whereas the ICECAP-O measures ‘control’ through identifying the participants’ level of independence, leading to disparity between the measures (Makai et el., 2014). A recent study by Richardson et al. (2015) comparing six preference-based measures, highlighted the differences both in the content and scale of the measures, leading to different utilities representing the same health states. The study found the measures vary in their descriptive systems to measure QoL which coupled with the different measurement scales leads to the incomparability of the preference-based measures. This is an issue for decision makers when attempting to compare outcomes generated from different preference-based measures across different aged care interventions.

There are several limitations to this review that are important to highlight. Whilst the review was exhaustive in terms of providing a comprehensive list of the available generic preference-based measures applicable for the older population, due to resource limitations it was not possible to gather evidence relating to the application of these measures using a systematic review approach. It is therefore possible that some studies conducted within the relevant time period, e.g., appearing in the grey literature, were not included in this review. Similarly, for practical purposes, the literature search was limited to published studies presented in the English language within the last 7 years, as well as studies that had applied the identified measures exclusively to the population of interest (older people aged 65 years and over). Despite these limitations, this review provides unique insights. It provides a detailed overview of the development and application of generic preference-based measures with populations of older people to date and discusses the issues surrounding their use with this population. Areas for further research relating to the development and application of generic preference-based measures with populations of older people are also highlighted.

Evidence from economic evaluations in the aged care sector can be used to make improvements in quality of care and QoL for older people. However, whilst economic evaluations are prevalent in the health care sector, economic evaluations in the aged care sector have been scarce as high quality evidence in this sector has not been seen as such a priority compared with the health care sector (Ratcliffe et al., 2012). Recent systematic reviews have highlighted the lack of economic evaluations in the aged care sector, despite evidence that improvements are needed (The Lancet, 2019). For example, Bulamu et al. (2018) conducted a systematic review in community aged care and only found 11 studies reporting economic evaluations. Furthermore, only five of the 11 studies had used CUA allowing comparison across the interventions with the common outcome measure of the QALY. All five of these studies used the EQ-5D-3L as their primary measure of outcome with only one study using the ICECAP-O. Not only did this review highlight the paucity of economic evaluations in the aged care sector, but it also demonstrates the dearth of economic evaluations conducted using CUA which enables the comparison of different interventions using the common outcome measure of the QALY.

A possible contributing factor to the dearth of economic evaluations conducted in this sector could be the lack of suitable measures to be used, as this chapter has highlighted. It has been recognised that measuring HRQoL of older adults should not just purely focus on health but also capture wider dimensions such as independence, social relationships, and participation in activities (Grewal et al., 2006; Milte et al., 2014; Ratcliffe et al., 2017). Several reviews conducted to identify QoL measures employed with older people have demonstrated the lack of suitable measures for economic evaluations in the aged care sector that encompass these broader dimensions of QoL. For example, Makai et al. (2014) in their systematic review of QoL measures (preference-based and non-preference-based) used for economic evaluations in health and social care for older people found most measures were not suitable because many measures were not preference-based. The review highlighted the ICECAP-O and the ASCOT as the most appropriate measures as they encompassed broader aspects beyond health but indicated both needed further validation to be applied in economic evaluations.

Similarly, Bulamu and colleagues systematic review identifying suitable measures in economic evaluations in the aged care sector found the EQ-5D was the most applied measure but recommended using it alongside measures such as the ICECAP-O and ASCOT that capture broader aspects of QoL in the absence of a suitable existing measure (Bulamu et al., 2015).

4.13 CONCLUSION

This chapter has demonstrated the lack of suitable QoL measures for application in economic evaluation with older people and has outlined the issues pertaining to their use with this population. Currently, there is no older person specific preference-based QoL measure that is suitable to be used with older people in receipt of aged care services for economic evaluation. Therefore, a preference-based measure needs to be developed that encapsulates the broader dimensions of QoL that older people in receipt of aged care value and that can also be used in economic evaluation. Creating such a measure will enable aged care interventions to be compared in terms of their costs and outcomes where outcomes are measured and valued according to the QoL of older people. As resources are limited economic evaluation can enable aged care policy makers and practitioners to compare interventions and allocate resources to service innovations and models of care which drive QoL improvements for older people in receipt of aged care services.

5.METHODOLOGICAL APPROACH FOR THE DEVELOPMENT OF THE QOL-ACC

5.1 INTRODUCTION

This chapter describes the research paradigm underpinning the development of the QOL-ACC descriptive system. A research paradigm is determined by a set of beliefs to help address and understand a research question to inform the methodological approaches and methods adopted. An overview of the three main types of research paradigms will be outlined and the paradigm chosen for this research will be justified. The methodological approaches to collect data will be presented and the approach for this research will be examined. Finally, the methods selected for the different development stages of the QOL-ACC and their respective justifications will be provided.

5.2 THE RESEARCH PARADIGM

A research paradigm is imperative when carrying out research to provide a holistic view of the research and to help guide decisions (Guba, 1990; Scotland, 2012). A research paradigm consists of different ontological and epistemological approaches with different viewpoints of the nature of reality and how knowledge is created. These perspectives determine what methodology and methods are used when conducting research (Scotland, 2012). Typically, there are three main research paradigms: positivism, interpretivism and pragmatism.

Positivism adopts the standpoint that “social phenomena and their meanings have an existence that is independent of social actors” (Bryman, 2012, p. 33) and one single reality exists in which we all live. Positivism is interpreted and applied by researchers in different ways and therefore can be hard to define (Bryman, 2012). However, in general, positivism is an objective standpoint with the belief that only one reality exists. This approach is more often associated with quantitative research rather than qualitative research. The approach recognises that “objects in the world have meaning prior to, and independently of, any consciousness of them” (Crotty, 1998, p. 27). The approach seeks to uncover knowledge through identifying causal relationships and adopts the perspective that only scientific evidence reflects true knowledge which is learnt through individual’s direct experiences, observations, and measurements (Creswell, 2013).

Interpretivism is an alternative viewpoint, informed by philosophies such as hermeneutics and phenomenology that aim to understand human nature from the perspective of the participants through their lived experiences. Interpretivism considers that “social phenomena and their meanings are continually being accomplished by social actors” (Bryman, 2012, p. 33) and that multiple realities exist. The approach seeks to construct knowledge by understanding and describing human nature and human interactions within the historical and social context in which they live. The perspective of interpretivism is that the social world can only be understood by the individuals experiencing it and places emphasis on understanding social phenomena from the individual’s perspective (Creswell, 2009). Interpretivism is typically inductive allowing the collection of data to determine the research findings rather than deductive (often associated with positivism) in which testing of hypotheses directs the data collection.

Pragmatism falls in between positivism and interpretivism and is the paradigm chosen for this research. Pragmatism adopts a standpoint that reality is constantly changing and being redefined depending on the situation and can be defined as “a deconstructive paradigm that debunks concepts such as ‘truth’ and ‘reality’ and focuses on ‘what works’ as the truth regarding the research questions under investigation" (Tashakkori & Teddlie, 2003, p. 713). Pragmatists believe that research can take place in a variety of social, historical, and political contexts and argue that the use of either qualitative or quantitative methods or the combination of both methods should be based upon the aims of the research and not purely on epistemological views (Cherryholmes, 1992; Johnson & Onwuegbuzie, 2004).

Pragmatism was chosen for this research because it enabled different viewpoints, methodology and methods to be adopted based on what worked best for each stage of the development of the QOL-ACC descriptive system, rather than being influenced by an epistemological viewpoint. The development of the QOL-ACC descriptive system required several stages of development (each with different aims), and it would not have been practical to adopt one type of research methodology or method for all these stages.

5.3 METHODOLOGICAL APPROACH

There are two main methodological approaches to data collection: quantitative (associated with positivism) and qualitative (associated with interpretivism). A quantitative approach develops knowledge through scientific methods of examining relationships between variables to develop theories and answer research questions and test hypotheses. It mostly involves gathering, observing, analysing, and interpreting numerical data to test hypotheses and identify patterns within the data through statistical procedures by comparing variables (a factor in the research that can change) by identifying how the independent variables impact upon the dependent variable (Teddlie & Tashakkori, 2009). Quantitative data collection is structured with the researcher being independent from the study participants. Methods for data collection involve primary data, e.g., surveys/questionnaires with closed questions (face-to-face, postal, online) and/or analysis of existing (secondary) data (Bryman, 2012).

In contrast, qualitative approaches are non-numerical in nature and adopt an in-depth approach to understand the social phenomena in question through identifying why and how rather than how much and how (Guest et al., 2013). A qualitative approach aims to explore and interpret meanings that individuals or groups of individuals apply to a given social context or problem aiming to understand the social world from the individual's perspective rather than from any meanings or theories a researcher may already hold (Creswell, 2009; Silverman, 2013). Data is collected directly from participants in a natural environment to allow the researcher to gain an in-depth insight and understanding of the individuals/groups' behaviour and interactions to interpret meanings to develop patterns to provide a deep understanding of the topic (Guest et al., 2013). The usual methods of qualitative data collection consist of in-depth interviews, focus groups, observations, document analysis and open-ended questionnaires.

Qualitative approaches are common in many disciplines such as sociology, health, and education but are not often associated within the field of health economics which has traditionally operated as a quantitatively focused discipline. However, qualitative methodology is becoming more common in health economics with several outcome measures being developed using qualitative methods such as the HRQoL measure for children (CHU9D) (Stevens, 2010), and the ICECAP suite of measures for adults and older people (Al-Janabi et al., 2012; Grewal et al., 2006).

The development of the QOL-ACC descriptive system adopted a mixed methods approach combining both quantitative and qualitative research methodologies. Johnson et al. (2007) defines mixed methods as research that "combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the purposes of breadth and depth of understanding and corroboration." (p. 123). Since the late 1980s and early 1990s, using both quantitative and qualitative methods have gained popularity, with researchers recognising that one methodological approach is not always sufficient to address research questions (Cresswell & Plano Clark, 2011).

Adopting a mixed methods approach in research is common in many disciplines, for example, studies in the field of sociology often combine quantitative and qualitative approaches to explore research problems. However, application of a mixed methods approach is a relatively new phenomenon in the discipline of health economics which has traditionally operated as a quantitative research focused field. Consequently, established preference-based measures (e.g., the EQ-5D-3L that was originally developed in the early 1970's) were developed using quantitative approaches from existing research studies and literature (Coast & Jackson, 2017). More recently, health economists have recognised the importance of qualitative approaches to develop preference-based measures to inform the later quantitative stages of research. For example, the content of the descriptive systems of the ICECAP-O, ICECAP-A and the CHU9D were developed from qualitative interviews with the population of interest prior to the quantitative stages of the development being undertaken (Al-Janabi et al., 2012; Grewal et al., 2006; Stevens, 2010).

A major advantage of adopting a mixed methods approach rather than solely a quantitative or qualitative methods is that a mixed methods approach increases the generalisability of the findings to the wider population (Gibson, 2017). Qualitative data methods produce a rich and contextualised insight into the research domain, but often the sample size is small, and therefore, the findings may be less generalisable than quantitative data that tends to generate larger samples (Gibson, 2017; Johnson & Onwuegbuzie, 2004). Using mixed methods enables the rich contextual data from the qualitative approach to be combined with the larger generalisable quantitative data to increase the findings relevance to the wider population (Johnson & Onwuegbuzie, 2004). This advantage of using a mixed methods approach was particularly relevant to this research because the overall aim is to develop the descriptive system of the QOL-ACC measure. The intention is for the QoL-ACC measure to be used with older people, and therefore it is imperative that the methods adopted increase the measure's generalisability and relevance to this wider population.

A mixed methods approach was also chosen for this research because the QOL-ACC consists of several stages of development, each with different aims. Therefore, different methods of data collection (quantitative and qualitative) were required at specific development stages to achieve these aims. The aims of each development stage along with the methods adopted and reasons for the methods chosen will be discussed in the following section.

5.4 METHODS

5.4.1 The Qualitative data approach (Stages 1,2,3)

The development of the QOL-ACC descriptive system adopts a bottom-up approach by involving older people receiving aged care services in the community from its inception. Typically, preference-based measures in the field of health economics have been developed using a top-down approach, that is an approach that is based on expert opinion and/or drawing on the literature (Coast & De Allegri, 2017; Stevens & Palfreyman, 2012). However, a major strength of adopting a bottom-up approach rather than a top-down approach is that it facilitates face and content validity, ensuring that the QOL-ACC consists of appropriate language and content that represents QoL from the perspective of older people receiving aged care services in the community. Indeed, Stevens and Palfreyman (2012) highlight that whilst the top-down approach has traditionally been utilised as the most common approach to develop most descriptive systems for preference-based measures to date, the bottom up approach is recommended as the preferred approach in all stages of measure development to increase the validity, acceptability, and reliability of the descriptive system.

The aim of the first development stage of the QOL-ACC was to understand and describe QoL from the perspective of older people through their lived experiences. Therefore, in-depth semi-structured interviews exploring what QoL meant to older people and what characteristics were important to experience a good QoL were undertaken to identify the salient dimensions. The aim of stage two was to develop draft items for each of the dimensions identified from stage one. Stage two involved the project advisory group (comprising members of the research team (n=7), aged care partners (n=2), and one consumer representative) examining the stage one data during a workshop to develop draft items for each of the dimensions based upon the words and phrases that older people had adopted. The aim of stage three was to test the face validity of the draft items (developed in stage two) for the QOL-ACC descriptive system with older people. Thus, semi-structured interviews were conducted to explore older people's views of the draft items to understand how older people interpret the items relative to their own experience of QoL.

Interviews can be structured, semi-structured and unstructured. Structured interviews consist of a prepared interview schedule that consists of pre-defined questions that are asked by the interviewer to each interviewee in the same sequence. In this type of interview there is no room to deviate from the interview schedule to explore other aspects that may arise in the interview. Unstructured interviews consist of a domain under investigation but do not involve specific questions, allowing the interviewer to explore the topic in-depth and to discuss other aspects that may arise during the interview (May, 2011).

Semi-structured interviews consist of an interview schedule with a series of open-ended questions based on the topic, but the interview is flexible as the researcher is able to ask additional questions, to prompt the participant to explore the subject in more detail, and to discuss any other relevant material arising during the interview (Bryman, 2012; May, 2011). The main advantage of a semi-structured interview is that it allows the researcher to direct the participant to the topic and to stimulate the participant's thoughts and beliefs around the subject which is not possible in an unstructured interview (Stevens, 2012). Semi-structured interviews have been successfully used in previous research exploring the QoL of older adults (King et al., 2012; Hendry & McVittie, 2004; Puts et al., 2007), and were chosen for the first development stage of the QOL-ACC to enable QoL to be discussed in detail and meanings behind participants' responses to be explored to gain a rich in-depth insight into older people's QoL. This stage required rich data in order to understand what was important to older people to experience a good quality of life, in order to develop dimensions for the descriptive system. An alternative qualitative method such as observing participants would only create natural occurring data, and therefore would not have been suitable for developing the descriptive system (Stevens, 2012).

Semi-structured interviews were also chosen for stage three of the development of the QOL-ACC descriptive system to test the face validity of the draft items of the QOL-ACC descriptive system. The draft items were developed during stage two by the project advisory group by examining the qualitative data from stage one and were based upon the words and phrases that participants had used to describe the dimensions during the interviews. Face validity is an important stage in the development of a measure to identify whether the items are appropriate and relevant to the population that the measure is intended for (Holden, 2010). Typically, face validity is often based on the views of the developers of the measures and/or professionals (top-down approach) and not necessarily on the views of the people who will be using the measure (Wiering et al., 2017). However, a bottom-up approach is recommended in order to increase face validity by ensuring the items consist of appropriate language and represent what is intended (i.e., the QoL of older people receiving aged care services in the community), (Ratcliffe et al., 2017; Ratcliffe et al., 2019; Stevens & Palfreyman, 2012). Therefore, interviews were chosen to incorporate older people’s views into this important stage of development.

One-to-one Interviews were chosen as a method rather than focus groups (interviews with a group of 4-10 individuals at the same time) because it was important to gain an in-depth understanding of QoL. An in-depth understanding of a topic is easier to achieve through interviews than focus groups where some participants may speak less than others leading to disproportionate contributions (Cresswell, 2013). There is also more chance of bias in focus groups as sometimes participants may be influenced by what other individuals may say, thereby altering their individual opinions and views (Guest et al., 2017; Knodel, 1995). Furthermore, this research involved interviewing older people in receipt of aged care services in the community who may be less willing and/or able to take part in focus groups because this would involve travelling to a shared location at an agreed time which may not be feasible due to transport and mobility problems. Conducting interviews in the participant’s choice of location (usually their own home) is a more suitable option for an older person.

Furthermore, interviews were preferred, rather than focus groups because of the material that may arise during the interview. Discussing QoL may involve sensitive material to some participants, and an interview allows participants to discuss material that they may not feel comfortable discussing in a group setting (Guest et al., 2013). Additionally, according to May (2011) using interviews as a form of data collection enables a rapport to be built between the interviewer and interviewee which is imperative for this research to understand older people's QoL.

5.4.2 Quantitative data collection (Stages 4 and 6)

The aim of stage four of the development of the QOL-ACC was to identify which draft items of the QOL-ACC descriptive system (generated from stage one and stage three of the research) performed the best psychometrically. Psychometric assessment is an important stage in the development of a measure to determine which items perform the best psychometrically and has been used previously in the development of QoL measures (Keetharuth et al., 2018). The aim of stage six of the development of the QOL-ACC descriptive system was to test the construct (convergent and known group) of the QOL-ACC descriptive system (developed in stage 5 – see section 5.4.3) by performing statistical analysis on the survey data. In order to perform psychometric tests, a large number of respondents are needed which is why a survey was chosen as this is an appropriate method of data collection when large sample sizes are needed (Bryman, 2012; Creswell, 2009). It was planned for this data to be collected electronically through an on-line survey supplemented by hard copy surveys for older people without regular access to the internet. Due to the large sample needed to conduct the psychometric testing it would not have been viable to collect all of the data face-to-face due to budget and time constraints. Additionally, COVID-19 restrictions at the time of data collection prevented any data from being collected face-to-face, and placed restrictions on hard copy survey distribution (due to concerns about the possibility of COVID-19 being transmitted through material surfaces) and therefore, this data was collected via an Australia-wide online panel company who had an existing membership of older people who were accessing aged care services in Australia.

5.4.3 Combining the qualitative and quantitative data (stage 5)

The aim of stage five was to identify the final items for the QOL-ACC descriptive system by combining the data from stage three and stage four. This approach was chosen because combining the use of qualitative and quantitative methods provides a richness of data that cannot be produced by solely one approach and a mixed methods approach has also been used previously to develop measures. For example, the AQOL measure was developed using mixed methodology (Hawthorne et al., 1999). However, often the use of the two approaches is not reported in detail (Keetharuth et al., 2018, Brazier et al., 2012). When the use of mixed methods is reported, it is usually sequential (the qualitative and quantitative methods are separate stages) rather than simultaneously (combining the quantitative and qualitative data) in measure development (Bryman, 2006).

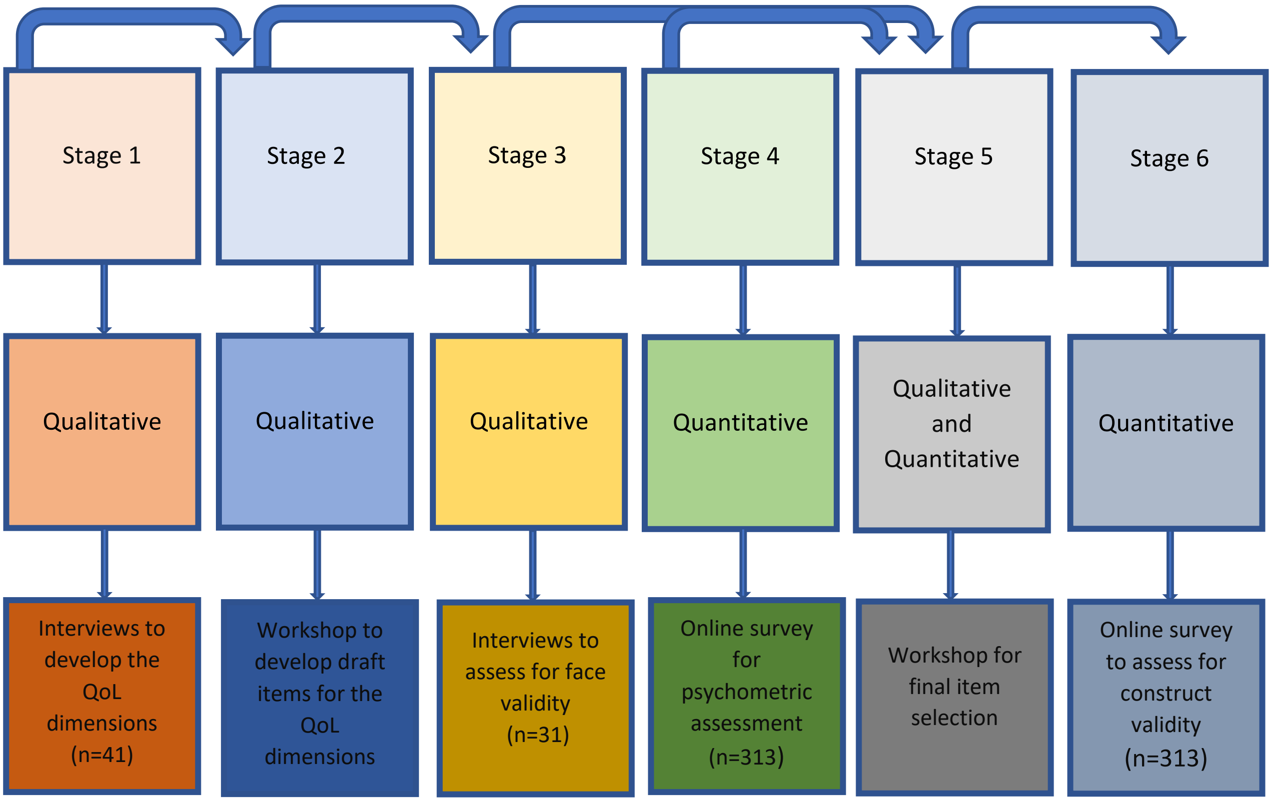
Combining quantitative and qualitative methods simultaneously was used successfully by Keetharuth et al. (2018) in the development of the Recovering Quality of Life (ReQoL) measure that is designed for use in mental health populations. The ReQoL measure was developed using a combination of qualitative methods (focus groups and interviews) and quantitative methods (survey) which was psychometrically analysed. The combined data was presented using a pictorial traffic light approach, in a workshop, to a group of service users, clinicians and researchers who decided on the final item selection of the measure based on the evidence presented. Keetharuth et al. (2018) recommend this approach (combining quantitative and qualitative data simultaneously) to be used to develop other outcome measures. Therefore, a similar approach to Keetharuth et al. (2018) was chosen for stage five of the development of the QOL-ACC (identifying the final items for the descriptive system). A traffic light pictorial approach was adopted to simultaneously combine the quantitative data from stage four and the qualitative data from stage three to ensure that the items chosen were psychometrically robust whilst also being acceptable and relevant for older people receiving aged care services in the community. This approach is discussed in more detail in Chapter 7.

5.4.4 The mixed method sequential approach

Adopting both quantitative and qualitative methods of data collection in a chronological order is known as a mixed method sequential approach and is associated with modern research where the decision to combine two approaches is pragmatic. As mentioned previously, stage one, stage two and stage three of the development of the QOL-ACC descriptive system adopted a qualitative approach (semi-structured interviews) which was followed by a quantitative data approach for stage four (online survey), a mixed methods approach for stage five (combination of data from stage 3 and stage 4), and a quantitative approach for stage six (online survey). Figure 5.1 provides an overview of the pragmatic research paradigm adopted to develop the QOL-ACC descriptive system.

Figure 5.1

The pragmatic research paradigm for the development of the QOL-ACC descriptive system



Stage one (in-depth semi-structured interviews) was entirely independent with the research questions, data collection and analysis to identify the dimensions for the QOL-ACC separate to the other stages of the research. However, the data from stage one (in-depth semi-structured interviews) was used to create the draft items (stage two). The draft items created in stage two informed stage three (semi-structured interviews to test for face validity) of the research.

Stage three was partially interactive with stage four, with the analysis of stage three data (semi-structured interviews to test for face validity) being combined with the analysis of stage four data (online survey) for the final interpretation of the items for the QOL-ACC descriptive system. This approach is known as data triangulation and is where more than one source of data is combined to provide a comprehensive understanding of the research allowing for multiple realities to be considered (Johnson & Onwuegbuzie, 2004). Stage six (online survey to test for construct validity) was partially interactive with stage three (online survey) because although the data analysis was separate for each of these stages, the sample used to analyse the data for stage three and six was the same sample.

5.5 CONCLUSION

To conclude, a pragmatic paradigm was chosen for this research to enable a mixed methodological approach to be adopted to achieve the different aims of each stage of the research. The development of a descriptive system for a preference-based measure requires several different stages of development, and it would not have been practical to adopt one type of methodological approach or data collection method for all the stages. The following three chapters will outline the development stages of the QOL-ACC descriptive system. Chapter six presents the results of the in-depth semi-structured interviews undertaken with older people in receipt of aged care services to identify the salient QoL characteristics. Chapter 7 presents the results from the semi-structured interviews to test the face validity of the draft items, and the results from the psychometric analysis of the online survey data. The integration of the findings of the qualitative data (face validity interviews) and the quantitative data (online survey) are outlined to select the final items for the QOL-ACC descriptive system. Chapter 8 presents the results from the online survey data to test the construct validity (convergent and known group) of the QOL-ACC descriptive system.

6. DEVELOPING DIMENSIONS FOR THE QOL-ACC

This chapter contains material from:

Cleland, J., Hutchinson, C., McBain, C., Walker, R., Milte, R., Khadka, J., & Ratcliffe, J. (2020). Developing dimensions for a new preference-based quality of life instrument for older people receiving aged care services in the community. *Quality of Life Research, 30*(2), 555-565.

6.1 INTRODUCTION

This chapter discusses the methodology and framework used to understand older people's perceptions and views about QoL. It presents the analysis and results from the qualitative research undertaken to identify the key characteristics that are important for older people to experience a good QoL. As outlined previously, the overall purpose of the research is to develop the descriptive system for a new measure amenable to preference-based scoring to measure the QoL of older people in receipt of aged care services in the community. The QOL-ACC is unique in the fact it uses a bottom-up approach to develop the descriptive system using older people's values and beliefs of what is important to them to have a good QoL rather than relying on existing measures that tend to be based on adults (not older people specifically) and have mainly been developed using expert opinion and/or drawing on the literature. A major strength of adopting a bottom-up approach rather than a top-down approach incorporating older people's perspectives on QoL from the outset is that it facilitates face and content validity, ensuring that the final developed measure will consist of appropriate language and is reflective of the most appropriate content for describing and capturing QoL from the perspective of older people in receipt of aged care services in the community.

6.2 METHODS

6.2.1 Recruitment

Ethical principles must be considered and adhered to when conducting any research (Silverman, 2013). Ethical approval for this project was granted from the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University (Project no. 8399). Participants were recruited from the five partner aged care organisations across four states: ECH and Helping Hand (South Australia) Uniting AgeWell (Victoria and Tasmania), Uniting (New South Wales) and Presbyterian Aged Care (New South Wales). All five organisations provide aged care services in the community.

Participants were recruited using purposive sampling. Purposive sampling is a form of non-probability sampling where the sample is selected to be representative of the population (Cresswell & Plano Clark, 2011; Patton, 2015). This method of sampling was chosen to ensure the sample was broadly representative of older people in Australia receiving HCPs, thereby maximising the validity of the sample. The five partner aged care organisations were provided with the eligibility criteria and an overview of the demographics of older people in Australia receiving HCPs (age, gender, HCP level) who then recruited using this criterion enabling the sample to be broadly representative. Participants were recruited based on the following selection criteria:

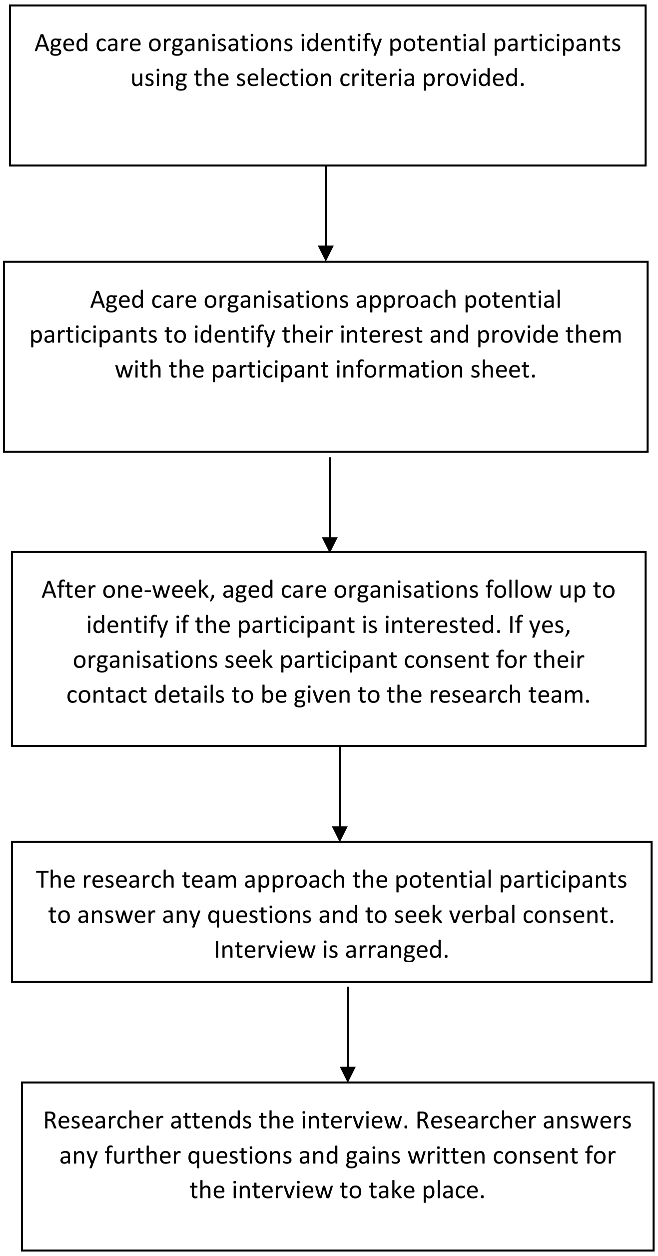
- Aged 65 years and over
- In receipt of a HCP (Level 1-4)
- Ability to speak English

- Normal cognitive functioning through to mild cognitive impairment/mild dementia (assessed by the aged care organisation using the Psychogeriatric Assessment Scale Cognitive Impairment Scale (PAS-Cog)) (Jorm et al., 1995).
- Ability to provide informed consent

Figure 6.1 outlines the recruitment process. The partner aged care organisations identified potential participants using the above selection criteria and approached the individuals to ask if they were initially interested in the research study. If the potential participant was interested, the provider gave them a participant information sheet to read (Appendix 3). The participant information sheet provided a description of the research, information about the recruitment process, confidentiality, and the right to withdraw. It also included contact details of the research team if the participant wanted to find out more information. After one week of receiving the participant information sheet, the organisation approached the potential participant to ask if they were interested in taking part in the research. If the participant was interested, they were asked to give verbal consent for their name and telephone number to be passed to the research team. Once the contact details of the participant were given, a telephone call was made to the potential participant to ask if they were still interested in taking part in the research and to answer any potential questions before an interview was arranged. The interview took place in the participant’s home. Prior to the interview taking place, any questions the participant had were answered and written consent was provided before the interviews commenced (Appendix 4).

Figure 6.1

Flow chart of the recruitment process for stage one of the development of the QOL-ACC descriptive system



6.2.2 Interviews

Five pilot interviews in South Australia were conducted to test the appropriateness of the questions used, to ensure the participants understood the nature of the questions and to test the structure of the interview. All five interviews were conducted successfully with no alterations or changes needed. Therefore, the five pilot interviews were included in the total interviews. Forty-one semi-structured interviews were conducted. I conducted 22 interviews and a research assistant based at the University of Sydney conducted the remaining interviews. A target sample size of 40 was chosen based on previous literature that suggests data saturation is present with this sample size with no new themes or ideas tending to arise after 40 interviews (Guest et al., 2006; Hagaman & Wutich, 2017). Participants were given the option to choose the location of the interview, and all participants chose to be interviewed in their own home. This choice of location was preferable as it was easier to ensure privacy and confidentiality in a private dwelling rather than a public place.

Prior to the interview commencing the interviewer ensured that the participant had read the participant information sheet and was given the opportunity to ask any questions. Once the interviewer was satisfied the participant fully understood the nature of the research, they were asked to read the participant consent form and both the participant and interviewer signed the consent form. Where the participant was unable to read due to impaired vision the interviewer read the consent form out loud to the participant. All interviews were audio-recorded with the permission of participants, to enable transcription.

The interview was structured into three sections (see Appendix 5 for the interview schedule). The first section consisted of open-ended questions about QoL in general to explore the meanings around the term QoL and the characteristics that were important to have a good

QoL. These open-ended questions enabled the interviewer to probe factors and issues relating to QoL in general. The participant was also asked questions relating to the aged care services they were receiving to understand the type of support they were receiving and whether this support impacted upon their QoL.

The second part of the interview consisted of a ranking cards exercise (Appendix 6). The participant was presented with 12 cards which each displayed a QoL characteristic (independence, safety, social relationships, hearing, vision, mental health, sleep, physical mobility, self-care, dignity, control, pain). These characteristics were based on a previous research study undertaken by Ratcliffe et al. (2017) who developed the cards from the content of the EQ-5D, ASCOT and AQoL (commonly used QoL measures) to compare younger and older people's preferences of QoL.

The participant was asked to place the cards independently in order from most important to least important and to discuss each of the cards and explain their choice of ordering. This enabled the interviewer to probe the participant about different characteristics of QoL and enabled a more in-depth discussion to understand the different characteristics that define QoL for older people and their relative importance to the individual's own QoL. The participant was asked if any cards were not important and should not be included and whether they thought any QoL characteristics were missing from the cards and should be included.

If participants were visually impaired the interviewer read the cards out loud to the participant. If any participants struggled with the task and were unable to rank all 12 cards the interviewer asked them to choose the three most important cards and a discussion was initiated around these characteristics. This part of the interview concluded with the researcher asking if there was anything else that the participant wanted to discuss about QoL that had not already been discussed. This enabled the participant to add any further thoughts and beliefs about QoL that they may not have discussed in the earlier stages of the interview.

The final part of the interview involved the participant completing the EQ-5D-5L, a widely used generic preference-based QoL measure (Herdman et al., 2011) (Appendix 7), and a short socio-demographic questionnaire (Appendix 8). The interview duration ranged from 21 to 69 minutes (mean = 33 minutes).

6.2.3 Data Analysis

All the interviews were sent to an approved Flinders University transcriber and were transcribed verbatim. Prior to the interview being transferred to the transcriber any personal identifiable details were removed and the interviews were given unique ID numbers to ensure confidentiality. All interview transcriptions were entered onto the qualitative software package NVivo Version 12 (QSR International Pty Ltd, 2018). NVivo is an efficient method of storing large volumes of interview data. The package enables codes for the data to be created, merged, split, and rearranged to enable in-depth coding to assist themes to be identified across the data. It also allows for multiple individuals to code the data increasing the accuracy of coding and analysing the data. NVivo is less time consuming than coding and analysing the data by hand, particularly when there are large volumes of data to be analysed (Houghton et al., 2017; Zamawe, 2015).

Framework Analysis

The interviews were analysed using the framework analysis approach. Framework analysis was developed as a response to the growth of qualitative research being undertaken in the social policy field and was initially developed for large-scale policy research in the United Kingdom at the National Centre for Social Policy Research in the 1980s (Ritchie & Spencer, 1994). This approach was used for a variety of research projects using different qualitative methodological approaches such as face-to-face interviews, focus groups and case studies.

Framework analysis is not associated with a specific theoretical framework and is suitable to be used in deductive analysis (where themes and codes are pre-determined in the analysis stage based upon a theoretical framework, previous literature, or expert opinion) and inductive analysis (where codes are developed as the analysis progresses and then consolidated into themes) (Gale et al., 2013). Since its development, framework analysis has been widely used in health and medical research (see Heath et al., 2012; Murtagh et al., 2006; Pickup et al., 2015).

Framework analysis is like thematic analysis and content analysis which are often seen as one approach rather than two separate approaches because of the similarities they share (Sandelowski & Leeman 2012; Vaismoradi et al., 2013). Content analysis is a descriptive approach that uses codes and categorises themes by quantifying the frequency of the codes and categories and meanings behind these patterns using a systematic approach. Thematic analysis, whilst similar is more of a qualitative approach that involves the researcher closely identifying themes and patterns arising from the data to create meaning and understanding to explore the phenomenon (Marks & Yardley, 2004: Vaismoradi et al., 2013). However, they share the same common objective to draw out common themes and patterns emerging from the data, and to identify meaning and reasons behind these themes (Gale et al., 2013). Framework analysis is like thematic analysis but is seen as more rigorous and transparent approach. The approach consists of several stages to develop themes and allows the researchers to view the data at different levels of abstraction and for the process of developing the themes to be documented throughout the analysis (Ritchie et al., 2014). Framework analysis was chosen to analyse the data for several reasons. Firstly, the focus of this research is QoL, and framework analysis has previously been applied successfully in QoL research. For example, Connell et al. (2012) identified QoL domains important to adults with mental health problems using framework analysis and Markham et al. (2009) used the approach to investigate the QoL of children with communication and speech impairments. Hill et al. (2014) addressed the QoL of children and adolescents with the health condition Osteogenesis Imperfecta, and Gorecki et al. (2012) examined the impact that pressure ulcers have on an individual's QoL using a framework approach.

Secondly, this method has also been used in QoL research that has developed QoL measures. Stevens (2010) used framework analysis to analyse interviews to understand how health impacted upon the QoL of children to develop the domains for the Child Health Utility measure (CHU9D), a paediatric preference-based HRQoL measure for children. Thirdly, framework analysis is suitable for research with a specific sample and clear objectives from the start. This aligns with the objective of developing dimensions for the QOL-ACC descriptive system (Ritchie & Spencer, 1994).

Finally, framework analysis is a comprehensive and rigorous approach that involves several systematic stages which provides a framework structure in which data can not only be compared within cases but also across cases which is imperative when analysing qualitative data (Gale et al., 2013). It is also transparent as each stage is clearly documented allowing for other people/researchers to visibly identify how the domains were developed for the QOL-ACC descriptive system.

According to Ritchie & Spencer (1994), framework analysis consists of five stages which are outlined below with details of how the research was analysed for each stage using this approach.

1. **Familiarisation**

   Familiarisation involves the researcher fully immersing themselves in the data to become familiar with its content to interpret the key findings emerging from the data by reading and re-reading transcripts.

   A research assistant at the University of Sydney and I both read the interview transcripts. We read and re-read our own interview transcripts and each other's interview transcripts to become familiar with the content of the data and to acquire an impression of the main themes emerging. This was particularly important as the interviews had been outsourced for transcription and therefore, we could not become familiar with the data through doing the transcriptions ourselves.

2. **Identifying a theoretical framework/coding**

   This stage involves extracting, conceptualising, and studying the data to identify the key themes and concepts emerging from the data.

   I open coded all of the interviews and the interviews were also open coded by a research assistant at University of Sydney to ensure that all of the relevant data was captured and classified, and codes retained the language of the participants. Open coding is where codes are developed from the words and meanings in the data and are not based on pre-determined codes. During the coding process, codes were applied to all of the data using a code to describe what I had interpreted as important and relevant to the topic of QoL. I met with the research team to analyse the data by examining and grouping together coded data into common *themes that were emerging from the data. For example, open codes such as 'happiness/contentment', 'humour', 'loneliness', 'loss', 'remaining in own home', 'worry' were grouped into the code of 'emotional wellbeing/psychological/worry'.*

This stage resulted in the following final codes being developed; 'independence-supported independent living' 'independence-control/decisions', 'physical health - mobility with aids', 'physical health- adapting to change', 'social connectedness- paid carers', 'social connectedness – family/friends connected', 'social connectedness-family/friends disconnected', 'activities-social connectedness', 'activities-keeping busy/active', 'activities-role continuity', 'activities-mental engagement', 'loss of activities', 'emotional wellbeing/psychological/worry'.

3. Indexing

Indexing involves categorising the data by themes using the final codes. All quotes from the data relating to the final codes (from the previous stage) are put together into a word table under each code to enable the data to be grouped by themes.

The data was categorised into the codes that had emerged from the previous stage by developing a Microsoft word table with quotes from the older people aligning with each code to enable the data to be identified into each theme. For example, all quotes from the participants relating to the code of 'social connectedness-paid carers' were put together under this code to enable the data relating to this theme to be identified clearly.

4. Charting

Charting requires the data to be summarised for each participant into a matrix so that the data is condensed and easily understandable. The summary data is created by identifying the quotes from the previous stage and interpreting and summarising the quote into a chart against each theme by each participant so the data can still be linked to each participant as well as to each theme.

A matrix was created in Excel that summarised the data by themes identified in the previous stages whilst still maintaining the link between the data and each participant. For example, under the theme 'supported-independent living', the data for participant 14 included was 'being independent is important to her as she doesn't want to rely on other people to do things for her'.

5. **Mapping and interpretation**

This final stage involves looking at the documents produced during the indexing and charting to help the researchers to understand the data and to support data synthesisation.

A one day workshop took place where I met with the research team to explore all of the data that I had charted and indexed. The research team and I examined the data, and we consolidated the themes to identify the main characteristics of QoL emerging from the analysis and to explore the relationships between the QoL themes. The process identified the key themes from this process which resulted in five dimensions being created from the key themes to be included in the next stage of the research. The themes of 'supported independent living' and 'control/decisions' were combined into the dimension of ***'independence'.*** *The themes of 'physical health - mobility with aids' and 'physical health- adapting to change' were combined into the dimension of* ***'mobility'.*** *The themes of 'social connectedness- paid carers', 'social connectedness – family/friends connected', 'social connectedness-family/friends disconnected' were combined into the dimension of* ***'social connections'****. The themes of 'activities-social connectedness', 'activities-keeping busy/active', 'activities-role continuity', 'activities-mental engagement', 'loss of activities' were combined into the dimension of* ***'activities'.*** *The theme of* *‘emotional wellbeing/psychological/worry’ remained as one theme and created the dimension of* ***‘emotional wellbeing’****.*

Statistical analysis

SPSS (version 25.0) (IBM Corp, 2017) was used to analyse the socio-demographic data to produce simple frequencies and percentages. The utility values for the EQ-5D-5L were calculated using the Australian pilot scoring algorithm that produces scores from -0.676 to 1 (Norman et al., 2013). The final Australian scoring algorithm is currently being developed.

6.3 RESULTS

6.3.1 Participant characteristics

Forty-one interviews were completed with older adults aged 68 to 95 years old (mean age of 83 years) (Table 6.1). Four participants chose to have a family member present during the interview. The family members did not formally participate in the research or influence the participant’s response in any way. Approximately three-quarters of the sample were female (73.2%) with the majority of participants born in Australia (68.3%). Most of the older adults lived alone (63.4%) with just under a third (29.3%) living with their spouse or partner. A quarter of older people interviewed (24.4%) had completed high school and just over a third (34.1%) had completed a degree.

Table 6.1

Stage one participant characteristics and the Australian home care population

Study Participants	***n* (%)**	**Australian Home Care Population**[a]	**%**
Gender, *n* (%)		Gender (%)	
Male	11 (26.8)	Male	34.4
Female	30 (73.2)	Female	65.6
Age, *n* (%)		Age, (%)	
65-79	12 (29.3)	65-79	34.5
80-89	21 (51.2)	80-89	47.0
>90	8 (19.5)	>90	18.5
Mean (SD)	82.8 (6.37)		
Range	68-95		
Country of birth, *n* (%)			
Australia	28 (68.3)		
UK	8 (19.5)		
Other	5 (12.2)		
Highest Educational Qualification, *n* (%)			
No qualifications	9 (22.0)		
Completed High School	10 (24.4)		
Undergraduate/professional qualification	14 (34.1)		
Postgraduate qualification	3 (7.3)		
Other	5 (12.2)		
Living arrangements, *n* (%)			
Living Alone	26 (63.4)		
Living with spouse/partner	12 (29.3)		
Living with other relatives	2 (4.9)		
Living with others (not relatives)	1 (2.4)		
Home Care Package level, *n* (%)		Home Care Package level, (%)	
Level 1 (basic care needs)	2 (4.9)	Level 1 (basic care needs)	11.5
Level 2 (low care needs)	19 (46.3)	Level 2 (low care needs)	41.3
Level 3 (intermediate care needs)	8 (19.5)	Level 3 (intermediate care needs)	20.6
Level 4 (high care needs)	12 (29.3)	Level 4 (high care needs)	26.6
Number of hours of support per week			
Mean (SD)	4.2 (3.00)		
Range	1-15		
Self-reported health, *n* (%)			
Excellent	2 (5.0)		
Very Good	4 (10.0)		
Good	19 (47.5)		
Fair	12 (30.0)		
Poor	3 (7.3)		
EQ-5D-5L Score, mean (SD)	0.56 (0.28)	EQ-5D-5L Score, mean (SD)[b]	0.85 (0.16)
EQ-VAS Score, mean (SD)	66.88 (18.46)		

Note. Source: [a] AIHW (2020b); [b] McCaffrey et al. (2016).

The most common HCP package was level 2 with nearly half of participants (46.3%) receiving this level of care. Participants reported they were receiving an average of 4.2 hours of support per week. Two participants rated their health as 'excellent' with the majority rating their health as 'good' (47.5%) or 'fair' (30.0%). Participant's HRQoL as approximated by the EQ-5D-

5L using the Australian general population specific scoring algorithm was on average significantly lower (mean 0.56, SD 0.28) than for the general population of similar age range (mean 0.85, SD 0.16) (McCaffrey et al., 2016). This finding was not unexpected given that the sample comprised dependent older people in the community receiving aged care services. The sociodemographic characteristics (age and gender data only available for comparison) and the distribution of HCP levels across the study sample are broadly representative of the population of older people currently receiving HCPs in Australia (AIHW, 2020b).

6.3.2 Dimensions

The qualitative analysis adopting the framework analysis approach resulted in five main dimensions being identified (Figure 6.2).

Figure 6.2

The dimensions identified in stage one of the development of the QOL-ACC descriptive system

Independence: Living the life you choose and making your own decisions.

Mobility: Being able to get to the places you need or want to go to (indoors and outdoors), using mobility aids if you use them.

Emotional wellbeing: Living your life without sadness, worry or stress.

Social Connections: Having social relationships e.g., with family and/or friends and connections to the community.

Activities: Spending time doing things you enjoy, whether alone or with other people.

The following sections outline the evidence for each of the five QoL dimensions emerging from the analysis.

Independence

The importance of being independent was identified by all participants as a key attribute of their QoL:

> *I think quality of life to me means everything. It means independence, to be in charge of yourself.* (Participant 24, female, 76 years)
>
> *Quality of life? Yes, well, that means to me that I still have independence.* (Participant 15, female, 91 years)

Most participants spoke about their desire to retain their own independence during the ageing process by continuing to do as much as possible for themselves; "*It's important that I can live on my own as long as possible and look after myself"* (Participant 10, female, 83 years). When talking about independence, participants often referred to making their own decisions and being in control of their own lives as an important component of independence:

> *Well, I like having control over what I do. I don't want to have people telling me what to do.* (Participant 18, male, 78 years)
>
> *We are independent…we definitely choose what we want to do.* (Participant 4, female, 78 years)

Being in control and making their own decisions was of particular importance as participants wanted to retain control over their own lives and minimise their reliance on other people; "*I'm independent. I don't rely on anybody"* (Participant 8, female, 83 years). Conversely, some participants spoke about their loss of independence and shared their frustration of having to rely on other people to do things for them:

> *The worst thing about getting old, is your lack of independence. I have to rely on somebody to take me to places, which I don't like. I mean I know that there is some help available, but it does interfere with your independence.* (Participant 2, female, 87 years)
>
> *I'm a person who's always tried to be very independent and it's been very hard to ask people for help.* (Participant 9, female, 91 years)

However, other participants acknowledged the need to accept help whilst retaining their independence:

> *Well, I like to be independent. I like to be able to look after myself as much as possible, but it is nice to have the help when you feel that you can't…I mean I suppose I could really struggle along without any help, but it'd be a struggle.* (Participant 19, female, 83 years)

Many participants spoke about how much they valued the support they received from aged care services to help them to remain independent; "*My package of care has been marvellous. It's helped me stay independent and not lose control of my environment"* (Participant 31, female, 81 years). Some participants acknowledged they would not be able to remain at home without the support they currently received:

> *They [aged care provider] are extremely important in my life in enabling me to stay at home by helping me around the house, helping me if I want to go shopping. You know, I have a carer who goes with me, a support worker goes with me, and they just make life so much easier.* (Participant 34, female, 73 years)

Other participants were also grateful for help with various daily tasks and activities of daily living that they recognised that they had difficulties undertaking and/or were no longer able to do:

> *I had no idea how run down I was because I just took charge of everything and did everything and once these lovely people were coming and going and everything and all*

> *of a sudden, I could sit down and take a bit more time.* (Participant 37, female, 76 years)

> *It [aged care package] helps me a great deal because there's things that I can't manage now because of health restrictions so it gives me a peace of mind that I know my house is clean…also if I need assistance to go for medical appointments, I find that a great assistance because I'm not keen on driving great distances now.* (Participant 35, female, 76 years)

Mobility

Almost all participants spoke about their physical mobility and the limitations they experienced which impacted upon their QoL:

> *One quality of life that I miss is my mobility. That's being unable to walk very far. It's lack of ability that's the greatest lack that I have. I am constrained from doing what I want to do, you know, because physically I'm constrained, not mentally but physically.* (Participant 2, female, 87 years)

For many participants, these changes meant they had to find ways of adapting to continue to do everyday tasks or activities that they had previously enjoyed:

> *I've always been someone who exercised…I still exercise at home although at course I can't use the equipment that I used at the gym….I do exercises with my arms which I've sort of made up myself, but it's just to keep - you know, this sort of thing and that sort of thing…to keep myself mobile as long as I can.* (Participant 17, female, 85 years)

> *Physically when you go to do it you no longer can do it. Now, up until a couple of years ago I could walk around and do all different things, just took it for granted…What you can't do you have to find another way….I still shuffle on through the house and that's fine, painful but I deal with that…down the track if I can't and it just becomes too much, then I'll get things set up so that I can ride a wheelchair through and do everything…What I can't do now I'll find another way.* (Participant 3, female, 76 years)

However, some participants experienced more severe restrictions as a result of their decline in mobility which prevented them entirely from doing what they previously had enjoyed:

> *That's [mobility] a little bit difficult at the moment. Apart from the ankle I could get around all right but it's just a bit awkward now. As I say, I used to walk around the village every day. I can't walk properly now without pain.* (Participant 36, male, 84 years)

> *I've always gardened, and I was getting quite distressed because the garden had become completely overrun. I found I can't even – I can bend over but down goes the [head] so you don't do it.* (Participant 9, female, 91 years)

In general, most participants were accepting of changes to their mobility and accepted some limitations as a normal and inevitable part of the ageing process; *"I'm grateful that I can still move, although I've got to hang onto everything and I'm in pain all the time. It's just a matter of accepting"* (Participant 7, female, 82 years).

However, some participants indicated that they often still felt frustrated by their lack of ability to do what they wanted to do:

> *Well, that's really what worries me most, is the gradual diminishing of things that I've been able to do without even thinking about it and that is very irritating.* (Participant 2, female, 87 years)
>
> *My mobility I suppose is the biggest thing and not being able to use my hands because hands are essential for doing everything, well nearly everything, you have to do from day to day and not being able to do things without having to use two hands or not able to reach things. Just general everyday activities I find very difficult to do and if I had the use of my hands or better use of my hands, I would enjoy life a lot more, I would think.* (Participant 21, female, 68 years)

Many participants discussed the importance of their mobility aids such as scooters, wheelchairs, walking frames and walking sticks to help them get around and carry on doing the things they enjoyed. Mobility aids were often seen as essential to participants' mobility to maximise their QoL:

> *I can't get around very much on my feet. I have a stick and my walker so that's very important to me.* (Participant 3, male, 81 years)
>
> *I do take my walker with me and I'm forever leaving my walking – I'm not happy unless I've got something to support me.* (Participant 1, female, 92 years)

Emotional wellbeing

Many participants thought emotional wellbeing was important to their QoL:

> *I'm happy and happy is quality of life.* (Participant 18, male, 78 years)
>
> *Quality of life means that I don't have – well, I wish not to have a lot of worries.* (Participant 35, female, 76 years)

A large majority of participants also spoke about their emotional well-being including general feelings of worry, 'feeling down' and anxiety:

> *I do sometimes feel, not depressed but I feel a bit anxious about things.* (Participant 41, female, 84 years)
>
> *I might get a bit down but usually I'm okay.* (Participant 21, female, 68 years)

For some participants, these feelings were linked to the fear of having to leave their own homes and move into residential care as illustrated by the following participants:

> *That's one thing about ageing - and it's your family, you have to fight them. They could've pushed me into one [residential home] and I thought 'no, I'm not having this'…I don't want to just have to sit like the poor old things, they just sit. It worries the life out of me.* (Participant 9, female, 91 years)
>
> *I have the horrors about going into care… I don't know how I'd cope with that.* (Participant 33, female, 91 years)

Other participants spoke about experiencing depression because of their physical decline which meant they were no longer able to participate in activities or hobbies that they previously enjoyed. For example, one participant had developed depression after being unable to continue her hobbies:

> *When I first lost my sight, I went into depression and being a bright person that was disastrous, but it took me two years to accept that I couldn't – I was a dressmaker, I was a China painter, I did all sorts of fine crafts, taught fine crafts and then not to be*

> *able to do any of it, that was very – it took a lot out of me.* (Participant 12, female, 93 years)

Another participant shared their feelings about a decline in their physical health affecting their ability to do everyday activities:

> *I don't like being dependent on things. My ability to unscrew things for example, I can't do it. My fingers won't do it anymore. You know, my physical ability is just going slack. I worked very hard all my life, but I was strong and healthy and all that is diminishing. It's the diminishing that upsets me most.* (Participant 2, female, 87 years)

Other instances of anxiety and depression amongst participants were related to family disagreements and fallouts which had caused distress:

> *I do suffer with the anxieties, and I do get worried. Last year I became very depressed, just through other family members that tried to make our lives very difficult.* (Participant 37, female, 76 years)

Social Connections

Almost all participants spoke about being connected to family and friends and how good relationships with those close to them were important for them to experience a good QoL; "*You need a few good friends, and you need good family, supportive family, and also neighbours are important when you're so much at home"* (Participant 34, female, 73 years).

Family was especially important to many participants; "*My family is the most important thing…my family mean a lot to me"* (Participant 14, female, 85 years). Participants looked forward to contact with family (face to face and via the telephone) and valued their support:

> *I've got a sister still; she was 90 last week and I see her - well I don't see her as often but we're on the phone every other day.* (Participant 12, female, 93 years)
>
> *Quality of life? I've got the family. You know, I go and see the family quite a bit.* (Participant 38, female, 95 years)

Relationships with friends were also important for many participants:

> *Well, friends I think are important, very important.* (Participant 1, female, 92 years)
>
> *Social relationships are very important, and I like helping people. I like being with people and having intelligent conversations.* (Participant 19, female, 83 years)

Participants' contact with friends varied with some participants having daily contact:

> *I think [Names] now at number two, they are simply fantastic friends. I tell them what I do. I tell them my life history; they tell me their life history and I've never had such good friends…Normally I would see them on a daily basis.* (Participant 18, male, 78 years)

Other participants had less contact with their friends but still valued the benefits that their friendships brought to them:

> *It gives you company because even though we're in the village we don't run to one another's homes. We have our clubhouse up the top…we've got a lot of activities which keeps us out and about, so it gets us out of our villas, so it's good, that we have the company of other people.* (Participant 35, female, 76 years)

Several participants also discussed being disconnected from friends because their friends had passed away or entered residential care:

> *I've just lost a very dear friend. Seventy-five years we've been friends. That was only two weeks ago. It's hard to watch them go, you know.* (Participant 14, female, 85 years)
>
> *Most of my friends have died anyway and two are in nursing homes, one in Victoria. The rest of them have gone.* (Participant 1, female, 92 years)

Other participants spoke about being disconnected from friends due to health impairments. For example, one participant spoke about how her lack of hearing prevented her from participating in social activities with her friends:

> *I'm as deaf as a post…I haven't joined anything because a couple of Sundays ago a lady up here said 'come to church me with me'…I couldn't hear the pastor… and then they had morning tea afterwards and she said 'oh, this is so and so and so and so' and I watched their mouths move…I couldn't hear them, couldn't hear a word. It was terrible and I get so embarrassed, and they lose interest and move off. I was so glad to get home, you know, it was unbearable…I've got no social life without it [hearing].* (Participant 8, female, 83 years)

Several other participants spoke about being disconnected from their friends due to transport issues or they didn't feel comfortable going out on their own as illustrated by the following participants:

> *It's limited [friendships] because I have to get someone to drive me wherever I go.* (Participant 15, female, 91 years)
>
> *I used to go on bus trips and all that kind of thing but now I just can't get up into the buses so I had to give that away. Then our dinner nights, I liked going to them too but then it's walking home in the dark and I'm frightened.* (Participant 38, female, 95 years)

Participants were also sometimes disconnected from family, mainly due to disagreements which often caused participants to worry and become anxious, and in some cases were a great cause of upset:

> *I've got no family that will support me…I was cut out of my family's life many years ago.* (Participant 10, female, 83 years)
>
> *Last year I became very depressed, just through other family members that tried to make our lives very difficult.* (Participant 37, female, 76 years)

For some participants, contact with their paid carers was the only social connection they experienced; "*I don't have social relationships with people except for the people who come here, carers"* (Participant 5, male, 82 years). Many participants looked forward to their carers visiting them:

> *One girl comes in and does the cleaning, two hours, and we have a little bit of a chatter and cup of tea…The other girl comes in and we go shopping and have a cup of coffee out so that's my enjoyment as far as the weeks concerned.* (Participant 38, female, 95 years)

Some participants expressed they had developed close bonds with these carers, for example, one participant spoke about the emotional connection she had developed with her carer:

> *I don't have any social life and I get very lonely…my cleaning lady is lovely. When she goes, she gives me a hug and she goes 'there you are, that'll do ya' because I said to her 'I long for somebody to give me a hug sometimes' so she gives me a hug. She's a lovely, lovely person; you've got no idea.* (Participant 8, female, 83 years)

Activities

Involvement in group activities, for example singing groups, craft classes and in independent activities, for example, crosswords, sewing were important to every one of the participants for their QoL:

> *I have a lot of my own activities. I have my TV, I have my books, I have my music…if I have time and I'm not lazy I do sewing; I do all these kinds of things? How can you be bored when you have a lot of things that you can do, a lot of things that will occupy you?* (Participant 27, female, 85 years)
>
> *I like to get out and – with my volunteering job at the library and relationships [at the] keep fit class and all those sorts of things.* (Participant 3, male, 81 years)

There were several reasons why participants chose to participate in activities. For example, some participants enjoyed the social connections that activities facilitated and their main reason for participating was the social contact they experienced with others:

> *Well, this probably might attribute to some people, but I go to what's called [name] here and we don't learn craft because that's behind us now, we all know knitting, crocheting, cross stitch, all that sort of thing, and that is my happiest day of the week, Wednesday morning. We have so much fun, we just talk to one another and laugh.* (Participant 41, female, 84 years)
>
> *I think we have enough social relations because I play bowls and go to church.* (Participant 13, male, 93 years)

Other participants spoke about taking part in activities to keep busy as a way of passing time, so the day went quicker:

> *I'm a person that likes to be doing something…I like to be active. I like to – I paint as a hobby… I like to have interest in things. I'm a member of the jazz club. I don't always get there as often as I'd like to…I just like to keep busy.* (Participant 14, female, 85 years)
>
> *I do go out quite a bit. I go out twice a week either shopping or for coffee with the carer and I go out with my daughter to morning melodies, and we go to the theatre sometimes. I just like getting out…I do lots of different crafts. I make cards. I paint. I do crochet and knitting. I keep busy.* (Participant 15, female, 91 years)

Several participants discussed how doing activities to keep their mind and brain active was particularly important to them as they got older:

> *I do lots of crosswords and I watch quiz shows. I've got to keep my mind busy. I think that's a really important thing when you're getting older, to keep your brain moving, you know, keep it going.* (Participant 32, female, 80 years)
>
> *They [aged care organisation] have social groups Monday, Tuesday, Wednesday and Friday and I go every Monday to those, so I've got enough to keep me active, keep the mind going.* (Participant 12, female, 93 years)

Role continuity was also raised by some participants with activities linked to previous roles and hobbies helping to maintain their identity:

> *Down the side of the unit there's a big area that…that was used for putting six fruit trees in and that keeps me busy out there. My business was gardening supplies and fertilisers…I also volunteer for [aged care provider]…I do a considerable amount of work at [aged care provider] which is where they bring in a lot of elderly people and we get them into the garden.* (Participant 18, male, 78 years)
>
> *I want to get back to singing. My voice has gone, and I want to get it back so I'm going to be getting back on the keyboard to keep my voice going. That's important to me because I was a singer, you see.* (Participant 32, female, 80 years)

There were also some participants that spoke about their loss from no longer being able to participate in activities, mostly because of physical decline, and the upset they experienced from no longer doing what they previously enjoyed:

> *What I really like doing is sewing on my machine and then putting on classical music as well. I haven't been able to do that for a while because I haven't been so well, and my hand's been giving me a bit of trouble because I have rheumatoid arthritis and so that's made a bit of a difference.* (Participant 17, female, 85 years)
>
> *Well, I can't do it at the moment, but I would like to have continued on my voluntary work but at the moment I'm not able to…I was a volunteer at [name], I ran that for 16 years and then I was doing my church op shop for quite a number, about 18, 19 years….now I have [walker] this is marvellous, absolutely marvellous…indispensable, but I have not been able to get my balance back…I especially miss that op shop, believe it or not, because I've always liked people.* (Participant 9, female, 91 years)

Other participants had accepted there were some activities they could no longer take part in; *"I'm not very – not as interested in bowls as I was because physical ability doesn't allow me to do that…I'm hoping to get back there but if the body won't let me do it, well…that's okay"* (Participant 13, male, 93 years). However, some participants had continued their activities to some extent by finding ways of adapting their hobbies so they could still participate; *"I mean I used to garden, and I can't really garden now except pot plants and things like that. I like to have the garden kept nice"* (Participant 19, female, 83 years).

6.4 DISCUSSION

Some of the QoL dimensions identified from the analysis are similar to those included in existing preference-based measures that have been applied with the older population previously (Cleland et al., 2019) that were outlined in Chapter four (Table 6.2). For example, the ICECAP-O has a control dimension similar to the concept in this research identifying levels of independence but uses 'I am able' in the item wording, reflecting the capability scale it adopts. The independence dimension created from this research is similar, identifying independence through decision-making and control over lives.

Table 6.2

Mapping the QOL-ACC dimensions to other preference-based measures

QOL-ACC Dimensions	Similar Dimensions
Mobility	Mobility (EQ-5D)
Emotional well-being	Anxiety / Depression (EQ-5D) Security (ICECAP-O) Dignity (ASCOT)
Independence	Control over daily life (ASCOT) Control (ICECAP-O)
Social connectedness	Social participation and participation (ASCOT) Attachment (ICECAP-O)
Activities	Usual activities (EQ-5D) Enjoyment and pleasure (ICECAP-O) Doing things that make you feel valued (ICECAP-O)

The ASCOT includes a social connections and participation dimension which aligns with the social connections dimension identifying levels of social contact people experience. Similarly, the EQ-5D covers depression and anxiety, identifying the extent of depression and anxiety individuals experience. The concept of emotional well-being in this research is similar as it includes happiness and feelings of stress and worry but is described in different terms to the EQ-5D dimension as it does not use the words ‘depression’ or ‘anxiety’ as older people tended to not regularly adopt these during the interview when talking about emotional well-being. Furthermore, feelings of stress and worry amongst older people were often expressed as being related to the fear of moving into residential care which is unique to this population.

Whilst the draft dimensions developed from this research share some similarities with dimensions in existing measures, there are also some important differences. For example, the ASCOT consists of a control dimension which is linked to independence but is described in different terms as it identifies levels of control over daily life rather than general feelings of independence and being able to make one's own decisions. Similarly, the ICECAP-O consists of the dimension attachment which is related to social relationships but is different to the social connections dimension developed in this research as it includes the concept of love in addition to friendships. Whilst the concept of love is no less relevant to people of an older age, it may not reflect the real life experiences of older people as many are widowed during their later life. This is particularly relevant to older females who on average live longer than males (AIHW, 2019). The social connections dimension created from this research has a broader focus incorporating social relationships with family and friends. The ICECAP-O also includes a security dimension which is partially related to the concept of emotional well-being as it focuses on concerns when thinking about the future. Likewise, the ASCOT includes a dignity dimension identifying if the way in which individuals are treated impacts on how they feel about themselves. However, the emotional well-being dimension created in this research is dissimilar to these two dimensions as it covers a generic concept of emotional wellbeing; specifically identifying feelings of happiness, stress and worry.

Although mobility is included in the EQ-5D, the wording used for the mobility dimension is not age appropriate. Many older people in this research discussed mobility in relation to their ability to get out and about (including with the use of mobility aids if they regularly used them). These issues are not encapsulated in the way that mobility is described within the EQ-5D measure as it does not make reference to mobility aids which are often used by older people receiving aged care services.

An activities dimension is included in the EQ-5D which focuses on ability to perform usual activities. Likewise, the ICECAP-O has two dimensions that are related to activities, one concentrating on doing things that make you feel valued and the other on enjoyment and pleasure. These activity dimensions are different to the activities dimension developed in this research because it focuses more on spending time doing things for enjoyment alone or with other people and therefore has a unique concept of older people's needs in relation to activities.

Whilst the qualitative approach adopted in this research to identify draft dimensions share some similarities with the development of the ICECAP-O descriptive system there are some important differences. Importantly, the ICECAP-O is a measure of capability and has Sen's capability approach as its fundamental theoretical foundation. The scoring system for ICECAP-O is anchored upon an absence of capability to full capability scale rather than anchoring on being dead and full health as is usual for generic preference-based measures which generate QALYs (Brazier et al., 2017). Research investigating the relationship between capability and functioning is in its infancy. However, there are some early indications that whilst these concepts are related, they are separate. Research conducted by van Leeuwen et al. (2015b) exploring measurement properties of the EQ-5D-3L, ASCOT and ICECAP-O with older adults found that responses to the EQ-5D-3L were more strongly associated with physical health than were responses to the ICECAP-O and ASCOT measures. Conversely, mental health status was more strongly associated with responses to the ICECAP-O, whilst self-perceived QoL and mastery was associated more strongly with responses to the ASCOT. Al-Janabi (2018) in his study of 943 family members of meningitis patients, similarly, identified that whilst a large proportion of responses indicated that capability equalled functioning (86%) across the dimensions of the ICECAP-A questionnaire, a proportion of responses (12%) demonstrated higher capability than functioning. Participants were more likely to report a difference between their capability and their functioning when their health status was impaired (as indicated by an EQ-5D-5L index score less than 1) as compared to those with unimpaired health status, or if they had caring duties, both groups of people who are likely to be reflected in aged care users.

Previous empirical studies have also identified discrepancies between capability and functioning. For example, Bulamu et al. (2017) reported relatively high capability in older adults using community aged care services (ICECAP-O mean score 0.76) in comparison with QoL (EQ-5D mean score 0.47). These identified differences highlight the importance of developing a new measure of QoL from inception with older people suitable for the aged care context that uses the content and language most often expressed by older people themselves.

The research findings generally concur with those of several previous studies which have demonstrated that the concept of QoL for older people goes beyond health status incorporating broader dimensions of QoL. For example, Ratcliffe et al.’s study comparing the preferences of younger and older people in relation to QoL indicated that older people valued being independent, physically mobile and being in control (Ratcliffe et al., 2017). Similar research conducted with older adults in a day rehabilitation centre in South Australia found that although older people valued health as important in relation to their QoL, wider dimensions such as independence, control and social relationships were also important (Milte et al., 2014). Other research has also highlighted independence and control as key dimensions of QoL amongst older people (Grewal et al., 2006; Netten et al., 2012a).

The main strength of this stage of the research is the person-centred approach adopted. This method enables the language used by older people to be retained throughout the development of the QoL dimensions which should ultimately result in greater content and face validity, and additionally, make the measure user-friendly. Furthermore, the dimensions have been developed directly from older people receiving community aged care services which means they are of greater relevance to this population. A diverse socio-demographic population broadly representative of older people accessing community aged care services in Australia were recruited across three different Australian states, thus strengthening the validity of the results.

The current study was also designed to be inclusive for older adults living with minor cognitive impairments and/ or mild dementia which is a strength of this research as this group are important users of aged care services. Older people living with cognitive impairment and dementia have traditionally been excluded from research of this nature and in the development of new QoL measures. The use of one-to-one interviews in a private setting enabled older people to discuss sensitive issues that they may not have felt comfortable discussing in a focus group setting. Most of the language and terminology used by the participants was consistent when describing QoL dimensions and the next stage of the research focuses on establishing appropriate wording to ensure the measure is suitable for all older people accessing aged care.

A potential limitation of this research is that the use of cards in the second stage of the interview may have had the potential to influence participant's responses. The cards were used to initiate further discussion around the dimensions participants had raised in stage one of the interviews. A very small number (n = 2) when reading the cards identified a QoL dimension from the cards that was important to them that they had not discussed in the first stage of the interview. However, this data was analysed separately to ensure the dimensions were developed from stage one of the interviews, and therefore any possible influence would be minimal in this respect.

Although a diverse sample of participants was recruited, it is important to recognise that hard to reach older adults may have been excluded from this research. The research does not include participants who could not communicate in English, and it is recognised that, in common with many other developed nations, Australia's population is diverse. However, interviewing older adults whose first language was not English was unfortunately outside the scope of this research due to resource limitations. Potential future research could focus on identifying the extent to which older people from CALD backgrounds value the same QoL dimensions as older people from Anglo/English speaking populations to identify if the measure is meaningful and acceptable to older people whose first language is not English.

6.5 CONCLUSION

This stage of the research has identified the key QoL dimensions articulated by older people in receipt of community aged care services about what is important to them to experience a good QoL. The dimensions have been developed directly from older people adopting a bottom-up approach and therefore have not been influenced by existing literature or other individuals such as carers, family members, or aged care organisations. This stage of the research represents a crucial first stage in this multiphase project working in partnership with older people to develop the descriptive system for the new preference-based QoL measure for informing quality assessment, and amenable to preference-based scoring for economic evaluation in community aged care. Chapter 7 will outline the next stage of the research which focuses on developing and testing the draft items for the QOL-ACC descriptive system from the five key dimensions identified and selecting the final items for the QOL-ACC descriptive system.

7. THE ANALYSIS AND INTEGRATION OF MIXED METHODS DATA TO DEVELOP THE FINAL ITEMS FOR THE QOL-ACC DESCRIPTIVE SYSTEM

7.1 INTRODUCTION

This chapter presents the findings from a mixed methods study to identify the final items for the QOL-ACC descriptive system. The chapter provides a detailed overview of stages three to five of the research project. Section 7.2 presents stage three of the research which involved conducting face validity interviews with older people receiving aged care in the community. The second section (7.3) of the chapter outlines stage four of the research; a quantitative online survey. Section 7.4 of the chapter details the integration of the data from stage three (interview data) and stage four (online survey) to identify the final items for the descriptive system for the QOL-ACC measure. The final section presents the discussion and conclusion.

The three stages of the development of the QOL-ACC outlined in this chapter build upon the previous stages of research. Stage one identified five salient attributes recognised by older people receiving aged care in the community as required to have a good QoL. The five dimensions identified were independence, mobility, emotional wellbeing, social connections, and activities (see Chapter 6). Stage two of the research project involved the Project Advisory Group (comprising members of the research team (n=7), aged care partners (n=2) and one consumer representative) examining the qualitative data to develop draft items for each of the five dimensions for the descriptive system. A workshop was held at which the data was reviewed to explore the ways in which older people had spoken about the five dimensions. Firstly, the project advisory group reviewed and examined the quotes from each participant relating to each dimension in order to familiarise themselves with the terminology and language the older people had adopted when speaking about the dimensions. Secondly, the language (e.g., words, terms, phrases) most commonly adopted for each dimension were mapped onto a large interactive whiteboard. Thirdly, the most common terms for each dimension were listed into a table for each dimension. For example, some of the most common words/phrases when referring to the dimension ‘independence’ were ‘making own decisions’, ‘living the life I choose’, ‘independence’, ‘control’. The project advisory group then developed items for each dimension using the most common terms adopted. There was no set number of items required or specified by the project advisory group for each dimension. The number of items developed were based upon the most common terms adopted and this varied for each dimension. From this workshop, 28 draft items were developed across the five dimensions based upon the words and phrases that older people had adopted during the interview when describing the dimensions to ensure the meaning of the QoL dimensions remained as much as possible.

7.2 STAGE 3: FACE VALIDITY INTERVIEWS

7.2.1 Recruitment

Ethical principles must be considered and adhered to when conducting any research (Silverman, 2013). Ethical approval for this stage of the project was granted from the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University (Project no. 8399).

Participants were recruited using convenience sampling through the project’s aged care partner organisations in South Australia, Victoria, and New South Wales. Convenience sampling is a form of non-probability sampling where participants are selected based on their availability to participate in the research (Guest et al., 2013). This method of sampling was chosen because the data collection was being conducted during the COVID-19 pandemic.

Therefore, there were restrictions in several states, and it was anticipated that these restrictions would negatively impact upon recruitment. However, although the partner aged care organisations were not asked to provide a random sample of participants, they were asked to provide participants with a range of socio-demographic characteristics including age, gender, care package and living arrangements. Eligibility to participate in the interviews was based on the following criteria:

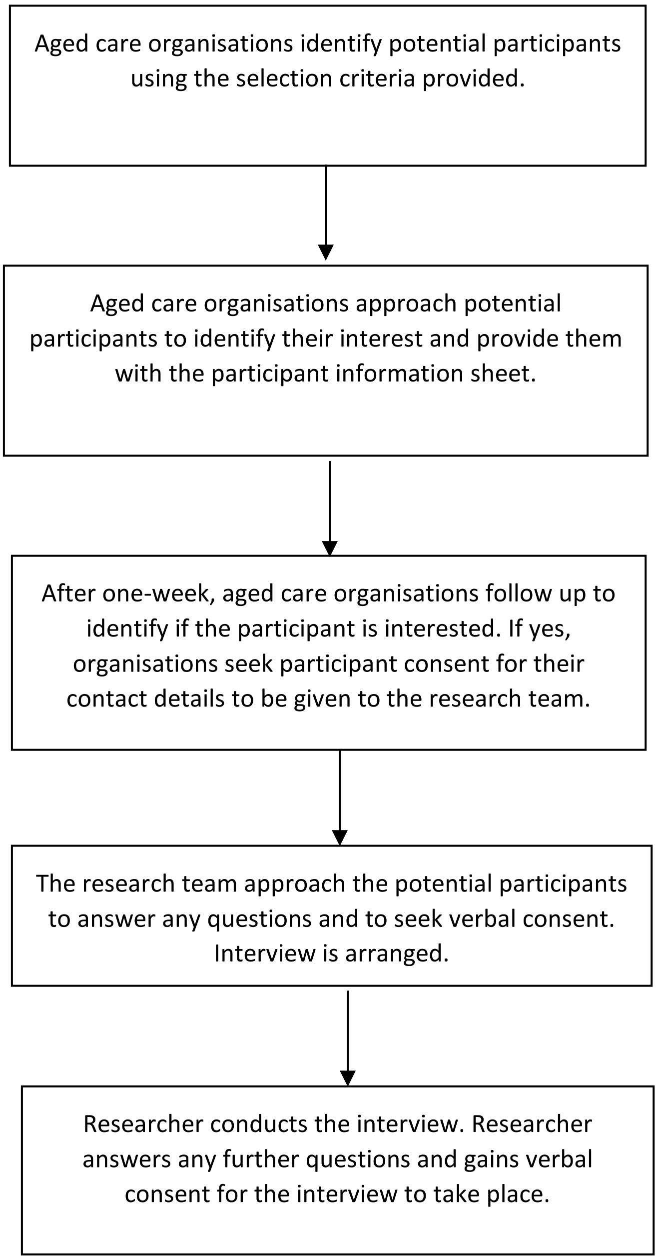
- Aged 65 years and over
- In receipt of a government HCP (Level 1-4)
- Ability to communicate in English
- Normal cognitive functioning through to mild cognitive impairment/mild dementia (assessed by the aged care organisation using the Psychogeriatric Assessment Scale Cognitive Impairment Scale (PAS-Cog) (Jorm et al., 1995)
- Ability to provide informed consent

The aged care organisations initially approached potential participants to ask if they would be interested in taking part in the research. The organisations gave the potential participants a participant information sheet which provided a more detailed description of the research, information about the recruitment process, confidentiality, and the right to withdraw. It also included contact details of the research team if the participant wanted to find out more information (Appendix 9).

After one week of receiving the participant information sheet, they recontacted the participants to ask if they were still interested in taking part and to gain their verbal consent for the researcher to approach the participant. If consent was given, the aged care organisation provided the research team with the contact details of the participant. The researcher then contacted the participant via telephone to confirm their interest in participating in the research, answer any questions they may have and to arrange a telephone interview. Covid-19 restrictions unfortunately prevented the research taking place face-to-face, and therefore, telephone interviews were chosen as an alternative method to collect the data. The recruitment process is outlined in Figure 7.1.

Figure 7.1

Flowchart of recruitment process for stage three of the development of the QOL-ACC descriptive system



Aged care organisations identify potential participants using the selection criteria provided.

Aged care organisations approach potential participants to identify their interest and provide them with the participant information sheet.

After one-week, aged care organisations follow up to identify if the participant is interested. If yes, organisations seek participant consent for their contact details to be given to the research team.

The research team approach the potential participants to answer any questions and to seek verbal consent. Interview is arranged.

Researcher conducts the interview. Researcher answers any further questions and gains verbal consent for the interview to take place.

7.2.2 Interviews

I conducted interviews in South Australia (*n*=10) and a researcher with prior experience of interviewing older people in an aged care setting conducted interviews in New South Wales (*n*=15) and Victoria (*n*=6). The consent form (Appendix 10), participant information sheet (Appendix 9), and the cards (Appendix 11) required for the interview were posted to the participant prior to the interview taking place. Prior to the interview commencing, the researcher explained the interview process, answered any questions, and gained verbal consent from the participant. We followed a semi-structured interview schedule to conduct the interviews developed by the wider project team in consultation with the Project Advisory Group (comprising representatives from aged care organisations and consumers) to ensure that the interviews were conducted in a similar manner (Appendix 12).

The face validity interviews had two main aims which were inter-related. Firstly, to gain feedback on the draft items to understand if they were clear and appropriately worded and described, and secondly for the participant to identify their preferred item/s for each dimension in order to reduce the number of items to take forward to the next stage of the research: psychometric testing (stage four). The interview consisted of two stages. The first stage of the interview involved the participant considering a series of cards comprising descriptions of key QoL dimensions developed during stage two from the stage one interviews. All participants were given five cards, each card represented one of the five dimensions of the QOL-ACC descriptive system and included the draft items (n=28) of the specific dimension. To assess for face validity of the items the researcher asked the participant whether the items representing each dimension were clear and understandable, whether the wording was appropriate, if they would be prepared to answer the questions, and whether they thought older people would understand the items. The researcher asked the respondent which item they preferred for each dimension, the reason for their preference and whether there was anything important to their QoL that was not captured in the items. The participants were also presented with five possible response sets for each of the items (Appendix 11) and asked which response set they preferred for each item. The response sets were based on frequency rather than severity as older people had discussed the QoL dimensions they experienced in terms of frequency, rather than severity, during the stage one interviews.

The final stage involved the participant completing the EQ-5D-5L (Herdman et al., 2011), and a short questionnaire that included questions about the participant's socio-demographics and their care, for example, gender, age, level of care package received, and average hours of care received per week (Appendix 8). The interview duration ranged from 26 to 78 minutes (mean = 39 minutes).

7.2.3 Analysis

Interviews were transcribed verbatim by a professional transcription service who were required to sign a confidentiality agreement with Flinders University. Prior to the interview being transcribed, all personal identifiable details were removed, and the interviews were given unique ID numbers to ensure confidentiality. All transcripts were imported onto the qualitative software package NVivo (QSR International Pty Ltd, 2018). The analysis of the interview data was driven through the purpose of this stage of the research which was to reduce the number of draft items for each dimension to progress to the next stage of the research (stage 4). Therefore, data from each participant was coded under each of the 28 items to reflect feedback on aspects such as clarity, acceptability, sensitivity, ambiguity, wording, and preferred item for each of the dimensions. For example, one of the participants comments was "*Worry to me is a word I don't even like. I don't even use it*" when talking about item 1 of the emotional wellbeing items, and therefore that comment was coded under the node that represented the item 'Emotional wellbeing – item 1'. I coded all of the interview transcripts and they were also independently coded by a research assistant at the University of Sydney to ensure that all of the relevant data was captured and classified into each node.

SPSS, Version 25.0 (IBM Corp, 2017) was used to analyse the socio-demographic data to produce simple frequencies and percentages. The utility values for the EQ-5D-5L were calculated using the Australian pilot scoring algorithm that produces scores from -0.676 to 1 (Norman et al., 2013). The final Australian scoring algorithm is currently being developed. The most preferred item for each dimension was also recorded for each participant in the SPSS database.

7.2.4 Results

Participant Characteristics

The socio-demographics of the sample are presented in Table 7.1. Interviews were carried out with 31 participants receiving aged care services in the community. Just over a third (67.7%) of participants were female with approximately half of participants aged 80-89 (51.6%). Most participants (71.0%) were born in Australia and just under half of participants (48.4%) lived alone. Approximately half of the participants (51.6%) were receiving a HCP level 2 and just under a third (29.0%) were receiving a HCP level 3. The average hours of self-reported support provided per week was 4.8 hours. Only one participant rated their health as 'excellent' with the majority rating their health as 'good' (41.9%) or 'fair' (29.0%). Participant's HRQoL as approximated by the EQ-5D-5L using the Australian general population specific scoring algorithm (Norman et al., 2013) was on average significantly lower (mean 0.49, SD 0.25) than for the general population of similar age range (mean 0.85, SD 0.16) (McCaffrey et al., 2016).

This finding was not unexpected given that the sample comprised dependent older people in the community receiving aged care services. The sociodemographic characteristics (age and gender data only available for comparison) and the distribution of HCP levels across the study sample are broadly representative of the population of older people currently receiving HCPs in Australia (AIHW, 2020b).

Table 7.1

Stage 3 participant characteristics and the Australian home care population

Study Participants	*n* (%)	Australian Home Care Population[a]	(%)
Gender, *n* (%)		Gender, (%)	
Male	10 (32.3)	Male	34.4
Female	21 (67.7)	Female	65.6
Age, *n* (%)		Age, (%)	
65-79	12 (38.7)	65-79	34.5
80-89	16 (51.6)	80-89	47.0
>90	3 (9.7)	>90	18.5
Mean (SD)	80.4 (6.81)		
Range	66-95		
Country of birth, *n* (%)			
Australia	22 (71.0)		
UK	6 (19.4)		
Other	3 (6.6)		
Highest Educational Qualification, *n* (%)			
No qualifications	5 (16.1)		
Completed High School	3 (9.7)		
Undergraduate/ professional qualification	10 (32.3)		
Postgraduate qualification	3 (9.7)		
Other	10 (32.3)		
Living arrangements, *n* (%)			
Living Alone	15 (48.4)		
Living with spouse/partner	12 (38.7)		
Living with other relatives	2 (6.5)		
Living with others (not relatives)	2 (6.5)		
Home Care Package level, *n* (%)		Home Care Package level, (%)	
Level 1 (basic care needs)	1 (3.2)	Level 1 (basic care needs)	11.5
Level 2 (low care needs)	16 (51.6)	Level 2 (low care needs)	41.3
Level 3 (intermediate care needs)	4 (12.9)	Level 3 (intermediate care needs)	20.6
Level 4 (high care needs)	9 (29.0)	Level 4 (high care needs)	26.6
Number of hours of support per week			
Mean (SD)	4.8 (3.96)		
Range	1-16		
Self-reported health, *n* (%)			
Excellent	1 (3.2)		
Very Good	4 (12.9)		
Good	13 (41.9)		
Fair	9 (29.0)		
Poor	4 (12.9)		
EQ-5D-5L Score, mean (SD)	0.49 (0.25)	EQ-5D-5L Score, mean (SD)[b]	0.85 (0.16)
EQ-VAS Score, mean (SD)	59.10 (22.22)		

Note. Source: [a] AIHW, (2020b); [b] McCaffrey et al. (2016).

Removal of items

16 draft items were removed leaving 12 items to take forward to stage four. Items were removed if they were unclear, ambiguous, addressed more than one component of the

dimension. Items were also removed if they were the least preferred. The following section provides details of why each item was removed for each dimension with examples.

Independence

As indicated by Table 7.2, just over three-fifths of participants (61.3%) preferred item 2 and a quarter of participants (25.8%) preferred item 1. However, some participants, such as the following participant, identified item 2 as unclear as the item addressed 2 separate aspects of independence; "*It's like two questions in one...they are 2 separate questions…Well sometimes to live the life you choose is not up to you to make decisions about that life, its other things, and circumstances"* (Participant 44, Male, 76 years).

Other participants noted that the items were very similar but preferred the wording of item 2:

> *Well, they're (item 1 and 2) very similar, but I feel to be able to live the life that we choose, and to make our own decisions. As you get older, we find with our children they take over the mother and father role. We feel that we listen, but we feel that we're still able to make those decisions our self.* (Participant 55, male, 95 years)
>
> *I'd rather a question where I feel that I can live the life I choose and make my own decisions…Yeah I think probably number two is better.* (Participant 71, female, 74 years)

Items 1 and 2 consisted of very similar wording and because more participants preferred item 2, item 1 was removed for the next stage of data collection.

Table 7.2

Independence frequencies

Item no.	Independence Items	*n* (%)	Outcome
1	I live the life I choose and make my own decisions	8 (25.8)	Removed
2	I feel that I can live the life I choose and make my own decisions	11 (61.3)	Retained
3	I am in charge of my own life	6 (19.4)	Retained
4	I have as much independence as I want	6 (19.4)	Retained

Mobility

The most preferred were item 3 (32.3%) and item 7 (29.0%). Not one participant preferred item 6 and items 1 and 4 were only chosen by one participant so these items were removed (see Table 7.3). One participant indicated that item 1 was ambiguous; *"Well, just 'I am mobile' that doesn't cover anything"* (Participant 72, Male, 80 years).

Some participants did not prefer item 4 because the item included the word 'easy'. Participants suggested that most older people would not find it easy to move around so thought the item may generate more negative responses than the other items as indicated by the following quotes:

> *I find it easy to move around'…that's the worst one…most people I know – I must admit, everybody I know is over 70 and they don't find it easy, they all need walking aids, or they have problems walking or moving about…So, I think that one's the worst one.* (Participant 67, female, 83 years old)
>
> *Not that I'd say I don't like, the word I find is easy to move around. A lot of people of this age group don't find it very easy to move around, so it's probably a legitimate question, and you'll probably get a lot of negativity towards that one because the aging population have either got walkers and walking sticks and that sort of thing.* (Participant 69, Male, 70 years)

Participants that did not prefer item 6 suggested the wording of the item made it unclear:

> *'I am physically mobile'. I mean if you're mobile, you're going to be physically mobile, aren't you? I don't know whether the word, physically, needs to be in there. I think that repeats to me. That's like repeating I'm mobile and mostly you relate that to physical mobility. And it is usually a physical thing anyway.* (Participant 71, Female, 74 years)
>
> *'I am physically mobile', which suggests to me that you don't have to use walking aids.* (Participant 45, Female, 74 years)

Items 2 and 3 were worded very similar with item 2 using the word 'want' and item 3 using the word 'need'. Item 2 was removed for the next stage of data collection as this was the least preferred item of the two items.

Item 5 was also removed due to the small number of participants (12.9%) choosing this item as their preferred item. One participant indicated that it wasn't their preferred item because it needed to be elaborated upon for clarity:

> *'I am able to move around', yes. I am on a walker, I have a balance problem, but I am able to move around. There are some things I can't do. Yes. I'm just wondering if I'd need to put a little bit more on that. I am able to move around as much as my disabilities allow…because with a walker and so forth, you are restricted to some extent, aren't you?* (Participant 60, Female, 83 years)

Table 7.3

Mobility frequencies

Item no.	**Mobility Items**	***n* (%)**	**Outcome**
1	I am mobile (with the use of mobility aids e.g., wheelchair, walker, stick if you use them)	1 (3.2)	Removed
2	I am able to get around as much as I need to (with the use of mobility aids e.g., wheelchair, walker, stick if you use them)	6 (19.4)	Removed
3	I am able to get around as much as I want to (with the use of mobility aids e.g., wheelchair, walker, stick if you use them).	10 (32.3)	Retained
4	I find it easy to move around (with the use of mobility aids e.g., wheelchair, walker, stick if you use them)	1 (3.2)	Removed
5	I am able to move around (with the use of mobility aids e.g., wheelchair, walker, stick if you use them)	4 (12.9)	Removed
6	I am physically mobile (with the use of mobility aids e.g., wheelchair, walker, stick if you use them)	0 (0)	Removed
7	I am physically mobile and can get out and about (with the use of mobility aids e.g., wheelchair, walker, stick if you use them).	9 (29.0)	Retained

Emotional wellbeing

The most preferred item by participants was item 5 (41.9%) with just over a fifth (22.6%) preferring item 3 and just under a fifth (19.4%) preferring item 2. Items 1 and 4 were the least preferred items (see Table 7.4). One participant commented that wording in items 1 and 4 were sensitive; "*Worry to me is a word I don't even like. I don't even use it"* (Participant 71, Female, 74 years).

Other participants indicated that item 4 was ambiguous:

> *If they were worried, they'd well, probably say they wouldn't be free from worry, would they? If they were worried and stressed, I don't know whether that could be sort of offered, do you know what I mean?* (Participant 56, Female 78 years)
>
> *Well, you've got and stress in brackets…but I would take the words stress out of the brackets, because when it's in brackets, it's then it's a case of it could be removed, and I would think it should be there.* (Participant 42, Male, 74 years)

Participants that did not prefer item 2 suggested the wording was negative and did not like the way in which the question was phrased:

> *Well, I would think that a lot of people in the age range would have difficulty in being terribly positive about those.* (Participant 53, Female, 85 years)
>
> *It depends on what you're trying to find out. Am I free of stress?...I'm not happy with it. I'd be more inclined 'I am generally stress free.'* (Participant 44, Male, 76 years)

Therefore, the two most preferred items (3 and 5) were included in the next stage of analysis and items 1, 2 and 4 were removed.

Table 7.4

Emotional wellbeing frequencies

Item no.	Emotional Wellbeing Items	*n* (%)	Outcome
1	I feel happy and free from worry	3 (9.7)	Removed
2	I am generally stress free / free of stress	6 (19.4)	Removed
3	I am generally happy	7 (22.6)	Retained
4	I am free from worry (and stress)	2 (6.5)	Removed
5	I am generally happy and stress free	13 (41.9)	Retained

Social Connections

As outlined in Table 7.5, the most preferred items were item 3 which was chosen by 43.3% of participants and item 4 which was preferred by 33.3% of the participants. Not one single participant chose item 2 or item 5. Item 5 was viewed as ambiguous to some participants, as illustrated by the following participant:

> *'I am happy with my close relationships', well that's just talking about all relationships and whether they're close or not…'I am happy with my close relationships', which ones? You know, you can be happy with some and not happy with others. It's a difficult question to answer.* (Participant 44, Male, 76 years)

One participant indicated that items 1 and 2 were not easy to answer because the word 'social connections' was ambiguous:

> *The one thing that it doesn't say is that - and I mean, if this applies to me, I have good social relationships with family and the few friends that I have, you know? It doesn't say if you've got many friends, or if you would like to have more friends or anything like that. It's talking about relationships that you've already got. I have very few connections to the community, other than my neighbours around me, and who I get on*

> *extremely well with. I don't have as many social relationships as I would like. It doesn't have that there and I think it should.* (Participant 45, Female, 74 years)

One participant thought item 6 was not easy to respond to as it was asking two questions rather than one question:

> *'I have as much contact as I like with family and friends', well they're different....well that could perhaps be relevant, but you could have a lot of contact with friends and not necessarily the family. Or family and no friends. You can't answer that when they're like that. I couldn't answer that.* (Participant 44, Male, 76 years)

Items 1, 2, 5 and 6 were removed because they were the least preferred items and some participants thought they were ambiguous. Items 3 and 4 were included in the next stage of analysis.

Table 7.5

Social Connections frequencies

Item no.	Social Connections Items	*n* (%)*	Outcome
1	I have as many social connections as I need	2 (6.7)	Removed
2	I have as many social connections as I would like	0 (0)	Removed
3	I have good social relationships with family and friends	13 (43.3)	Retained
4	I enjoy close relationships with family and friends	10 (33.3)	Retained
5	I am happy with my close relationships	0 (0)	Removed
6	I have as much contact as I like with family and friends	5 (16.7)	Removed

*1 participant did not answer

Activities

Table 7.6 shows the most preferred items which were item 6 which was chosen by 42.9% of participants and item 5 that was preferred by just over a fifth (21.4%) of participants.

Items 1 and 2 were removed as they were only chosen by two participants. One participant was unsure about the word ‘busy’ being used in the items:

> *Maybe the word busy, may not need to be there because if they're enjoying them, they're obviously spending time on them and I would assume then, perhaps which I shouldn’t be doing probably, but I will say it that way – that they're probably busy, you know.* (Participant 71, Female, 74 years)

One participant indicated they did not like the way in which item 4 was phrased; “*‘I feel’ to me is kind of indecision. I’d rather be more definite about things rather than this ‘I feel’”* (Participant 67, Female, 83 years). Another participant found item 4 difficult to understand; “*Some of them were a bit hard to understand, in this one, I thought…Well, I have enough leisure activities and hobbies to keep me busy, but it doesn't say whether you'd like any of those things”* (Participant 72, Male, 80 years).

Therefore, three items (1, 2, 4) were removed because they were the least preferred, difficult to understand or contained words that some participants did not like. Items 3, 5 and 6 were taken through to the next stage of data collection.

Table 7.6

Activities frequencies

Item no.	Activities Items	n (%)*	Outcome
1	I have enough (leisure) activities / hobbies to keep me busy	2 (7.1)	Removed
2	I am as busy as I would wish with my leisure activities	2 (7.1)	Removed
3	I am as busy with my leisure activities as I like to be	3 (10.7)	Retained
4	I feel that I have enough leisure activities to keep me busy	3 (10.7)	Removed
5	I feel that I have enough leisure activities to keep me occupied	6 (21.4)	Retained
6	I have leisure activities / hobbies I enjoy	12 (42.9)	Retained

*3 participants did not answer

Response options

During the interview the participants were presented with five sets of response options based on frequency (labelled set A, B, C, D or E). Each of the response options consisted of a five-point scale. The participants were asked to choose the response option set that they liked the most to accompany the items. Response set E was chosen as the most preferred (24.5%) by participants (‘none of the time’, ‘a little of the time’, ‘some of the time’, ‘most of the time’ and ‘all of the time’). Therefore, response set E was used as the response option for the items in the next stage of data collection (stage four).

To summarise, 16 items were removed based on the comments from the participants. None of the items were viewed as offensive or judgemental. However, some participants expressed that the items were ambiguous, could be interpreted differently or were unclear, and therefore, they would have difficulty answering the item. Other participants did not prefer items addressing more than one component of a dimension or items including sensitive wording. Items were also removed if they were the least preferred items for a dimension. Removing items based on participants’ preferences was important because whilst some participants expressed their views of why they did/did not like an item, other participants did not provide a comprehensive response to why they preferred or did not prefer an item but were happy to indicate their preferred item. This process reduced the candidate items from 28 to 12 final items to take through to the next stage of data collection (stage four) which is discussed in section 7.3.

7.3 STAGE 4 QUANTITATIVE SURVEY

7.3.1 Recruitment

Ethical approval was granted by the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University (Project no. 2201). Recruitment for the quantitative survey was via an Australia-wide online panel company through an existing membership of older people who were accessing aged care services in Australia. Participants were invited via email or via their member portal to take part in the survey. Eligibility to participate in the survey was based on the following criteria:

- Aged 65 years and over
- In receipt of a government HCP (Level 1-4) or accessing CHSP
- Ability to communicate in English
- Ability to provide informed consent

The criteria were widened from phase three of data collection (face validity interviews) to also include older people accessing CHSP. Older people in receipt of a CHSP are the most prevalent group of aged care services users and because this stage of the research required a relatively large sample in order to conduct quantitative in-depth psychometrics it was an appropriate stage to include this group. Including older people in receipt of both CHSP and HCP ensures wider applicability of the final measure. This stage of the research (psychometric testing of the QOL-ACC items) required a large sample size which would not have been possible to collect face-to-face due to budget and time constraints.

7.3.2 Survey

Prior to completing the survey, respondents were asked to read the online participant information sheet (Appendix 13) that provided details about the survey and outlined how their consent would be sought if they completed the survey. At the start of the survey, respondents were asked a series of brief initial screening questions relating to the eligibility criteria and if they did not meet the eligibility criteria the older person was thanked for their time and informed they did not meet the criteria. The use of screening questions also enabled targets to be set by age, gender, and type of aged care package to ensure broad representation within the sample population. The screening questions and survey can be found in Appendix 14.

The main aim of the survey was to identify the best single item (item reduction) for each of the five dimensions through psychometric analysis of the data to take through to the next stage of the analysis (stage five). Therefore, the survey began by asking the respondents to answer 13 draft QOL-ACC items generated from the interviews in stage three. Twelve items were included from stage three of the research plus one additional item for the social connections dimension ('I have as many connections to the community as I would like'). An additional item was included based on the expertise of the aged care organisations who recommended including a community focused item in addition to the existing items for the social connections dimension as community was an important aspect for older people receiving care to be socially connected. When reviewing the draft items during a steering group, three of the representatives from aged care organisations raised that there were no items for the social connections dimension that related to the community. The aged care representatives indicated, that from their experience providing services to older people, that older people referred to connections with the community as being important to their quality of life in relation to any social connections they experienced. Therefore, although this was not a strong theme that emerged in the first stage of the interviews it was acknowledged that the opinion of the aged care organisations (stakeholders) was important and therefore an additional item was included for the dimension of social connections. Unfortunately, this item was unable to be tested for face validity as the stage three interviews (face validity) had already taken place.

The survey also included the EQ-5D-5L (Herdman et al., 2011), the ASCOT (Netten et al., 2012a), the QCE-ACC (Khadka et al., 2020) and some socio-demographic questions and questions about the amount and type of care they received. Respondents were allowed to skip questions if they did not want to provide a response. Respondents completed the survey in a setting of their choice subject to them having internet access.

7.3.3 Analysis

Survey responses were collated by the panel company. The data was transferred onto SPSS, Version 25.0, a statistical package for the social sciences (IBM Corp, 2017) with each respondent assigned a unique ID number to ensure anonymity. Once all the data was collected, the SPSS database was transferred securely to the research team using a password protected database.

Socio-demographics characteristics of the sample were presented as simple frequencies and percentages using SPSS. The EQ-5D-5L utility scores were produced using the Australian pilot scoring algorithm which is based on a DCE approach with an Australian general population sample (Norman et al., 2013). The pilot Australian scoring algorithm was used as the final Australian general population EQ-5D-5L scoring algorithm is currently under development, and therefore, is not publicly available. Utility scores for the EQ-5D-5L range from -0.676 to 1 where scores less than 0 equate to a health state worse than death.

The analysis was guided by the purpose of the research which was to identify a high quality and highly informative psychometrically robust item per dimension based on the psychometric properties. This was undertaken using Classical Test Theory (CTT) and a modern Psychometric method (Rasch Analysis). These two methods have been used extensively before to assess the psychometric properties and validity of new measures (Khadka et al., 2013; Mokkink et al., 2010; Young et al., 2009) and when combined enable an in-depth analysis to be undertaken for both individual items and the measure level. CTT is a framework of analysis used to explore data and consists of several parameters such as acceptability, targeting, internal consistency reliability (Cronbach's alpha), and item dependency (Cappelleri et al., 2014; Petrillo et al., 2015).

Acceptable cut off values for all of the following assessments are shown in Table 7.7 (green = excellent, amber = acceptable, red = unsatisfactory). Acceptability involves identifying how well the items are completed and this was assessed by identifying missing data for the items (Petrillo et al., 2015). Large amounts of missing data can indicate respondents may not have a good understanding of the survey questions or the survey is largely not relevant whereas low levels of missing data would indicate the survey was acceptable to older people.

Targeting identifies ceiling and floor effects (Petrillo et al., 2015; Terwee et al., 2006). The ceiling effect is when respondent's responses cluster around the highest response category and when respondent's responses cluster around the lowest response category it is known as the floor effect. If ceiling and/or floor effects are present it can limit content validity and reduce reliability of a survey and can limit the measurement of change over time if using the survey on several occasions.

Table 7.7

Description of the traffic light system based on psychometric properties

Parameters	**Grading/Description**
Classical Test Theory Based psychometric properties	
Acceptability	Green: The percentage of missing data: ≤ 5% Amber: The percentage of missing data: > 5% ≤ 40% Red: The percentage of missing data: >40%
Targeting	Green: End-point categories ≤ 5% Amber: End-point categories > 5% ≤ 40% Red: End-point categories >40%
Internal consistency reliability	Green: 0.95 ≥ Cronbach's α ≥ 0.70 Amber: 0.70> Cronbach's α ≥ 0.60 or Cronbach's α >0.95 Red: Cronbach's α ≥ 0.60
Item dependency	Green: Inter-item correlations ≥ 0.6 Amber: Inter-item correlations ≥ 0.3 < 0.6 Red: Inter-item correlations <0.3
Modern Psychometrics (Rasch Analysis) based properties	
Response categories	Green: All the categories are ordered and evenly spaced Amber: All the categories are ordered but categories are nor evenly spaced Red: Disordered categories
Differential Item Functioning (DIF) (assessed for gender and service type)	Green: DIF ≤ 0.5 logits Amber: DIF > 0.5 ≤1.00 logits Red: DIF > 1.0 logits
Item Information Function (IIF)	Green: Item with high-level information and wider measurement range (a bell-shaped graph) Amber: Item with low-level information and wider measurement range/item with high information and narrow measurement range Red: Item with a low-level information and narrow measurement range

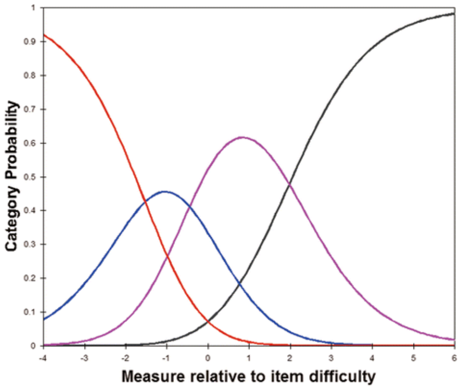
Internal consistency assesses reliability by examining the extent to how closely related a set of items are to each other and this was assessed using Cronbach alpha (Kandel et al., 2017; Schiffman et al.,2000). Item dependency refers to the correlation between two variables to identify the strength of the relationship to identify if the items are measuring the similar concept/s and was measured using the Pearson correlation co-efficient (Kandel et al., 2017; Pesudovs et al., 2007; Schiffman et al., 2000). Items for each dimension need to be highly correlated to indicate that items are measuring the same concept and therefore redundant. Presence of redundant items does not add to a survey and increases respondent burden.

Rasch analysis is a modern psychometric approach that enables a more in-depth analysis of measure quality than CTT. Rasch analysis features uni-dimensionality, hierarchical order, and equal scaling. The Rasch model converts raw scores considering these features of measurement to estimate how hard an item is to complete and the ability of the person responding to the item, thereby estimating the logit for each response by each person. Logit is an interval level measurement scale used to calibrate items on a latent measurement continuum. Logit depicts weighted value of an item, the hierarchical order of items and dictates that the ordering of items must be unchanged, thereby assuming uni-dimensionality of a scale (Boone, 2016). Rasch analysis involves several different tests such as response scale analysis, Item Information Functioning (IIF) item fit statistics and Differential Item Functioning (DIF) (Boone, 2016; Tennant et al., 2004).

Response scale analysis assesses if the response categories are ordered and evenly spaced to ensure they each have their own distinct meaning which is assessed by observing the probability curves (a graph that demonstrates the chance of each response being selected). See Figure 7.2 for an example of a category probability curve graph. When categories are not overshadowed by other categories (i.e., peaks of the categories are not overlapped) on the graph, that indicates the category has its own distinct meaning. The point at which the categories cross over is the category threshold which means the likelihood of selecting each response category would be the same (Linacre, 2002).

Figure 7.2

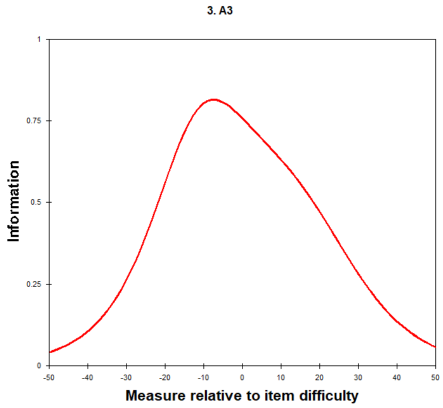
Example of a category probability curve graph



IIF demonstrates the amount of information of an item carries relative to the construct being measured over the scale range (Bond et al., 2020; Khadka et al., 2021). IIF is assessed by a graph which details the amount of information an item provides (i.e., ϴ values). An IIF is a bell shaped curve, and it is constructed by taking the inverse square of the standard error of the item (Baylari & Montazer, 2009). The Y-axis details the item information level (0-1), and the X axis details the relative item measure in logits. An item information ranges from 0 to 1 and it is not only the information represented by the peak on the graph but also the coverage, i.e., the extent of the graph across the x axis. The peak of the IFF occurs at or just above the item difficulty (i.e., construct level) and an item with higher information over a relatively wider range of the construct (i.e., ϴ values). See Figure 7.3 for an example of an IIF graph.

Figure 7.3

Example of an IIF graph



Item fit statistics measure the extent to which the items in the QOL-ACC align with the expectation of the Rasch model and provides evidence of measuring what they should be measuring. There are two types of fit statistics: infit (inlier sensitive) and outfit (outlier sensitive). Both the fit statistics are depicted as mean square standardized residuals (MNSQ). Items with MNSQ values within a range of 0.7 to 1.3 are considered good to the Rasch model (Bond et al., 2020; Khadka et al., 2010).

DIF tests whether population subgroups respond to an item differently. DIF occurs when an item is perceived and responded to differently by population subgroups after controlling for overall scale scores (Bond et al., 2020; Khadka et al., 2021). DIF involves assessing the mean difference in item measure between different groups within the sample enabling an understanding of the items regardless of population subgroup. DIF analysis was conducted by age (65-74 years v 75-84 years v 85+ years), gender (male v female) and aged care package (CHSP v HCP) for this sample. It is expected that there should be no difference for the subgroups of the survey sample as the meanings of the items should be the same within the study population.

The Classical Test theory analysis was undertaken using SPSS, Version 25.0 (IBM Corp, 2017) and the Rasch Analysis was undertaken using Winsteps, version 4.7.1 (Linacre, 2021).

7.3.4 Results

Acceptability

The online panel company initially approached 1878 individuals. 1479 did not meet the inclusion criteria as they were not receiving aged care services at home, and therefore, they were not asked to complete the survey. 399 respondents met the eligibility criteria and 313 out of the 399 (78.4%) individuals completed the survey. There was no missing data for any of the items who completed the survey demonstrating good acceptability of all the items for the five domains for the study population.

Socio-demographics of the sample

The socio-demographics of the sample are presented in Table 7.8. A total of 313 individuals completed the survey. Just over half (54.6%) of respondents were female with a large majority of respondents aged 65-74 (50.5%) and 75-84 (43.1%). Approximatively three-quarters of respondents (76.4%) were born in Australia. Half of the participants (50.5%) lived with their spouse or partner and 41.9% lived alone. More respondents were receiving a lower level of care package such as the CHSP, level 1 and level 2 than the higher level packages (level 3 and level 4) which is representative of the current prevalence of CHSP and HCP users in Australia (Australian Department of Health, 2020e; Australia Department of Health, 2021a).

Table 7.8

Stage five respondent characteristics and the Australian home care population

Study Respondents	***n* (%)**	**Australian Home Care Population[a,b]**	**(%)**
Gender, *n* (%)			
Male	142 (45.4)		
Female	171 (54.6)		
Age, *n* (%)			
65-79	254 (81.2)		
80-89	56 (17.9)		
90>	3 (1.0)		
Mean (SD)	75 (5.9)		
Range	65-91		
Country of birth, *n* (%)			
Australia	238 (76.4)		
UK	33 (10.5)		
Other	42 (13.4)		
Highest educational qualification, *n* (%)			
No qualifications	42 (13.4)		
Completed high school	95 (30.4)		
Undergraduate/ Professional qualification	109 (34.8)		
Postgraduate qualification	44 (14.1)		
Other	23 (.3)		
Living arrangements, *n* (%)			
Living alone	131 (41.9)		
Living with spouse/partner	158 (50.5)		
Living with relatives	16 (5.1)		
Living with others (not relatives)	8 (2.6)		
Level of care, *n* (%)		Level of care, (%)	
CHSP	120 (38.3)	CHSP	85.5
Level 1	58 (18.5)	Level 1	1.7
Level 2	68 (21.7)	Level 2	6.0
Level 3	25 (8.0)	Level 3	3.0
Level 4	27 (8.6)	Level 4	3.9
Unsure	15 (4.8)		
Number of hours of support per week			
Mean (SD)	3.3 (5.73)		
Range	1-72		
Self-reported health, *n* (%)			
Excellent	1 (3)		
Very good	45 (14.4)		
Good	104 (33.2)		
Fair	121 (38.7)		
Poor	42 (13.4)		
Self-reported quality of life, *n* (%)			
Excellent	14 (4.5)		
Very good	89 (28.4)		
Good	132 (42.2)		
Fair	70 (22.4)		
Poor	8 (2.6)		
EQ-5D-5L Score, mean (SD)	0.53 (0.31)	EQ-5D-5L Score, mean (SD)[c]	0.85 (0.16)
EQ-VAS Score, mean (SD)	63.12 (21.40)		

Note. Source: [a] Australian Department of Health (2020e); [b] Australian Department of Health (2021a); [c] McCaffrey et al. (2016)

Only one respondent rated their health as ‘excellent’ with the majority rating their health as ‘good’ (33.2%) or ‘fair’ (38.7%). A large majority of respondents (70.6%) rated their QoL as ‘very good’ or ‘good’. Respondents’ HRQoL as approximated by the EQ-5D-5L using the Australian general population specific scoring algorithm was on average significantly lower (mean 0.53, SD 0.31) than for the general population of similar age range (mean 0.85, SD 0.16) (McCaffrey et al., 2016). This finding was not unexpected given that the sample comprised dependent older people in the community receiving aged care services. However, it was slightly higher than the HRQoL for the face validity sample (mean 0.49, SD 0.25) which would be expected as this sample included CHSP recipients which tend to receive a lower level of care than HCP recipients.

Targeting

As shown in Table 7.9, more than 40% of respondents responded to ‘all of the time’ (higher level response category) for the independence items indicating ceiling effects are present. Ceiling effects were also present for both mobility items (see Table 7.10). As indicated in Table 7.12, more than 40% of the respondents responded to ‘all of the time’ for two of the three social connection items (‘I have good social relationships with family and friends’ and ‘I enjoy close relationships with family and friends’) indicating ceiling effects. Ceiling effects were expected across these three domains as the majority of the respondents were receiving basic and/or low level home care packages and therefore expected to have less issues with independence, mobility, and social engagement. Ceiling and floor effects were not present for any of the emotional wellbeing items or the activities items (see Table 7.11 and Table 7.13).

Table 7.9

Independence items response categories

Item	**Categories**	***n* (%)**
I feel that I can live the life I choose and make my own decisions	All of the time	134 (42.8)
	Most of the time	121 (38.7)
	Some of the time	39 (12.5)
	A little of the time	18 (5.8)
	None of the time	1 (0.3)
I am in charge of my own life	All of the time	155 (49.5)
	Most of the time	114 (36.4)
	Some of the time	33 (10.5)
	A little of the time	10 (3.2)
	None of the time	1 (0.3)
I have as much independence as I want	All of the time	130 (41.5)
	Most of the time	110 (35.1)
	Some of the time	56 (17.9)
	A little of the time	14 (4.5)
	None of the time	3 (1.0)

Table 7.10

Mobility items response categories

Item	**Categories**	***n* (%)**
I am physically mobile and can get out and about (with the use of mobility aids, e.g., wheelchair, walker, stick if you use them)	All of the time	137 (43.8)
	Most of the time	100 (31.9)
	Some of the time	35 (11.2)
	A little of the time	35 (11.2)
	None of the time	6 (1.9)
I am able to get around as much as I want to (with the use of mobility aids, e.g., wheelchair, walker, stick if you use them)	All of the time	134 (42.8)
	Most of the time	108 (34.5)
	Some of the time	34 (10.9)
	A little of the time	29 (9.3)
	None of the time	8 (2.6)

Table 7.11

Emotional wellbeing items response categories

Items	**Categories**	***n* (%)**
I am generally happy	All of the time	67 (21.4)
	Most of the time	166 (53.0)
	Some of the time	58 (18.5)
	A little of the time	20 (6.4)
	None of the time	2 (0.6)
I am generally happy and stress free	All of the time	50 (16.0)
	Most of the time	149 (47.6)
	Some of the time	80 (25.6)
	A little of the time	31 (9.9)
	None of the time	3 (1.0)

Table 7.12

Social connections items response categories

Item	**Categories**	***n* (%)**
I have as many connections to the community as I would like	All of the time	87 (27.8)
	Most of the time	108 (34.5)
	Some of the time	63 (20.1)
	A little of the time	42 (13.4)
	None of the time	13 (4.2)
I have good social relationships with family and friends	All of the time	152 (48.6)
	Most of the time	99 (31.6)
	Some of the time	31 (9.9)
	A little of the time	23 (7.3)
	None of the time	8 (2.6)
I enjoy close relationships with family and friends	All of the time	151 (48.2)
	Most of the time	109 (34.8)
	Some of the time	29 (9.3)
	A little of the time	16 (5.1)
	None of the time	8 (2.6)

Table 7.13

Activities items response categories

Item	Categories	*n* (%)
I have leisure activities/hobbies I enjoy	All of the time	93 (29.7)
	Most of the time	90 (28.8)
	Some of the time	65 (20.8)
	A little of the time	45 (14.4)
	None of the time	20 (6.4)
I have enough leisure activities to keep me occupied	All of the time	111 (35.5)
	Most of the time	94 (30.0)
	Some of the time	62 (19.8)
	A little of the time	31 (9.9)
	None of the time	15 (4.8)
I am as busy with my leisure activities as I like to be	All of the time	99 (31.6)
	Most of the time	108 (34.5)
	Some of the time	51 (16.3)
	A little of the time	36 (11.5)
	None of the time	19 (6.1)

Internal consistency

As indicated in Table 7.14, internal consistency reliability of the items for all five dimensions was high as indicated by the Cronbach Alpha scores of ≥0.70 (Tavakol & Dennick, 2011). This indicates all the items have good reliability and are fit for purpose.

Table 7.14

Cronbach alpha co-efficient of the items

Dimension	Cronbach's alpha
Independence	0.83
Mobility	0.84
Emotional Wellbeing	0.91
Social connections	0.81
Activities	0.90

Item dependency

The Pearson correlation co-efficient measures the correlation between two variables to identify the strength of the relationship. It is a test to explore whether items are providing different information (when not highly correlated) or providing similar information (when highly correlated). If items are highly correlated, it means that they are similar and therefore only one item is needed from the pair as they are essentially measuring the same concept.

As shown in Table 7.15, the relationship between the independence items ‘I am in charge of my own life’ and ‘I feel that I can live the life I choose’ demonstrated a high correlation (>0.60) indicating they were correlated and therefore measuring the same concept. However, the items ‘I am in charge of my own life’ and ‘I have as much independence as I want’ exhibited a slightly low correlation (<0.60) suggesting they were not correlated as highly and were measuring different information for that construct.

The association between the social connection items ‘I have good social relationships with family and friends’ and ‘I have as many social connections to the community as I would like’ and the association between ‘I enjoy close relationships with family and friends’ and ‘I have as many connections to the community as I would like’ were not correlated (<0.60) indicating they may be measuring different concepts which would be expected as one of the items is addressing relationships with the community and the other items are related to family and friends and older people may potentially see these relationship as different. However, the relationship between ‘I enjoy close relationships with family and friends’ and ‘I have good social relationships with family and friends’ exhibited a high correlation (>0.60) indicating they were measuring the same concept.

Both the mobility items, the emotional wellbeing items and the activities items demonstrated a high correlation (>0.60) indicating they each are measuring the same concept.

Table 7.15

Pearson correlation co-efficient matrix of the items for each dimension

	I feel that I can live the life I choose and make my own decisions	I am in charge of my own life	I have as much independence as I want
I feel that I can live the life I choose and make my own decisions	1.0		
I am in charge of my own life	0.65	1.0	
I have as much independence as I want	0.65	0.58	1.0
	I am physically mobile and can get out and about (with the use of mobility aids, e.g., wheelchair, walker, stick if you use them)	I am able to get around as much as I want to (with the use of mobility aids, e.g., wheelchair, walker, stick if you use them)	
I am physically mobile and can get out and about (with the use of mobility aids, e.g., wheelchair, walker, stick if you use them)	1.0		
I am able to get around as much as I want to (with the use of mobility aids, e.g., wheelchair, walker, stick if you use them)	0.73	1.0	
	I am generally happy	I am generally happy and stress free	
I am generally happy	1.0		
I am generally happy and stress free	0.83	1.0	
	I have as many connections to the community as I would like	I have good social relationships with family and friends	I enjoy close relationships with family and friends
I have as many connections to the community as I would like	1.0		
I have good social relationships with family and friends	0.51	1.0	
I enjoy close relationships with family and friends	0.47	0.77	1.0
	I have leisure activities/hobbies I enjoy	I have enough leisure activities to keep me occupied	I am as busy with my leisure activities as I like to be
I have leisure activities/hobbies I enjoy	1.0		

I feel that I have enough leisure activities to keep me occupied	0.75	1.0	
I am as busy with my leisure activities as I like to be	0.70	0.84	1.0

Rasch model based psychometric assessments

Response category function

Response categories for the items for all the five dimensions were ordered and evenly spaced demonstrated by the peaks not overlapping on the graphs (Tables 7.16-7.20). This indicates that the distribution of response categories for all dimensions were good and, in the order as expected.

Item Information Function

As indicated by Tables 7.16-7.20, items within each dimension demonstrated similar IIF. All of the independence items have similar humps indicating that the items provide information at both low and high values of the construct, but the information is higher towards higher values of the construct being measured. Similar to the independence, items, the two mobility items have similar humps to each other indicating that the items provide information at both low and high values of the construct, but the information is slightly higher towards the higher values of the construct being measured. The social connections items demonstrate that the items provide information at both low and high values of the construct but there is a distinct high peak demonstrating that the item is more informative at higher values than lower values. All of the emotional wellbeing items have staggered peaks which means they provide similar information at three different ranges of the construct but no or low information between these three peaks. The three activities dimensions each had three humps indicating the items provide information at both low and high values of the construct.

Table 7.16

Independence: Response categories and Item Information function

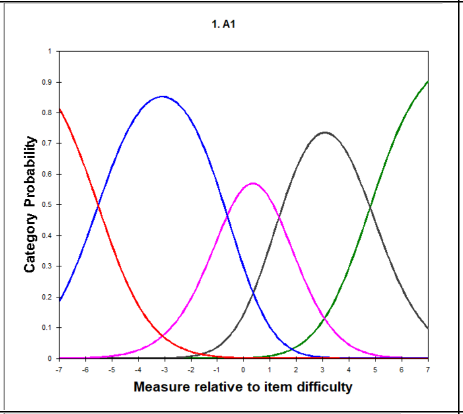
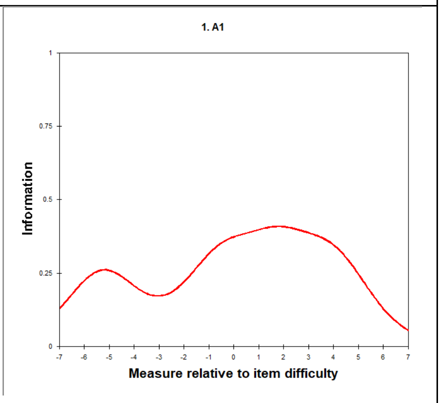
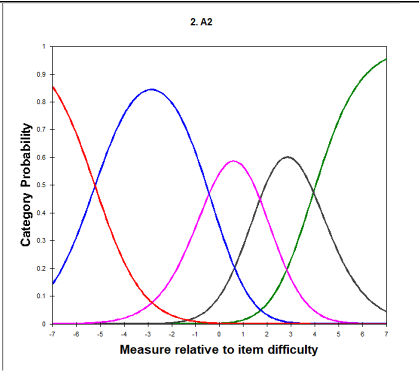
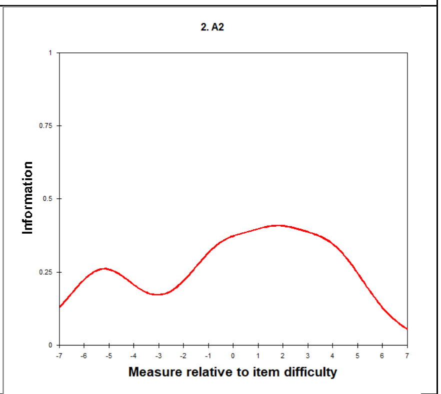
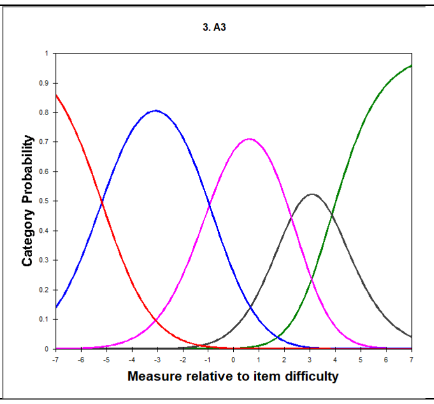
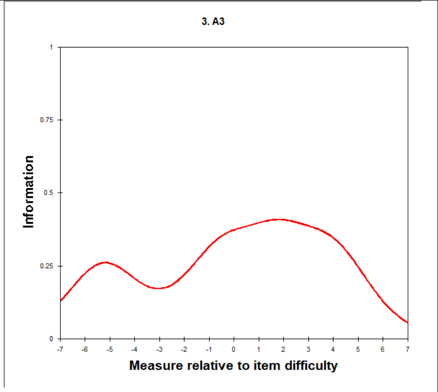
Independence	**Response Categories**	**Item Information Function**
I feel that I can live the life I choose and make my own decisions		
I am in charge of my own life		
I have as much independence as I want		

Table 7.17

Mobility: Response categories and Item Information function

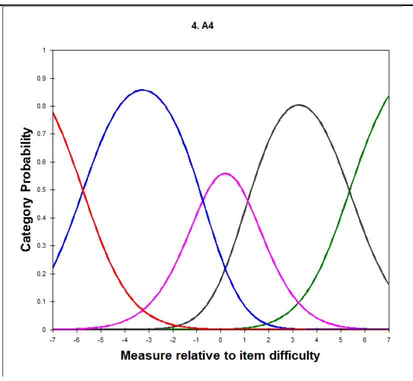
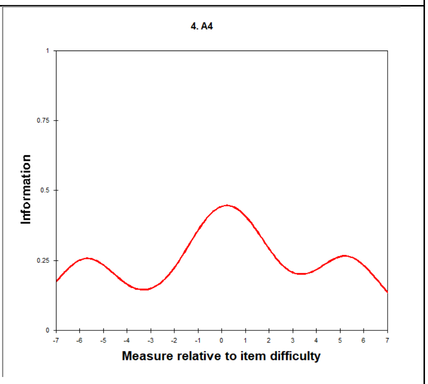
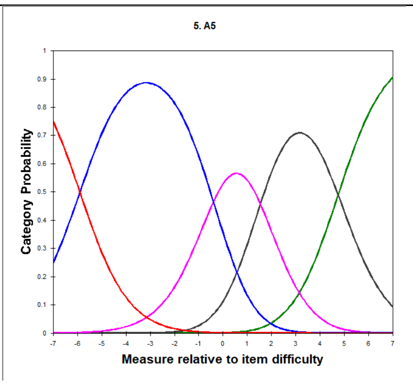
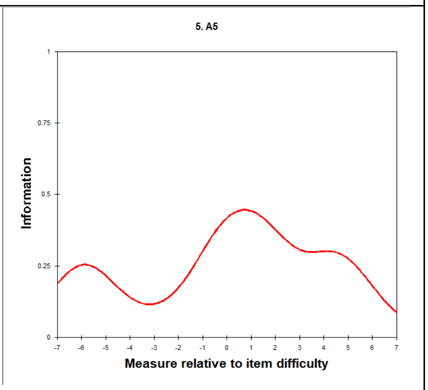
Mobility	**Response Categories**	**Item Information Function**
I am physically mobile and can get out and about (with the use of mobility aids, e.g., wheelchair, walker, stick if you use them		
I am able to get around as much as I want to (with the use of mobility aids, e.g., wheelchair, walker, stick if you use them)		

Table 7.18

Emotional wellbeing: Response categories and Item Information function

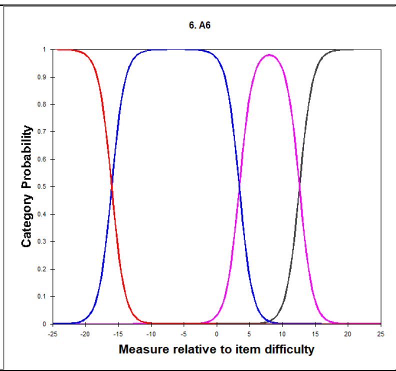
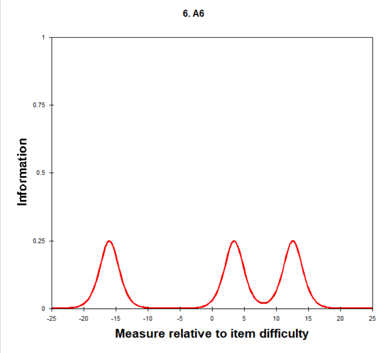
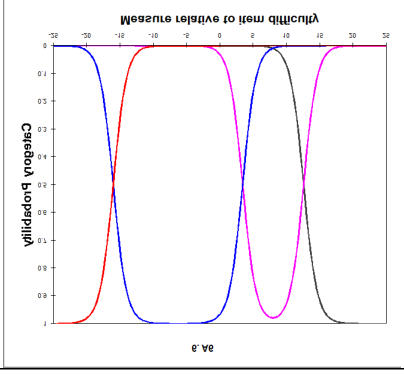
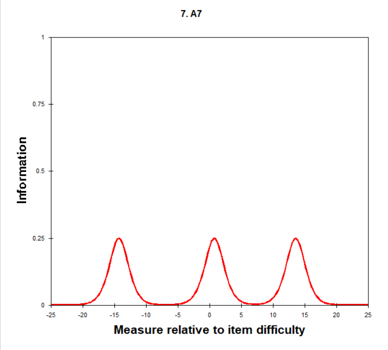
Emotional wellbeing	**Response categories**	**Item Information Function**
I am generally happy		
I am generally happy and stress free		

Table 7.19

Social Connections: Response categories and Item Information function

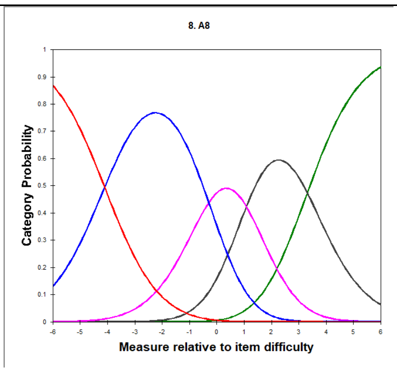
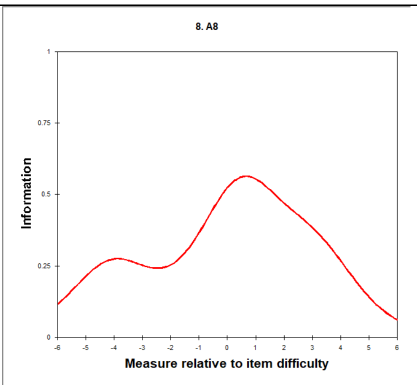
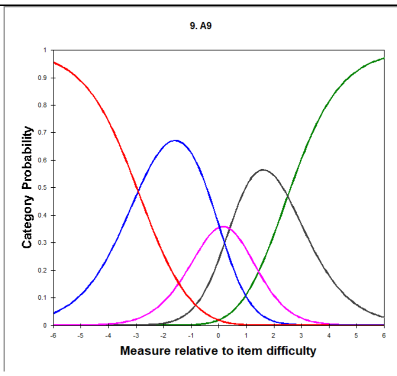
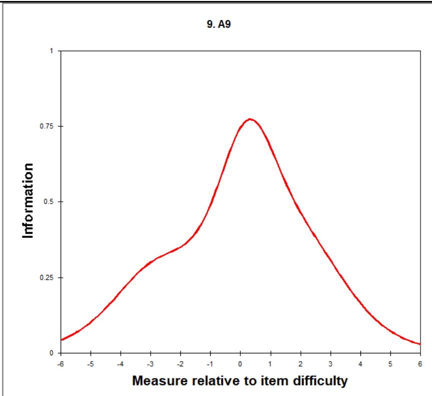
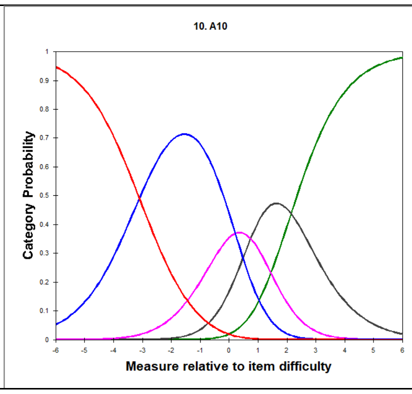
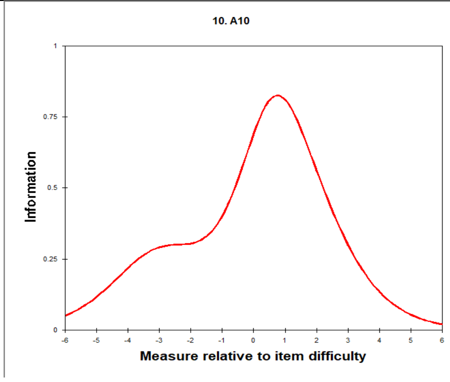
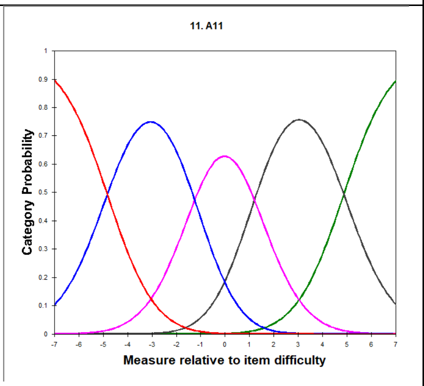
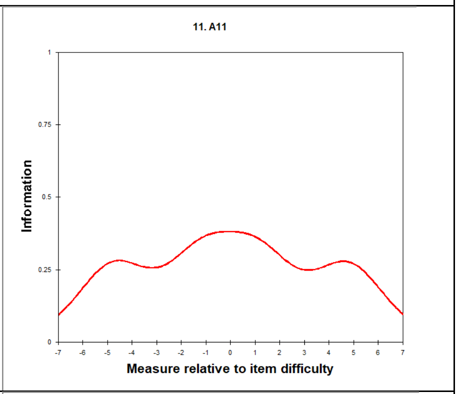
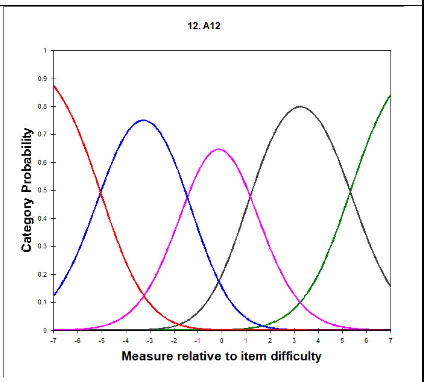
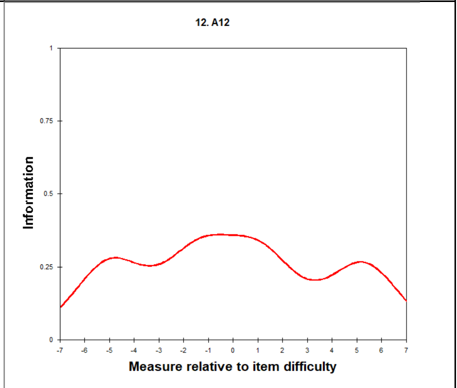
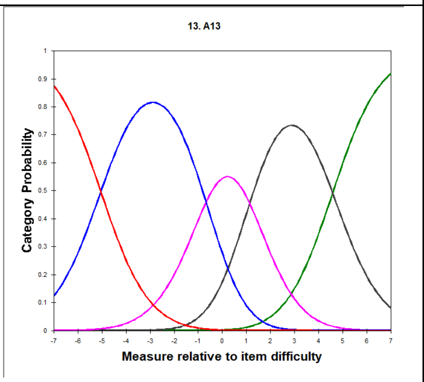
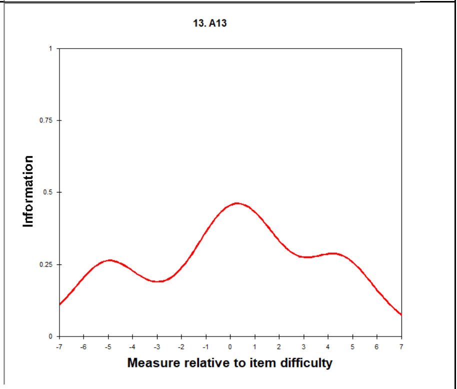
Social Connections	**Category function**	**Item Information Function**
I have as many connections to the community as I would like		
I have good social relationships with family and friends		
I enjoy close relationships with family and friends		

Table 7.20

Activities: Response categories and Item Information function

Activities	Category function	Item Information Function
I have leisure activities/hobbies I enjoy		
I feel that I have enough leisure activities to keep me occupied		
I am as busy with my leisure activities as I like to be		

Item fit statistics

Table 7.21 shows the results for the item fit statistics test. All the items demonstrated a good fit (MNSQ value between 0.70-1.30) apart from the item ‘I have as many social connections to the community as I would like’ which demonstrated an acceptable fit (1.40).

Table 7.21

Item fit statistics

Item	Infit MNSQ	Outfit MNSQ
Independence		
I feel that I can live the life I choose and make my own decisions	0.88	0.89
I am in charge of my own life	1.03	0.94
I have as much independence as I want	1.07	1.04
Mobility		
I am physically mobile and can get out and about (with the use of mobility aids, e.g., wheelchair, walker, stick if you use them)	0.99	0.83
I am able to get around as much as I want to (with the use of mobility aids, e.g., wheelchair, walker, stick if you use them)	0.99	0.80
Emotional Wellbeing		
I am generally happy	0.96	0.48
I am generally happy and stress free	0.97	0.50
Social connections		
I have as many connections to the community as I would like	1.40	1.38
I have good social relationships with family and friends	0.71	0.69
I enjoy close relationships with family and friends	0.80	0.83
Activities		
I have leisure activities/hobbies I enjoy	1.30	1.29
I feel that I have enough leisure activities to keep me occupied	0.74	0.73
I am as busy with my leisure activities as I like to be	0.93	0.93

Differential Item Functioning

Table 7.22 shows the differential item functioning of the items by gender, age, and type of aged care package. The independence, mobility, social connections, and activities items demonstrated no or an acceptable level of DIF. The emotional wellbeing items indicated no or an acceptable level of DIF for gender and type of care package. However, the emotional wellbeing item 'I am generally happy' demonstrated unacceptable levels of DIF when examining for certain age comparisons (1.57 [65-74 v 85+]; 1.84 [75-84 v 85+]). The younger age group (65-74) compared to the older age group (85+) and the middle age group (75-84) compared to the older age group (85+) reported unacceptable levels indicating these age groups would respond differently to the question. However, it is possible that the older group of people perceive happiness differently to the younger old people and the middle old people as they are nearing the end of their life so may be more burdened with physical health issues that could affect their general feelings of happiness.

Table 7.22

Differential Item functioning

Item	DIF specification	DIF (logit)
Independence		
I feel that I can live the life I choose and make my own decisions	Male v Female	-0.19
	65-74 v 75-84	-0.04
	65-74 v 85+	-0.39
	75-84 v 85+	-0.36
	CHSP v HCP1	-0.16
	CHSP v HCP2	0.22
	CHSP v HCP3	-0.37
	CHSP v HCP4	-0.84
I am in charge of my own life	Male v Female	0.15
	65-74 v 75-84	-0.13
	65-74 v 85+	0.33
	75-84 v 85+	0.46
	CHSP v HCP1	0.66
	CHSP v HCP2	-0.02
	CHSP v HCP3	0.23
	CHSP v HCP4	0.94
I have as much independence as I want	Male v Female	0.05
	65-74 v 75-84	0.16
	65-74 v 85+	0.05
	75-84 v 85+	-0.11
	CHSP v HCP1	-0.45
	CHSP v HCP2	-0.18
	CHSP v HCP3	0.17
	CHSP v HCP4	-0.08
Mobility		
I am physically mobile and can get out and about (with the use of mobility aids, e.g., wheelchair, walker, stick if you use them	Male v Female	0.12
	65-74 v 75-84	-0.11
	65-74 v 85+	0.14
	75-84 v 85+	0.24
	CHSP v HCP1	-0.48
	CHSP v HCP2	0.30
	CHSP v HCP3	0.09
	CHSP v HCP4	0.38
I am able to get around as much as I want to (with the use of mobility aids, e.g., wheelchair, walker, stick if you use them)	Male v Female	-0.12
	65-74 v 75-84	0.10
	65-74 v 85+	-0.14
	75-84 v 85+	-0.24
	CHSP v HCP1	0.49
	CHSP v HCP2	-0.30
	CHSP v HCP3	-0.09
	CHSP v HCP4	-0.36
Emotional Wellbeing		
I am generally happy	Male v Female	-0.66
	65-74 v 75-84	-0.27
	65-74 v 85+	1.57
	75-84 v 85+	1.84
	CHSP v HCP1	0.90

	CHSP v HCP2	0.42
	CHSP v HCP3	-0.68
	CHSP v HCP4	0.06
I am generally happy and stress free	Male v Female	0.67
	65-74 v 75-84	0.27
	65-74 v 85+	-1.59
	75-84 v 85+	-1.86
	CHSP v HCP1	-0.91
	CHSP v HCP2	-0.43
	CHSP v HCP3	0.70
	CHSP v HCP4	-0.06
Social Connections		
I have as many connections to the community as I would like	Male v Female	-0.55
	65-74 v 75-84	0.02
	65-74 v 85+	-0.74
	75-84 v 85+	-0.77
	CHSP v HCP1	-0.25
	CHSP v HCP2	0.60
	CHSP v HCP3	0.12
	CHSP v HCP4	0.05
I have good social relationships with family and friends	Male v Female	0.11
	65-74 v 75-84	0.11
	65-74 v 85+	0.00
	75-84 v 85+	-0.11
	CHSP v HCP1	0.25
	CHSP v HCP2	-0.28
	CHSP v HCP3	0.06
	CHSP v HCP4	0.38
I enjoy close relationships with family and friends	Male v Female	0.47
	65-74 v 75-84	-0.16
	65-74 v 85+	0.82
	75-84 v 85+	0.98
	CHSP v HCP1	0.01
	CHSP v HCP2	-0.36
	CHSP v HCP3	-0.18
	CHSP v HCP4	-0.48
Activities		
I have leisure activities/hobbies I enjoy	Male v Female	0.70
	65-74 v 75-84	0.40
	65-74 v 85+	0.06
	75-84 v 85+	-0.34
	CHSP v HCP1	0.13
	CHSP v HCP2	-0.09
	CHSP v HCP3	-0.30
	CHSP v HCP4	-0.22
I feel that I have enough leisure activities to keep me occupied	Male v Female	-0.28
	65-74 v 75-84	-0.44
	65-74 v 85+	-0.19
	75-84 v 85+	0.47
	CHSP v HCP1	-0.16
	CHSP v HCP2	0.18
	CHSP v HCP3	0.14
	CHSP v HCP4	-0.11
I am as busy with my leisure activities as I like to be	Male v Female	-0.45
	65-74 v 75-84	0.00
	65-74 v 85+	0.11
	75-84 v 85+	0.11
	CHSP v HCP1	0.03
	CHSP v HCP2	-0.08
	CHSP v HCP3	0.15
	CHSP v HCP4	0.33

7.4 STAGE 5 COMBINING THE QUALITATIVE AND QUANTITATIVE DATA

7.4.1 Analysis

The qualitative data for the draft items was taken from the face validity interviews (stage three) and charted onto an Excel spreadsheet with the items across the horizontal axis and participant comments across the vertical axis. The comments were colour-coded into red (negative comments) if the participant thought the item was ambiguous, implied judgement, unclear, not easy to answer, or contained sensitive or distressing words. The comments were coded as amber (neutral comments) for mixed or neutral comments and comments were coded as green (positive comments) if the participant liked the comment and expressed it was clear, unambiguous, or easy to understand.

The quantitative data from stage four was colour-coded based on acceptable standards for psychometric analysis (Kandel et al., 2017; Mokkink et al., 2010; Young et al., 2009). This approach was adopted by Khadka et al. (2013) which outlined psychometric standards for patient-reported measures (PROS) by assigning 'A' (excellent psychometric properties), 'B' (acceptable psychometric properties) or 'C' (unsatisfactory psychometric properties). This criterion was adapted using colours rather than letters ('A' coded as green, 'B' coded as amber, and 'C' coded as red) for each item. This process allowed the items with the best properties to be clearly identified. Table 7.7 (section 7.3.3) details the criteria with the cut off and threshold values used to assign traffic light coding to the items to identify the items with the best psychometric performance.

The quantitative and qualitative data was collated using the traffic light grading pictorial approach. The use of the traffic light pictorial method was chosen for this study because the development of the measure involved both academic and non-academic individuals to attend a panel meeting to decide on the final items for the descriptive system for the QOL-ACC. Presenting the integrated qualitative and quantitative data in a pictorial format at the meeting made the data easy to understand for all panel members regardless of their level of psychometric knowledge. A panel of experts (comprising of members of the project research team (n=6), one psychometric expert, aged care providers (n=2) and one consumer representative) met to discuss the data from stage three and stage four to reach a consensus on which items to include for the QOL-ACC descriptive system. An overview of the demographics of the participants for stage three and stage four was provided, and an explanation of how the qualitative and quantitative data had been coded was also explained. The traffic light pictorial image was presented to the panel for each of the dimensions and a discussion took place based on the evidence from the data. All the attendees examined the data and the aged care organisation representatives gave their expert opinion to reach a consensus for the best item to represent each of the five dimensions of the QOL-ACC descriptive system.

7.4.2 Results

The expert panel also agreed that there should be one item per dimension where possible for the QOL-ACC descriptive system for ease of use and practicality taking into consideration the population for whom the measure is intended. Table 7.23 shows the traffic light pictorial for each of the dimensions. ‘I have as much independence as I want’ was chosen as the final item for the independence dimension. As indicated, this item demonstrated the best psychometric properties of the three independence items and the feedback from participants was positive. Furthermore, some of the participants had mentioned they preferred the items that addressed one question rather than two questions, such as ‘I feel that I can live the life I choose and make my own decisions’. Therefore, it was agreed it was preferable to choose an item that addressed one question for ease of use. The panel also agreed that choosing an item including the word of the dimension (independence) would be easier for respondents to interpret 'I am able to get around as much as I want to (with the use of mobility aids, e.g., wheelchair, walker, stick if you use them)' was chosen as the final item for the mobility dimension. Both mobility items demonstrated similar psychometric properties. However, the item that was selected was the most preferred by participants (32.3%) and feedback from participants was more positive for the final mobility item than the alternative item ('I am physically mobile and can get out and about (with the use of mobility aids, e.g., wheelchair, walker, stick if you use them').

The final item chosen to represent the emotional wellbeing dimension was 'I am generally happy'. This item was selected as it performed well psychometrically and received positive comments from participants. The panel agreed that the final item would be easier to understand as it contained one aspect (happy) rather than two aspects (happy and stress) which the panel considered would be easier to interpret and respond to. 'I have good social relationships with family and friends' was selected to represent the social connections dimension. This item performed well psychometrically and received positive feedback from participants. This item was also the most preferred item (43.3%) by participants. The item chosen for the activities dimension was 'I have leisure activities/hobbies I enjoy'. As shown, this item performed well psychometrically and was the most preferred item by participants (42.9%). The comments about the item were mostly positive by participants and the panel agreed the simplicity of the wording was appropriate for older people to understand.

Table 7.23

Traffic light coding for the draft items for each dimension

QOL-ACC items	Face Validity	Traditional (Classical Test Theory) Based psychometric properties				Modern Psychometrics (Rasch Analysis) based properties					
		Acceptability	Targeting	Internal consistency reliability	Item dependency	Response category function	Item fit statistics	Item Information function	Differential Item Functioning		
									Gender	Age	Service type
I feel that I can live the life I choose and make my own decisions	🟩	🟩	🟥	🟩	🟩	🟩	🟩	🟨	🟩	🟩	🟩
I am in charge of my own life	🟩	🟩	🟥	🟩	🟩	🟩	🟩	🟨	🟩	🟩	🟨
I have as much independence as I want	🟩	🟩	🟥	🟩	🟩	🟩	🟩	🟨	🟩	🟩	🟩
I am physically mobile and can get out and about (with the use of mobility aids e.g., wheelchair, walker, stick if you use them)	🟩	🟩	🟥	🟨	🟩	🟩	🟩	🟨	🟩	🟩	🟩
I am able to get around as much as I want to (with the use of mobility aids e.g., wheelchair, walker, stick if you use them)	🟩	🟩	🟥	🟨	🟩	🟩	🟩	🟨	🟩	🟩	🟩
I am generally happy	🟩	🟩	🟨	🟨	🟩	🟩	🟩	🟨	🟩	🟨	🟩

I am generally happy and stress free	🟩	🟩	🟨	🟨	🟩	🟩	🟩	🟨	🟨	🟩	🟩
I have as many social connections to the community as I would like*	-	🟩	🟨	🟩	🟨	🟩	🟨	🟩	🟩	🟩	🟩
I have good social relationships with family and friends	🟩	🟩	🟥	🟨	🟩	🟩	🟩	🟩	🟩	🟩	🟩
I enjoy close relationships with family and friends	🟩	🟩	🟥	🟨	🟩	🟩	🟩	🟩	🟩	🟨	🟩
I have leisure activities / hobbies I enjoy	🟩	🟩	🟨	🟩	🟩	🟩	🟩	🟨	🟨	🟩	🟩
I feel that I have enough leisure activities to keep me occupied	🟩	🟩	🟨	🟩	🟩	🟩	🟩	🟨	🟩	🟩	🟩
I am as busy with my leisure activities as I like to be	🟩	🟩	🟨	🟩	🟩	🟩	🟩	🟨	🟩	🟩	🟩

*****There is no face validity data for this item as this item was generated after the face validity stage (See section 7.3.2).

Table 7.24 below outlines the final items selected to represent the 5 dimensions of the QOL-ACC descriptive system.

Table 7.24

Final items for the five dimensions for the QOL-ACC descriptive system

Dimension	Item	Reason for selection
Independence	I have as much independence as I want.	This item demonstrated the best psychometric properties and the feedback from participants was mainly positive. The panel members agreed it was preferable to choose an item that addressed one question for ease of use and included the word of the dimension (independence).
Mobility	I am able to get around as much as I want to (with the use of mobility aids e.g., wheelchair, walker, stick if you use them).	The psychometric properties were similar for both items. Therefore, this item was selected based on it being the most preferred and the positive feedback from the face validity interviews.
Emotional Well-being	I am generally happy.	This item was selected as it performed well psychometrically and received positive comments from participants. The panel members agreed his item would be easier to understand as it contained one aspect (happy) rather than two aspects (happy and stress).
Social Connections	I have good social relationship with family and friends.	This item was selected because it performed well psychometrically. It received positive feedback from participants and was also the most preferred item.
Activities	I have leisure activities / hobbies I enjoy.	This item performed well psychometrically and was the most preferred item by participants. The panel members agreed the simplicity of the wording was appropriate for older people to understand.

7.5 DISCUSSION

This chapter has described the final stages in the development of the QOL-ACC descriptive system integrating both quantitative and qualitative methods to select the final items for each dimension. Whilst a mixed method approach is common in research (Johnson & Onwuegbuzie, 2004), traditionally the development of preference-based QoL measures across health and social care settings have strongly relied on the use of quantitative methods or qualitative methods rather than mixed method approaches. For example, the dimensions of the ICECAP-O were developed from in-depth qualitative interviews with older people and an extensive literature search (Coast et al., 2008; Grewal et al., 2006). Whereas other measures such as the EQ-5D developed its dimensions from existing literature and then adopted quantitative methods to assess the items (The EuroQol Group, 1990). The US Food and Drug Administration (FDA) recommend in their guidelines that both quantitative and qualitative methods should be used in measure development and where possible its users should be included in measure development (U.S. Department of Health and human services: Food and Drug Administration, 2009). However, this is very rare and as Keetharuth and colleagues have noted, when mixed methods have been applied in the development of measures, the approaches have often been used sequentially rather than the two approaches being integrated to determine final item selection (Keetharuth et al., 2018). The mixed methodology approach adopted for the final item selection for the QOL-ACC descriptive system was based upon the work by Keetharuth et al. (2018) who successfully combined the two approaches in the development of the ReQoL for mental health populations.

Face validity assessment is a key stage in the development of a measure which can only be attained through qualitative data collection with the population for whom the measure is intended. The qualitative evidence produced for this stage through interviews with older adults receiving aged care services in the community would not have been able to be generated through purely quantitative methods. The involvement of the population in which the measure is intended for in its development is imperative to ensure that the items chosen truly reflect what is important to older people. This approach ensures the dimensions are relevant, and appropriate, thus increasing the validity and reliability of the measure and its responsiveness to self-completion.

Whilst the views of older people are imperative when developing a measure, it is also important to ensure the measure performs psychometrically. Psychometrically analysing the quantitative data assesses whether the items are measuring what they should be measuring, thus ensuring they meet the necessary psychometric standards. Ensuring that the best items are chosen for a descriptive system involves considering both the face and content validity evidence and the psychometric evidence. The psychometric and face validity evidence was positive for most of the items which was not surprising because the items were developed from the interviews with older people about the meaning of QoL (stage one of the research), thus maintaining the meanings and language of the participants.

This stage of the research has shown the importance of integrating both qualitative and quantitative approaches to inform the research and demonstrates how these two approaches can be successfully combined. The integration of both these approaches are imperative to develop a psychometrically robust measure that is relevant to older people receiving aged care services in the community. Additionally, including a panel of experts from aged care organisations and consumer representatives demonstrates that it is possible to involve people from different backgrounds and organisations to examine complex data and meaningfully contribute to decisions about final item selection if the data is presented in a comprehensible understandable format. The pictorial traffic light approach adopted for the analysis of the data ensured that all panel members could meaningfully contribute to discussions about final item selection without advanced qualitative and psychometric knowledge. The involvement of aged care providers and consumer representatives in this stage of the research is important to ensure that the final items for the descriptive system reflect the dimensions of QoL that aged care organisations can be expected to impact upon. This is imperative to ensure the QOL-ACC can be used for QoL assessment as part of a broader suite of quality indicators and for economic evaluation in the aged care sector in the future.

Although a diverse sample of participants was recruited, it is important to recognise that hard to reach older adults may have been excluded from this research. The research does not include participants who could not communicate in English, and it is recognised that, in common with many other developed nations, Australia's population is culturally diverse. However, including older adults whose first language was not English was unfortunately outside the scope of this research due to resource limitations.

Stages three to five of the development of the QOL-ACC outlined in this chapter were carried out during the COVID-19 pandemic, and therefore the data collection method had to be adapted. Face-to-face validity interviews (stage three) were originally planned with older people in their homes but due to restrictions these interviews had to take place via the telephone. Initially, the target sample was 40 older adults receiving aged care services but due to the impact that COVID-19 had on recruitment and the interviews needing to be telephone-based, the sample was slightly smaller (*n*=31). It was initially expected that it may be challenging to keep the participants engaged during the interview as the interviews were telephoned based. However, because the interviews were conducted when the majority of participants were in lock down, many participants welcomed the opportunity to speak with the interviewers and provided in-depth responses to questions. Furthermore, the QoL cards that the participants had received in the post to use in the interview kept the participants engaged, and often the participants had spent time considering the cards prior to the interview as they had more free time due to COVID-19 restrictions.

Furthermore, all of stage four (online survey) data collection had to be conducted online due to COVID-19 restrictions. It was originally planned that the majority of the data would be collected online due to the large sample size needed to conduct psychometric testing and restrictions in budget and time. However, it was planned that some of the data would be collected face to face but COVID-19 restrictions prevented any data for this stage being collected face to face. Therefore, it is recognised that hard to reach groups including older people who may not have access to a computer or the internet to complete the survey may have been excluded.

7.6 CONCLUSION

To conclude, this chapter has outlined three key stages in the development of the final items of the QOL-ACC descriptive system: face validity, psychometric assessment, and the combination of these methods to inform final item selection. This measure is unique in its development as to our best knowledge no other measure has been developed for older people in receipt of aged care services in the community using both rigorous psychometric analysis (quantitative) and a robust qualitative method involving older people to ensure that their perspectives and preferences are included. This approach means that the QOL-ACC will be relevant and acceptable to its population, older people in receipt of aged care services in the community. The next chapter will focus on assessing the construct validity of the QOL-ACC descriptive system to identify if the measure is psychometrically robust and whether it is a valid measure of QoL of older people in receipt of aged care services in the community.

8. CONSTRUCT VALIDITY OF THE QOL-ACC

8.1 INTRODUCTION

This chapter outlines the construct validity (convergent validity and known group validity) of the QOL-ACC descriptive system. Convergent validity was assessed by examining the relationship between the QOL-ACC and three other preference-based measures: ASCOT (SCRQoL), EQ-5D-5L (HRQoL) and the QCE-ACC (quality of care experience measure developed from the literature review in Chapter 3). The known group validity of the QOL-ACC was examined by identifying if the QOL-ACC was able to differentiate between older people with different levels of self-reported health and between older people with different levels of self-reported QOL. The chapter concludes by assessing if the QOL-ACC descriptive system has acceptable construct validity.

8.2 METHODS

8.2.1. Data collection and recruitment

Older people receiving either a CHSP or a HCP were recruited via an Australia-wide online panel company comprising over 10,000 Australian adults of all ages and asked to complete an online survey. The data sample used to assess the construct validity of the QOL-ACC is the same sample that was used for stage four of the research. For further specifics of the recruitment of this sample please see Chapter 7, section 7.3.1.

8.2.2 Survey

The online survey involved the respondents completing the QOL-ACC measure, the EQ-5D-5L (Herdman et al., 2011), the ASCOT (Netten et al., 2012a), the QCE-ACC (Khadka et al., 2020), and a series of brief socio-demographic questions (Appendix 14).

QOL-ACC

The QOL-ACC has five dimensions (mobility, emotional wellbeing, independence, social connections, and activities) and each item has five response levels. Further details of the development of the QOL-ACC and its dimensions are provided in Chapters 6 and 7.

EQ-5D-5L

The EQ-5D-5L is a generic preference-based measure that measures HRQoL life. The measure consists of five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression with five response levels for each item. The EQ-5D-5L has the option of being administered with the visual analogue scale (EQ-VAS). The EQ-VAS is a vertical scale with two endpoints 'the best health you can imagine' and 'the worst health you can imagine' in which individuals are asked to record their self-rated health on the scale (0-100) (Herdman et al., 2011). The Australian pilot scoring algorithm (Norman et al., 2013) was used to calculate the scores for the analysis.

ASCOT

The ASCOT is a preference-based social care measure that assesses an individual's social care needs and wants, (SCRQoL). The measure consists of eight dimensions: control over daily life, personal cleanliness and comfort, food and drink, personal safety, social participation and involvement, occupation, accommodation, cleanliness and comfort, and dignity. Each dimension comprises of four response levels (ideal, no unmet needs, some unmet needs, high unmet needs) based on Sen's theory of capabilities (Netten et al., 2012a).

QCE-ACC

The QCE-ACC is a preference-based measure that measures the quality of care experience of older people receiving aged care services. The measure was recently developed from a study that was commissioned by the Royal Commission into Aged Care Quality and Safety in Australia (Ratcliffe et al., 2020). The comprehensive literature review that I led underpinning the development of the QCE-ACC identified nine key themes relating to quality of care; respect and dignity, spiritual, cultural, religious and sexual identity, aged care staff skills, relationships with aged care staff, informed choices, social relationships and the community, supporting older people's health and wellbeing, safety and comfort and the ability to make complaints and provide feedback (see Chapter 3 for further details). Following consultation with advisory groups members the nine themes were refined into six dimensions for the validation stage. Six dimensions were chosen because DCE designs typically consist of five or six dimensions for easy comprehension and completion by individuals (Jonker et al., 2019). The six dimensions of the QCE-ACC are respect and dignity, services and supports, decision-making, staff skills and training, social relationships, and complaints, each with five response levels.

The preference weighted scoring system was developed using DCE methodology in which members of the Australian general population were asked to make hypothetical choices between service providers with different quality of care characteristics based upon the QCE descriptive system (Ratcliffe et al., 2020). The QCE-ACC has recently been validated in a sample of older people receiving aged care in the community and in residential care by assessing its psychometric performance and validity using Classical Test Theory and modern Rasch analysis. The QCE-ACC performed well psychometrically and met tests of construct, convergent and known group validity. These assessments demonstrated that the QCE-ACC was appropriate to be applied in both residential and community aged care to assess quality of care experiences.

Implementing the QCE-ACC in aged care settings can demonstrate variances in quality of care across providers and can also be used to provide longitudinal data to assess performance of aged care providers over time (Khadka et al., 2020).

8.2.3 The approach for assessment of validity

When developing a new measure, such as the QOL-ACC, it is important to assess for validity to evaluate whether the instrument measures what it pertains to measure (Terwee et al., 2018; U.S Department of Health and Human Services, 2009). Content validity and construct validity are different techniques for assessing the validity of a measure (Bowling & Ebrahim, 2005). Content validity is the extent in which the content of the measure assesses the characteristics of what it intends to measure relevant to the target population. Content validity of the QOL-ACC was initially assessed through in-depth interviews with older people receiving aged care services to develop the dimensions of the QOL-ACC (see Chapter 6 for further details) and then further provided through face validity assessments of the draft items with older people receiving aged care services in the community (see Chapter 7 for further details).

This chapter details the assessment of the construct validity of the QOL-ACC descriptive system. Construct validity is the extent to which a measure validly measures the construct it intends to measure (Mokkink et al., 2018; Prinsen et al., 2018). Convergent validity and known group validity are two different types of construct validity. Convergent validity examines whether the measure correlates with other measures that claim to be measuring a related concept, and if so to what extent. Assessing convergent validity is achieved by making prior hypotheses of the expected correlations between the measures and then testing the hypotheses. It is expected that a new measure would be strongly correlated with an existing measure that intends to measure a similar construct. Ideally, it would be preferable to assess a new measure against a gold standard. However, there is no such measure in existence, and therefore, the QOL-ACC was assessed against two preference-based QoL measures (EQ-5D-5L and the ASCOT) and a preference-based quality of care experience measure (QCE-ACC). The QOL-ACC was assessed against the overall scores of the QCE-ACC and the EQ-5D-5L because the individual dimension scores are not yet available (Norman et al., 2013). The ASCOT dimensions can be scored individually, and therefore, the QOL-ACC was assessed against the overall score and the individual scores of the ASCOT.

A series of prior hypotheses were constructed of the expected relationships between the QOL-ACC and the other measures (Table 8.1). It was expected that the QOL-ACC would exhibit a positive and significant correlation with the EQ-5D-5L, ASCOT, QCE-ACC, and the EQ-VAS. The EQ-5D-5L measures HRQoL, the ASCOT measures SCRQoL, the QCE-ACC measures quality of care and the EQ-VAS measures self-rated health which are all related constructs to older-person specific QoL. It was predicted that the weakest correlation would be between the QCE-ACC and the QOL-ACC because although it is expected that an individual's quality of care may impact upon their quality of life, they are essentially two separate constructs. It was predicted that the strongest relationship would be between the QOL-ACC and the ASCOT because the ASCOT measures SCRQoL which is the most similar construct to older person-specific QoL.

Table 8.1

A priori hypothesized association between the QOL-ACC and other constructs

Constructs	Expected associations with the QOL-ACC
Preference-based QOL	
EQ-5D-5L	It is expected that the EQ-5D-5L and the QOL-ACC would be positively correlated, and that the correlation would be significant. The EQ-5D-5L measures generic HRQoL and the QOL-ACC measures older person-specific QoL which are related constructs.
ASCOT	It is expected that the ASCOT and the QOL-ACC would be positively correlated, and that the correlation would be significant. It is anticipated that the correlation between the ASCOT and the QOL-ACC would be more strongly correlated than between the EQ-5D-5L and the QOL-ACC. The ASCOT measures SCRQoL and it is likely that SCRQoL would exhibit higher correlations with older person-specific QoL (measured by the QOL-ACC) than generic HRQoL (measured by the EQ-5D-5L). SCRQoL and older person-specific QoL are related constructs.
Quality of care in aged care	
QCE-ACC	It is expected that the QOL-ACC and the QCE-ACC would be positively correlated, and that the correlation would be significant. The QCE-ACC measures quality of aged care which should be correlated to an older person's QoL as it would be expected that an older person's quality of care may impact upon their QoL and vice versa. However, older person-specific QOL and quality of aged care are two separate constructs and therefore, it is anticipated that the correlation would be weaker between the QOL-ACC and the QCE-ACC than the QOL-ACC and the EQ-5D-5L and the ASCOT.
Self-reported Health	
EQ-5D VAS	It is expected that there would be a positive and significant correlation between the QOL-ACC and the EQ-5D VAS. It is anticipated that older people who are receiving care services who report higher levels of health (measured by the EQ-5D VAS) would rate their QoL (measured by the QOL-ACC) higher also.
ASCOT dimensions	
Control	The ASCOT control dimension relates to an individual having the choice to do things they want to do and enjoy. It would be expected that this dimension would have a moderate correlation with the QOL-ACC dimensions of activities and independence.
Dignity	The ASCOT dignity dimension relates to the way in which an individual is helped and treated. This dimension is more closely related to quality of care and therefore it is expected that there will be a weak correlation between this dimension and the five QOL-ACC dimensions.
Social participation	The ASCOT social participation dimension relates to how much social contact an individual experiences. It is expected that there would be a strong and positive correlation between this dimension and the social connections QOL-ACC dimension as they are measuring the same concept.
Occupation	The ASCOT occupation dimension relates to individuals being able to spend their time doing things they value and/or enjoy. It is expected that this dimension would have a moderate and positive correlation with the QOL-ACC activities dimension and with the QOL-ACC independence dimension as they are measuring similar concepts.
Food and drink	The ASCOT food and drink dimension relates to an individual receiving adequate food and drink. It is expected the correlation between this dimension and the QOL-ACC dimensions would be weak as this dimension is more closely related to quality of care and is not measuring the same concept of any of the QOL-ACC dimensions.
Safety	The ASCOT safety dimension relates to how safe an individual feels. It is expected the correlation would be weak between this dimension and the QOL-ACC dimensions because none of the QOL-ACC dimensions are measuring safety.

Accommodation	The ASCOT accommodation dimension relates to how clean and comfortable an individual's house is. It is expected that the correlation between this dimension and the QOL-ACC dimensions would be weak as this dimension relates more to quality of care.
Personal care	The ASCOT personal care dimension relates to how clean and presentable an individual is. It is expected that this dimension would exhibit a weak correlation with the QOL-ACC dimensions because this dimension is more closely related to quality of care.

Note. HRQoL = Health-Related Quality of Life; QoL = Quality of Life; SCRQoL = Social Care-Related Quality of Life.

Known group validity assesses the extent in which a measure can discriminate between groups that have known different characteristics and expected to have different QOL scores. Known group validity for the QOL-ACC was assessed by examining the extent of the differentiation between older people receiving aged care services with different levels of self-reported health and between older people receiving aged care services with different levels of self-reported QoL.

8.2.4 Statistical Analysis

Winsteps software, Version 5.0.0 (Linacre, 2021) was used to calculate interval level score and overall scores for the dimensions of the descriptive system of the QOL-ACC using Rasch analysis. The Rasch analysis produced logit scores which were then rescaled from 0 (lowest score) to 100 (highest score) for ease of use.

Convergent validity was assessed by initially producing simple histograms to identify if the responses of the measures were normally distributed to determine whether to use Spearman's rank absolute correlation co-efficient (non-normal data) or Pearson's correlation coefficient (normal distributed data). None of the measures had normal data distribution, and therefore, the Spearman's rank absolute correlation co-efficient (*p* values) was undertaken to assess the relationship between the QOL-ACC and the other measures. Based on the Consensus-based Standards for the Selection of Health Measurement Instruments checklist (COSMIN) (Mokkink et al., 2018; Terwee et al., 2018), correlations of 0.00 - 0.30 are deemed negligible, >0.30 – 0.50 low, >0.50 to 0.70 moderate and >0.70 to 0.90 high.

To determine if the QOL-ACC had sufficient convergent validity, a widely accepted threshold in the literature is that 75% or more of the hypotheses had to be accurate in relation to the strength and direction of the association between the QOL-ACC and the other measures demonstrated by the analysis (Abma et al., 2016; Terwee et al., 2006).

Known group validity was assessed by the Kruskall-Wallis test to identify if the QOL-ACC was able to discriminate between groups by assessing whether the median QOL-ACC scores were significantly different between self-rated QoL scores and also between self-rated health scores. Following the Kruskall-Wallis testing, Dunn's test was performed to assess differences between groups (multiple pairwise comparison). The analysis was carried out using SPSS, Version 25.0 (IBM Corp, 2017).

8.3 RESULTS

8.3.1 Respondent characteristics

The socio-demographic details of the sample have previously been reported in Chapter 7, section 7.3.4.

8.3.2 QOL-ACC responses

The responses to each of the dimensions of the QOL-ACC are shown in Table 8.2. Approximately two-fifths of respondents indicated they experienced the highest level of mobility and independence and nearly half (48.6%) reported they experienced the highest level of social relationships. However, this was slightly lower for emotional wellbeing (21.4%)

and activities (29.7%). Overall, there was good coverage across all the response levels of each dimension with a large majority of respondents (more than 70%) reporting the highest two levels of QOL for each of the dimensions other than activities (58.4%).

There was a significant relationship observed between the respondents that were receiving a HCP and the respondents that were receiving CHSP for the mobility, emotional wellbeing, and independence dimensions. This is not surprising given that older people receiving a HCP are likely to have higher care needs than those receiving HCPs. Although the relationship between the type of care received and social connections, and the type of care received and activities was not significant, older people receiving HCP had lower levels of QoL for these two dimensions than those receiving a CHSP, again reflecting the higher dependency levels associated with HCPs than CHSPs.

Table 8.2

Responses to the QOL-ACC dimensions

QOL-ACC Dimension	**Total**	**CHSP**	**HCP**	***p****
		n (%)		
I am able to get around as much as I want to				
All of the time	134 (42.8)	71 (59.2)	58 (32.6)	<0.001
Most of the time	108 (34.5)	35 (29.2)	67 (37.6)	(25.2)
Some of the time	34 (10.9)	9 (7.5)	22 (12.4)	
A little of the time	29 (9.3)	4 (3.3)	24 (13.5)	
None of the time	8 (2.6)	1 (0.8)	7 (3.9)	
I am generally happy				
All of the time	67 (21.4)	20 (16.7)	44 (24.7)	0.05 (9.52)
Most of the time	166 (53.0)	74 (61.7)	83 (46.6)	
Some of the time	58 (18.5)	22 (18.3)	34 (19.1)	
A little of the time	20 (6.4)	4 (3.3)	15 (8.4)	
None of the time	2 (0.6)	0 (0)	2 (1.1)	
I have as much independence as I want				
All of the time	130 (41.5)	60 (50.0)	65 (36.5)	0.02 (12.1)
Most of the time	110 (35.1)	43 (35.8)	60 (33.7)	
Some of the time	56 (17.9)	15 (12.5)	39 (21.9)	
A little of the time	14 (4.5)	2 (1.7)	11 (6.2)	
None of the time	3 (1.0)	0 (0)	3 (1.7)	
I have good social relationships with family and friends				
All of the time	152 (48.6)	67 (55.8)	79 (44.4)	0.39 (4.14)
Most of the time	99 (31.6)	32 (26.7)	60 (33.7)	
Some of the time	31 (9.9)	11 (9.2)	19 (10.7)	
A little of the time	23 (7.4)	8 (6.7)	14 (7.9)	
None of the time	8 (2.6)	2 (1.7)	6 (3.4)	
I have leisure activities/hobbies I enjoy				
All of the time	93 (29.7)	39 (32.5)	49 (27.5)	0.27 (5.18)
Most of the time	90 (28.7)	40 (33.3)	46 (25.8)	
Some of the time	65 (20.8)	22 (18.3)	40 (22.5)	
A little of the time	45 (14.4)	14 (11.7)	29 (16.3)	
None of the time	20 (6.4)	5 (4.2)	14 (7.9)	

*Pearson's chi-squared was used to generate *p* values.

Table 8.3 shows the mean score of the EQ-5D-5L, EQ-5D VAS, QCE and ASCOT by each QOL-ACC dimension's response levels. The mean score of all the measures were higher for those respondents selecting the highest response level of each of the five QOL-ACC dimensions. Lower mean scores were reported for those respondents selecting the lowest response levels of the five QOL-ACC dimensions. The analyses provide evidence of monotonicity of response categories of the QOL-ACC dimensions, that is, the respondents with better scores as measured by other instruments were endorsing higher response options across all the QOL-ACC dimensions.

Table 8.3

Mean EQ-5D-5L, EQ-5D VAS, QCE and ASCOT by QOL-ACC dimension

QOL-ACC Dimension#	**EQ-5D-5L**	**EQ-5D-VAS**	**QCE**	**ASCOT**
N	Mean (SD)			
I am able to get around as much as I want to				
All of the time (134)	0.71 (0.18)	71.6 (18.0)	0.90 (0.13)	0.72 (0.09)
Most of the time (108)	0.45 (0.30)	59.4 (20.8)	0.89 (0.12)	0.69 (0.10)
Some of the time (34)	0.38 (0.28)	56.5 (20.1)	0.85 (0.13)	0.64 (0.11)
A little of the time/ None of the time (38)	0.25 (0.37)	49.2 (23.5)	0.82 (0.16)	0.54 (0.18)
*p**	<0.001	<0.001	0.0006	<0.001
I am generally happy				
All of the time (67)	0.68 (0.25)	71.7 (19.2)	0.94 (0.10)	0.74 (0.07)
Most of the time (166)	0.56 (0.26)	66.4 (19.7)	0.89 (0.11)	0.70 (0.10)
Some of the time (58)	0.34 (0.33)	49.8 (18.7)	0.82 (0.16)	0.61 (0.09)
A little of the time/ none of the time (22)	0.26 (0.35)	47.0 (23.8)	0.81 (0.18)	0.53 (0.15)
*p**	<0.001	<0.001	<0.001	<0.001
I have as much independence as I want				
All of the time (130)	0.64 (0.28)	69.7 (20.1)	0.92 (0.10)	0.74 (0.81)
Most of the time (110)	0.53 (0.28)	64.9 (19.9)	0.86 (0.15)	0.68 (0.10)
Some of the time (56)	0.37 (0.28)	50.9 (19.2)	0.86 (0.10)	0.59 (0.15)
A little of the time/ None of the time (17)	0.15 (0.35)	41.8 (18.1)	0.75 (0.21)	0.50 (0.14)
*p**	<0.001	<0.001	<0.001	<0.001
I have good social relationships with family and friends				
All of the time (152)	0.62 (0.25)	68.4 (19.3)	0.93 (0.09)	0.73 (0.07)
Most of the time (99)	0.48 (0.32)	61.2 (21.9)	0.85 (0.14)	0.66 (0.11)
Some of the time (31)	0.44 (0.31)	56.8 (21.0)	0.80 (0.17)	0.58 (0.18)
A little of the time (31)	0.33 (0.39)	49.6 (22.3)	0.80 (0.15)	0.58 (0.13)
*p**	<0.001	<0.001	<0.001	<0.001
I have leisure activities/hobbies I enjoy				
All of the time (93)	0.60 (0.30)	69.9 (20.2)	0.95 (0.08)	0.73 (0.84)
Most of the time (90)	0.60 (0.26)	65.6 (21.4)	0.89 (0.13)	0.71 (0.08)
Some of the time (65)	0.51 (0.28)	61.3 (19.2)	0.88 (0.12)	0.66 (0.13)
A little of the time/None of the time (65)	0.34 (0.34)	51.8 (20.8)	0.78 (0.16)	0.59 (0.15)
*p**	<0.001	<0.001	<0.001	<0.001

Note. # Lowest two levels (A little of the time and None of the time) were collapsed for analysis due to low cell counts.
*Kruskall-Wallis test was used to generate *p* values.

8.3.3 Construct Validity

Convergent Validity

QOL-ACC and QOL

It was hypothesised that there would be a positive relationship between the QOL-ACC and the other QoL measures (ASCOT, EQ-5D-5L, EQ-VAS). This hypothesis was based upon the measures demonstrating related constructs (i.e., QoL). However, it was expected that the QoL measures would not demonstrate very strong correlations with the QOL-ACC because the QOL-

ACC assesses older person-specific QoL whereas the ASCOT and the EQ-5D-5L assess generic QoL. It is known from the research undertaken to develop the dimensions of the QOL-ACC (see Chapter 6) and previous research in this area (Grewal et al., 2007; Milte et al., 2014; Ratcliffe et al., 2017) that older people's QoL encapsulates broader aspects that go beyond health status. However, it was predicted that the strongest correlation would be demonstrated between the QOL-ACC and the ASCOT. The ASCOT assesses SCRQoL which is a similar construct to the QoL of older people receiving aged care services that the QOL-ACC measures, and therefore the ASCOT has a broader focus on QoL than the EQ-5D which is more focused on HRQoL. This hypothesis was supported with the highest convergent validity observed between the QOL-ACC and the ASCOT (0.62, *p*<0.001) aligning with the prior hypothesis that the ASCOT would exhibit the strongest relationship of all the measures (Table 8.4).

Table 8.4

Relationship between the QOL-ACC and the other measures (Spearman's test and p value)

	QOL-ACC	**Mobility**	**Independence**	**Emotional wellbeing**	**Social Connections**	**Activities**
EQ-5D-5L	0.54 (<0.001)	0.53 (<0.001)	0.44 (<0.001)	0.42 (<0.001)	0.31 (<0.001)	0.29 (<0.001)
EQ-5D VAS	0.47 (<0.001)	0.37 (<0.001)	0.38 (<0.001)	0.38 (<0.001)	0.26 (<0.001)	0.31 (<0.001)
QCE-ACC	0.52 (<0.001)	0.22 (<0.001)	0.36 (<0.001)	0.35 (<0.001)	0.43 (<0.001)	0.47 (<0.001)
ASCOT	0.62 (<0.001)	0.36 (<0.001)	0.51 (<0.001)	0.46 (<0.001)	0.46 (<0.001)	0.42 (<0.001)
Control	0.52 (<0.001)	0.41 (<0.001)	0.57 (<0.001)	0.34 (<0.001)	0.28 (<0.001)	0.30 (<0.001)
Dignity	0.18 (0.001)	0.06 (0.32)	0.18 (0.002)	0.20 (0.0003)	0.15 (0.006)	0.15 (0.007)
Social participation	0.57 (<0.001)	0.28 (<0.001)	0.43 (<0.001)	0.38 (<0.001)	0.50 (<0.001)	0.44 (<0.001)
Occupation	0.59 (<0.001)	0.34 (<0.001)	0.52 (<0.001)	0.39 (<0.001)	0.38 (<0.001)	0.45 (<0.001)
Food and drink	0.38 (<0.001)	0.31 (<0.001)	0.26 (<0.001)	0.27 (<0.001)	0.27 (<0.001)	0.26 (<0.001)
Safety	0.38 (<0.001)	0.25 (<0.001)	0.28 (<0.001)	0.31 (<0.001)	0.28 (<0.001)	0.24 (<0.001)
Accommodation	0.42 (<0.001)	0.31 (<0.001)	0.38 (<0.001)	0.27 (<0.001)	0.32 (<0.001)	0.25 (<0.001)
Personal care	0.42 (<0.001)	0.33 (<0.001)	0.39 (<0.001)	0.27 (<0.001)	0.32 (<0.001)	0.29 (<0.001)

It was hypothesised that the QOL-ACC dimensions of *activities* and *independence* would have a moderate correlation with the ASCOT control dimension. The *activities* dimension exhibited a moderate correlation (0.30, *p*<0.001) with the ASCOT control dimension and a higher correlation was found between the ASCOT control dimension and the *independence* dimension indicating a stronger relationship between these two dimensions (0.57, *p*<0.001) (Table 8.4). This is not surprising as the ASCOT control dimension measures an individual's choice to do things they want to do, and this is a similar concept to independence.

It was predicted that the ASCOT dimension of social participation would be highly and positively correlated with the QOL-ACC dimension of *social connections* as they are both measuring the same concept. This hypothesis was met with a positive relationship observed (0.50, *p*<0.001). It was predicted there would be moderate correlations between the ASCOT occupation dimension and the *activities* and *independence* dimensions because the ASCOT occupation dimension is about individuals being able to spend their time doing things they enjoy, and this is a similar concept to independence and participating in activities. As expected, there were moderate relationships observed between the ASCOT occupation dimension and *activities* (0.45, *p*<0.001) and *independence* (0.52, *p*<0.001) (Table 8.4).

It was predicted that the ASCOT dimensions of safety, dignity, food and drink, accommodation and personal care would not exhibit a strong correlation with any of the QOL-ACC dimensions because these dimensions are more closely related to quality of care. Overall, this hypothesis was supported with no strong correlations observed between these ASCOT dimensions and the five QOL-ACC dimensions (Table 8.4).

It was hypothesised that the relationship between the QOL-ACC and the EQ-5D-5L would exhibit a positive correlation. However, it was predicted that this correlation would not be as strong as between the QOL-ACC and the ASCOT because the EQ-5D-5L measures generic HRQoL and is not specific to older people. There were moderate relationships observed between the EQ-5D-5L and *mobility*, *independence*, *emotional wellbeing,* and *social connections*. There was weaker evidence of a relationship between the EQ-5D-5L and *activities* (0.29, *p*<0.001). The EQ-5D-5L had moderate convergent validity (0.54, *p*<0.001) with the QOL-ACC, again supporting the prior hypothesis that these two measures would be related but the relationship would not be as strong as the relationship between the ASCOT and the QOL-ACC (Table 8.4).

QOL-ACC and EQ-VAS

It was predicted that the QOL-ACC and the EQ-VAS would exhibit a positive correlation due to the EQ-VAS being a self-report measure of health. It would be expected that older people receiving aged care services who report higher levels of health would also report higher levels of QoL as they are related constructs. However, the EQ-VAS demonstrated moderate relationships with *mobility, independence, emotional wellbeing,* and *activities* and a weak relationship with *social connections.* The lowest convergent validity of all the measures was demonstrated between the QOL-ACC and the EQ-VAS (0.47, *p*<0.001) (Table 8.4) aligning with the hypothesis that there would be a relationship, although it was expected that the association would have been slightly stronger, and therefore, this hypothesis was not met.

QOL-ACC and quality of care

It was hypothesised that the QOL-ACC and the QCE-ACC would be correlated. This hypothesis was based upon Donabedian's quality of care model which is discussed in more detail in

Chapter one. In summary, Donabedian (1982) proposes that quality of care has three components; structures (organisational structures supporting care such as polices, regulations and funding), processes (the processes taken in the delivery of care such as organisational features and allocation of aged care packages), and outcomes (the outcomes/effects of the care received) (Donabedian, 1982). The model proposes that these three elements are all inter-related with good structure of care leading to good processes in care which in turn leads to good outcomes (Castle and Ferguson, 2010). Therefore, the quality of care that an older person receives may negatively or positively impact upon their care outcomes, such as QoL. It was predicted that the QOL-ACC and the QCE-ACC would be correlated but the correlation would be weaker than the correlation between the QOL-ACC and the QOL measures because although QoL and quality of care are related, they are separate constructs.

There were moderate relationships observed between the QCE-ACC and *independence, emotional wellbeing, social connections and activities* and a weak relationship between the QCE-ACC and *mobility.* The QOL-ACC demonstrated a moderate convergent validity with the QCE-ACC (0.52, p<0.001), but the association was not as strong as the EQ-5D-5L and the ASCOT (Table 8.4). This outcome supported the prior hypothesis that there would be an association, but it would not be as strong as the QCE-ACC measures quality of care and the QOL-ACC measures QoL and they are two separate constructs. Out of 12 priori-hypotheses (Table 8.1), 11 hypotheses (91.6%) were met and supported by the data indicating strong evidence of convergent validity of the QOL-CC descriptive system.

Known Group Validity

The QOL-ACC was able to discriminate between respondents who had different levels of self-reported health (Figure 8.1) and different levels of self-reported QoL (Figure 8.2). Poor self-reported QoL ratings were associated with poor QOL-ACC scores (Chi-squared=118.7, df=4. *p*<0.001) with significant differences between groups. When compared between different groups by self-reported QOL ratings, all groups demonstrated statistically significantly different QOL-ACC scores (*p*<0.001 for all and p=0.04 between very good and excellent groups) except between the groups (poor and fair) (*p*=0.19).

Poor self-reported health ratings were associated with poor QOL-ACC scores (Chi-squared=66.4, df=3. *p*<0.001) with significant differences between groups. When compared between different groups by health ratings, except between very good and good (*p*=0.38) all other groups demonstrated statistically significantly different QOL-ACC scores (*p*<0.001 for all and *p*=0.006 between fair and poor).

Figure 8.1

QOL-ACC scores by self-reported health

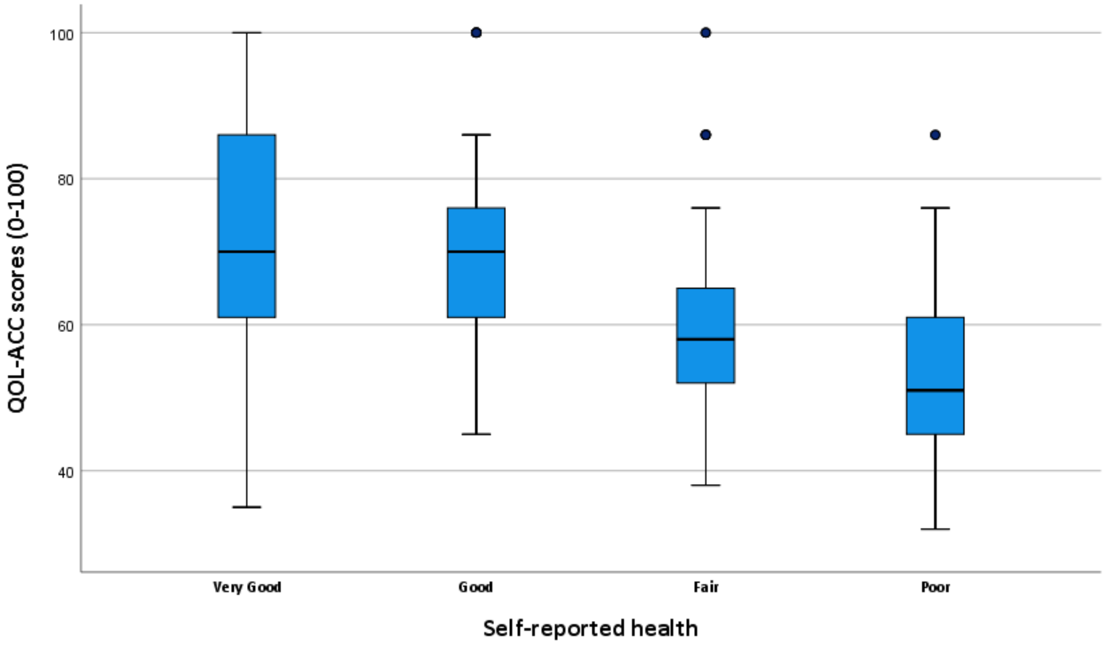
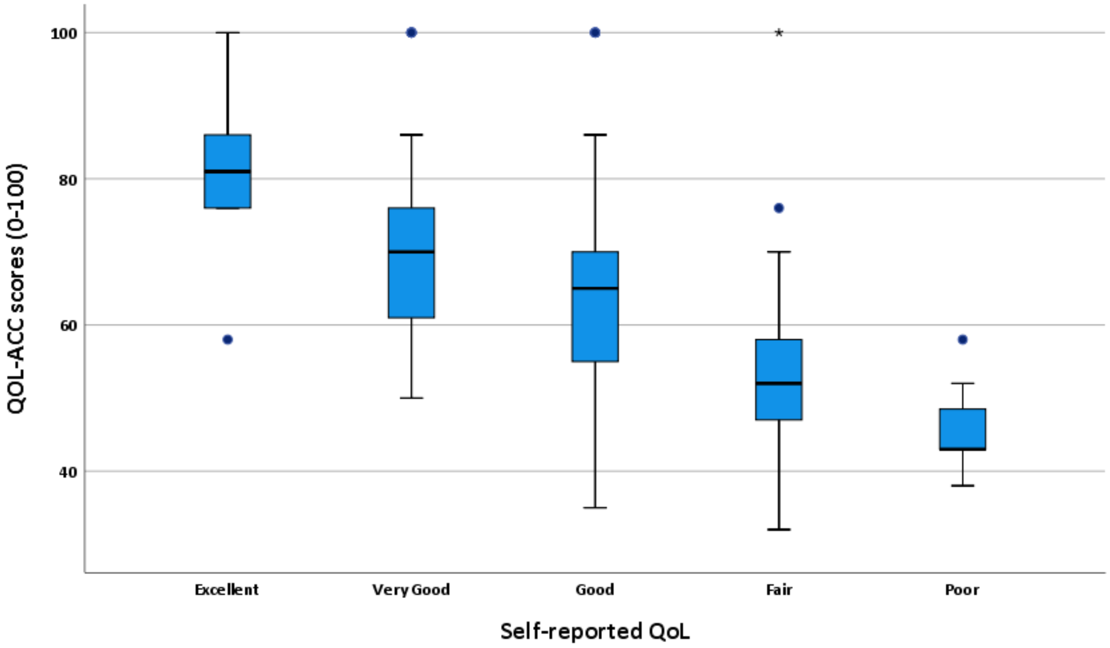


Figure 8.2

QOL-ACC scores by self-reported QoL



8.4 DISCUSSION

This research has demonstrated that the QOL-ACC is a valid measure to assess older people's QoL who are in receipt of aged care services in the community. This is an important stage of the development of the QOL-ACC and builds upon the previous stages of its development that demonstrated both the content and face validity of the QOL-ACC with older people in receipt of aged care services in the community (See Chapter 6 and 7). This stage of development of the QOL-ACC (assessing the construct validity) was also undertaken with the target population group (older people in receipt of aged care services in the community) further ensuring its validity.

A widely accepted threshold in the literature is that 75% or more of the hypotheses have to be met to ensure adequate convergent validity (Abma et al., 2016; Terwee et al., 2006). Overall, the analysis demonstrated that the QOL-ACC has acceptable convergent validity with 11 out of the 12 hypotheses (91.6%) being met. The relationship between the QOL-ACC and the EQ-5D VAS was predicted to be positively correlated because it would be expected that older people who are receiving aged care services in the community who report higher levels of health would experience higher levels of quality of life. However, although the two concepts were related, the lowest convergent validity of all the measures was demonstrated between the QOL-ACC and the EQ-VAS, and it was expected that the association would have been slightly stronger.

The QOL-ACC demonstrated positive and significant correlations with the ASCOT, EQ-5D-5L, EQ-VAS and the QCE-ACC. However, despite the positive and significant correlations, the strength of the associations between the QOL-ACC and other instruments were low to moderate. The findings imply that the QOL-ACC and the other instruments do have some correlations, but the strength of the correlations was not strong enough to make the QOL-ACC redundant. That is, the QOL-ACC is providing sufficiently different information of QOL construct than measured by other instruments assessed in this study. As predicted, the strongest relationship was between the QOL-ACC and the ASCOT which was not surprising given the ASCOT measures SCRQoL which is a similar construct to older people’s QoL who are receiving aged care services. Similar to the QOL-ACC, the ASCOT captures wider aspects of QoL than the EQ-5D-5L which is more narrowly focused on HRQoL in a health context.

There was a positive correlation between the QOL-ACC and the QCE-ACC indicating that the quality of care an older person receives impacts upon their QoL. However, the correlation was moderate suggesting that although quality of care and QoL are related, they are two separate constructs. This was not surprising given the QOL-ACC measures the QoL of older people in receipt of aged care services (outcomes) and the QCE-ACC measures the quality of care of older people receiving aged care services (process). This analysis provides evidence to support the Donabedian model in which the process of care (measured by the QCE-ACC) and the outcomes of care (such as QoL measured by the QOL-ACC) are associated with better quality of care leading to better outcomes such as improved QoL (Donabedian, 1982). This result indicates that quality of care and QoL should be measured as two separate constructs in aged care but are complimentary to each other.

The results of the known group validity suggested that the QOL-ACC was able to differentiate between older people with different levels of self-reported health and between older people with different levels of self-reported QoL. The analysis demonstrated that older people in receipt of aged care services that had higher levels of self-reported health had higher levels of QoL as measured by the QOL-ACC. This was also the case with respondents who reported higher levels of health achieving higher QoL scores as indicated by the QOL-ACC.

It is important to acknowledge the limitations of this research. It is recognised that hard to reach older adults in receipt of aged care services in the community may have been excluded from this research. Older people from CALD backgrounds were under-represented in the research because unfortunately it was not possible to involve older people who were not able to understand and converse in English due to resource limitations. Furthermore, COVID-19 restrictions were in place during the data collection period which meant that all of the data collection had to be online, and face-to-face data collection was not possible. It is recognised that by collecting data online, older people who may not have access to a computer and/or not be computer literate may have been excluded from this research.

Furthermore, Winsteps software, Version 5.0.0 (Linacre, 2021) was used to calculate interval level score and overall scores for the dimensions of the descriptive system of the QOL-ACC using Rasch analysis. Preferably, scores should be calculated using a scoring algorithm based on assessing the public's preferences for different combination of states. However, a scoring algorithm for the QOL-ACC has not yet been developed, and therefore, calculating scores using Rasch analysis was the next best alternative rather than using the QOL-ACC summative scores.

8.5 CONCLUSION

To conclude, the analysis presented in this chapter provides strong evidence for the construct validity of the QOL-ACC descriptive system, in terms of both convergent validity and known group validity. Each stage of the development of the QOL-ACC measure has involved older people in receipt of aged care services in the community to ensure high content validity of the measure. Therefore, the QOL-ACC descriptive system is a valid measure to assess the QOL of older people in receipt of aged care services in the community and is more responsive to measure the QOL of older people than the generic QOL measures. In order for the QOL-ACC measure to be used in economic evaluation, it will require the development of a preference-weighted scoring algorithm in order for QALYs to be generated. Future research including the development of a preference-weighted scoring algorithm will be discussed in the final chapter of this thesis.

9. CONCLUSION

9.1 INTRODUCTION

The purpose of the thesis was to develop a descriptive system for the first preference-based older person-specific QoL measure in Australia amenable to preference-based scoring co-created with older people receiving aged care services in the community. The thesis focused on identifying the QoL characteristics important to older people in receipt of aged care services in the community to develop the draft descriptive system which was then subjected to robust psychometric tests for validation. This chapter summarises the main findings, limitations to the research, future research, and its significance in the aged care sector in Australia and internationally.

9.2 THE IMPORTANCE OF THIS RESEARCH

As discussed in Chapter two, Australia's population is ageing which has significantly increased the demand for aged care services in Australia (AIHW, 2021a). Australians are living longer, often with frailty, and other health conditions and many older people choose to remain in their own home as long as possible (Kendig et al., 2014; Kendig et al., 2017; Ratcliffe et al., 2020). These changing demographics have placed an increased demand on aged care services, in particular care and support within the home (AIHW, 2021a). As a result of the changing landscape of the aged care sector, numerous aged care reforms have been introduced with recent reforms placing an emphasis on the need for improvements to be made to the quality of care provided to improve the QoL of older Australians. A key introduction in 2015 was Consumer Directed Care (CDC) which was a contrast to the traditional provider directed care that had previously been in place. The CDC approach provided choice and control to the older person about their care services with the aim of maximising their QoL and wellbeing

(Australian Department of Health, 2012). The recent Royal Commission into Aged Care Quality and Safety highlighted major shortfalls in the aged care sector with services failing to meet the needs of older Australians. The current aged care sector was identified as not supporting older people's QoL, difficulties were experienced in navigating the system and accessing care with long waiting lists present.

The inquiry highlighted the poor assessment systems that were currently in place to measure the quality of the aged care providers (Royal Commission into Aged Care Quality and Safety, 2021). Recommendations were made to overhaul the aged care sector to improve the QoL of older Australians through the provision of high quality care with an emphasis on placing the older person at the centre of aged care. It was recognised that older people require care that improves their QoL, and as a result, a recommendation was made for a QoL assessment tool to be applied to measure the QoL of older Australians receiving care as part of ongoing quality assessments. This recommendation highlights the significance of research in this sector outlined in this thesis and the intrinsic link between the QoL and quality of care of older people in receipt of aged care services in the community.

The quality of the care provided to an older person is likely to impact upon their QoL with higher quality of care linked to a better QoL (Carey et al., 2018; Dyer et al., 2018; Ratcliffe et al., 2020). Chapter three detailed a comprehensive literature review identifying international grey and peer reviewed literature relating to quality of care in aged care. Nine key themes were identified as important to the quality of care experience: treating older people with respect and dignity; acknowledging and supporting older people's spiritual, cultural, religious and sexual identity; the skills and training of the aged care staff providing care; the relationships between older people and the aged care staff; social relationships and the community; supporting older people to make informed choices; supporting older people’s health and well-being; ensuring safe care is delivered; and the ability for older people and their families to make complaints and provide feedback. Traditionally, quality of care has been measured by process, organisational and clinical indicators which is not ideal as this method of assessment assumes that better care is provided but there is no guarantee of this result (Castle & Ferguson, 2010; O’Reilly et al., 2007). The findings from the literature review emphasise the need for the measurement of quality of care to go beyond clinical, process and organisational indicators and incorporate the wider aspects of the quality of care experience that enhance an older person’s QoL again signifying the importance of this research outlined in this thesis.

Chapter four provided an overview of health economics discussing the different techniques in health economic evaluations, namely CUA which is the most prevalent type of economic evaluation in healthcare settings. CUA can make comparisons between aged care interventions using the common unit of outcome, the QALY which is calculated through the application of preference-based measures (Brazier et al., 2017).

The development of preference-based measures such as the ASCOT, HUI measures, AQoL measures, QWB-SA, EQ-5D and the ICECAP-O were outlined with comparisons made between their descriptive systems, dimensions, and development of their scoring algorithms. An overview of the application of these measures with older people in different contexts was identified and it was found the EQ-5D was the most common preference-based measure applied to date with older people. Whilst it was evident that a variety of preference-based measures have been applied with the aged care population, it was evident that the majority have a strong focus on health status and neglect the wider aspects of QoL that are important to older people such as independence, control, dignity, and social relationships (Grewal et al., 2006; Milte et al., 2014; Ratcliffe et al., 2017). The ASCOT and the ICECAP-O were developed to acknowledge that the measurement of health needed to go beyond the traditional concept of health and include broader dimensions of QoL. The ICECAP-O is an older-person-specific preference-based measure that was developed with older people to measure the broader aspects of QoL (Al-Janabi et al., 2012; Coast et al., 2008). However, the ICECAP-O is based on Sen's capability theory (Sen, 1993), and therefore, is not compatible with QALYs and its application in economic evaluation is contentious (Brazier et al., 2017). The ASCOT is a measure of SCRQoL that also captures broader dimensions of QoL, but its focus is on measuring the QoL of individuals receiving social care, and therefore does not include dimensions such as physical health and emotional wellbeing. Therefore, its developers recommend using it alongside a generic preference-based measure (Netten et al., 2012a). Furthermore, the ASCOT is not older person specific and so does not necessarily reflect the preferences and views of older people about what encapsulates QoL. The review highlighted the lack of QoL measures that are suitable to be used in economic evaluations in the aged care sector and demonstrated the need for a new preference-based measure to be developed to fill this gap that reflects the views and preferences of older people that can be applied in economic evaluations in aged care.

9.3 DEVELOPMENT STAGES OF THE QOL-ACC

Traditionally, most existing preference-based measures have been developed using a top-down approach with the descriptive system being developed from existing literature and/or expert opinion (Stevens & Palfreyman, 2012). However, it is beneficial to adopt a bottom-up approach by including the population of interest which is the approach adopted in this research. Every stage of the development of the QOL-ACC involved older people, therefore increasing the face validity and content validity of the measure by using appropriate language and content that accurately reflects the views and preferences of older people in receipt of aged care services in the community of what determines QoL. This is a unique approach and as far as I am aware is the first time in Australia, and internationally, a descriptive system for an older-person specific preference-based measure has been developed with older people receiving aged care services from its inception.

The first stage of the development of the QOL-ACC addressed objective one of the thesis which was to identify the QoL characteristics important to older people in receipt of aged care services in the community. Forty one interviews were undertaken with older people in receipt of aged care services in the community to understand what characteristics were important to them to experience a good QoL. Five salient dimensions were found to be important to older people; independence, social connections, emotional wellbeing, mobility, and activities. This stage of the research supported findings from previous literature (Grewal et al., 2006; Milte et al., 2014; Ratcliffe et al., 2017) identifying that QoL for older people in receipt of aged care services goes beyond health status and incorporates broader dimensions. Although some of these dimensions identified were similar to dimensions included in other preference-based QoL measures, there were some important differences highlighting the need for a new measure to be created. For example, the EQ-5D includes a mobility dimension, however the mobility dimension is not worded appropriately for older people as many older people use mobility aids, and the dimension makes no reference to the use of mobility aids or their perception of whether or not they are mobile. There is no single preference-based measure that reflects all of the dimensions identified from this stage of research, signifying the uniqueness of this measure and its relevance and importance in the aged care sector to measure QoL.

Stage two of the development of the QOL-ACC addressed objective two of the thesis which was to develop draft items for the descriptive system based on the QoL characteristics identified by older people in receipt of aged care services in the community. This stage involved developing draft items for each of the five dimensions. Items were developed by the research team and consumer and aged care partners by examining the qualitative data to understand how older people had spoken about the QoL dimensions that were most meaningful to them. Twenty eight draft items were developed using the words and phrases that older people had typically adopted when speaking about the dimensions to ensure that the meanings behind the five dimensions remained. Again, this approach signifies the uniqueness of not only including older people, but also including aged care representatives who are directly involved in delivering aged care services to older people and therefore can provide their expert opinion and experience.

Stage three of the development of the QOL-ACC addressed objective three of the thesis which was to test the face validity of the draft QoL items with older people in receipt of aged care services in the community. Testing the face validity of measure is a key stage in the development of a measure to ensure it is valid, acceptable, and reliable within the target population. Thirty one semi-structured interviews were carried out with older people in receipt of aged services in the community to test the face validity of the draft items. Participants provided feedback on the items and indicated their preferred item for each dimension. The findings of this stage suggested that none of the items were viewed as judgmental or offensive. However, a few participants indicated that some of the items were unclear, ambiguous, addressed more than one component of a dimension or that they would have difficulty in answering the item. Based on this feedback and the participants most preferred item for each dimension, 16 items were removed leaving 12 draft items to include for the next stage of the development of the measure.

Stage four of the development of the measure addressed objective four of the thesis which was to test the psychometric properties of the draft QoL items with older people in receipt of aged care services in the community. This stage involved assessing the psychometric properties of the draft items developed in stage three of the research (n=12) and one additional item (based on the expertise of the aged care organisations), achieved through a quantitative online survey with 313 older people in receipt of aged care services in the community. The respondents were asked to answer the draft QOL-ACC items for each dimension to identify the best single item for each dimension through psychometric analysis of the data. This was achieved by using Classical Test Theory (CTT) and a modern Psychometric method (Rasch Analysis) which have been used previously to assess the psychometric properties and validity of new measures (Khadka et al., 2013; Mokkink et al., 2010; Young et al., 2009). The findings from this stage of the research demonstrated that the items were measuring what they intended to measure, and most items demonstrated excellent psychometric properties meeting the necessary psychometric standards. This was not a surprising result as the items content had been developed from the qualitative interviews with older people in stage one and had been assessed for face validity with older people (stage three).

Stage five of the development of the QOL-ACC addressed objective five of the thesis which was to combine the quantitative and qualitative data to select the final items for each QoL dimension to develop the final descriptive system for the QOL-ACC. This stage involved combining the qualitative data from stage three of the research and the quantitative data from stage four of the research to decide on the final items for the QOL-ACC descriptive system. A unique pictorial traffic light approach was adopted based on the previous work by Keetharuth et al. (2018) in the development of the ReQoL measure in which the qualitative evidence and the quantitative evidence was graded red, amber, or green for each item which enabled the best items to be clearly identified. The final item for each dimension for the QOL-ACC descriptive system was decided by a panel of experts (comprising of members of the project research team, a psychometric expert, and aged care representatives) who analysed the evidence with the aim of reaching a consensus on the final QOL-ACC items.

Stage six of the development of the QOL-ACC addressed the final objective of the thesis which was to test the descriptive system for construct validity with older people in receipt of aged care services in the community. An important stage in developing a measure is to assess whether the measure validly measures what is intends to measure (Bowling & Ebrahim, 2005) and this was achieved through assessing convergent validity and known group validity. Convergent validity of the QOL-ACC (overall and at item level) was assessed against existing preference-based measures; ASCOT, the EQ-5D-5L and the QCE-ACC. Known group validity was assessed by evaluating whether the QOL-ACC was able to discriminate between older people with different self-reported health and between different levels of self-reported QOL. The analysis provided strong evidence to demonstrate the construct validity of the QOL-ACC descriptive system at an overall level and also at item level. The QOL-ACC descriptive system demonstrated expected correlations between similar constructs, thereby demonstrating its convergent validity.

However, the correlations were moderate indicating that the QOL-ACC descriptive system and the other measures are not the same indicating the importance of this new measure. The analysis demonstrated evidence to support the Donabedian model in which the process of care and the outcomes of care are associated with better quality of care leading to better outcomes, such as improved QoL (Donabedian, 1982). The QOL-ACC descriptive system was also able to differentiate between respondents with different self-reported health and between respondents with different self-reported QoL, providing evidence of its known group validity.

9.4 LIMITATIONS

It is important to highlight the limitations to this research. Some of these limitations have already been discussed in previous chapters but will be summarised in this section to provide a comprehensive picture of the limitations to the thesis as a whole.

The quality of care literature review outlined in Chapter three consisted of two stages. The first stage included searching grey literature on recently published government reports and research and policy documents. The second stage involved searching peer-reviewed articles on two databases. Unfortunately, due to resource and time constraints it was not possible to conduct an international grey literature search, and therefore, it is recognised that international grey literature was not included. However, this research was part of a Royal Commission into Aged Care Quality and Safety with a key focus on Australian quality of care and therefore, it did include Australian grey literature which is a strength of the research. A further limitation was that most of the relevant studies included were based in residential care settings. This is not surprising given that most research to date on quality of care in aged care has been heavily focused on residential settings. Due to the increased demand for care and support at home and the increasing proportions of older people receiving care at home this finding highlights the importance of measuring quality of care and its relationship to QoL not only in residential care settings but also in home care settings.

Chapter four included a review of preference-based measures applied within the older population. Due to resource and time constraints, it was not possible to conduct a systematic review of the measures, and therefore, it is likely that some relevant articles may have been excluded from this review. Furthermore, the search was limited to a seven year period, and it is possible that relevant articles outside of this time period were excluded. However, a seven year period was chosen due to limited time and resources and the period ensured that the two most recently developed preference-based measures were included (ASCOT and ICECAP-O).

There are some limitations to the data collection for stage one (in-depth interviews), stage three (semi-structured interviews) and stage four (online survey). Although a diverse sample of older people in receipt of aged care services in the home were recruited, it is important to recognise that hard to reach older adults may not have been included. For example, older people from CALD backgrounds were under-represented. Older people who could not communicate in English were not included in the research. Ideally this group of older people would have been included, but limited resources meant this was unfortunately not possible. However, a sister research project has since commenced, undertaken by the wider project team with older people receiving aged care services in the community from five different CALD backgrounds. The aim of this project is to gain a more in-depth understanding of what attributes are important for older people from five different CALD backgrounds to experience a good QoL and to identify the similarities and any differences between this population and the wider population of older people included in this research.

Data collection for stage three (semi-structured interviews) and stage four (online survey) was conducted during the COVID-19 pandemic which meant that the data collection had to be adapted. The semi-structured face validity interviews with older people were originally proposed to be carried out face-to-face, however, COVID-19 restrictions prevented this from happening and the interviews had to take place on the telephone, rather than face-to-face. The impact of the COVID-19 restrictions and conducting the interviews via the telephone impacted upon the recruitment of participants with the final sample size (*n*=31) slightly less than originally planned (*n*=40).

Data collection for stage four (online survey) was conducted online. Originally, it was intended that the majority of data would be collected online, but that some data would also be collected face-to-face. Unfortunately, because of the large sample size required for psychometric testing it was recognised that it would not be possible to collect all of the data face-to-face as this was out of the scope of the project in terms of budget and time restrictions. However, COVID-19 restrictions prevented any data for this stage being collected face-to-face and therefore it is recognised that older people that do not have access to a computer and/or are not computer literature would have been excluded.

9.5 FUTURE RESEARCH

The next key stage of the research will involve developing a preference-weighted scoring algorithm for the QOL-ACC. This is an important final stage in the development of a preference-based measure and is imperative in order for the QOL-ACC to be amenable to economic evaluation. Unfortunately, this stage of development of the QOL-ACC was out of the scope of this thesis, however the research is currently being undertaken by the wider project team. As mentioned previously there has been a lack of economic evaluations across the aged care sector despite the benefits linked to their application (Bulamu et al., 2015; Makai et al., 2014; Ratcliffe et al., 2010). This important final stage of research will enable the QOL-ACC to be applied in economic evaluations to provide evidence of the cost-effectiveness of new models of care and service innovations by incorporating older people's values and measurements of QoL. This will potentially result in more evaluations being conducted in this sector.

This thesis has focused on the development of the QOL-ACC with older people receiving aged care services in the community. It is important to understand that this research has been conducted alongside research undertaken by the wider project team developing the QOL-ACC with older people in residential care. This is to ensure that the QOL-ACC is suitable to be applied with both of these populations by understanding if any differences exist about what QoL means to older people in the community and in residential care, and to also ensure that the QOL-ACC descriptive system is appropriate, relevant, and psychometrically robust for both of these groups. This means that the QOL-ACC will not only be suitable to be used with older people receiving aged care services in the community but also for older people in residential care, widening its application across the aged care sector.

Further research could be undertaken to translate the QOL-ACC into different languages to enable its application in non-English speaking countries and within Australia with older people whose first language may not be English. This research could involve linguistically validating the measure in other countries. There is also the potential to adapt the QOL-ACC for use in other countries by identifying if differences exist between older people receiving aged care services in Australia and in other countries. This could result in adaptations of the QOL-ACC appropriate to be applied with older people receiving aged care services in other countries by reflecting any cultural differences that may exist.

9.6 SIGNIFICANCE

The population in Australia is predicted to continue to age (AIHW, 2021a) and it is imperative that the QoL of older adults receiving care services is assessed. The recent Royal Commission into Aged Care Quality and Safety recognised that a higher level of care provided should potentially result in higher levels of QoL experienced. Indeed, a key recommendation resulting from the inquiry was the routine collection of QoL data as part of quality assessments in aged care (Royal Commission into Aged Care Quality and Safety, 2021). The QOL-ACC can fill this gap by being applied in routine application of quality assessments by aged care providers to measure impact of services and outcomes can be used as evidence that they are meeting the new aged care quality standards. The QOL-ACC can be used by aged care providers to monitor older people’s quality of life from when they first enter the system as part of their ACAT assessment and throughout their period of time receiving services. It can also be used to monitor the impact of new services, interventions, and government reforms by administering the measure to older people prior, during and post the new intervention, service, or reform to identify any impacts on older people’s quality of life.

Future research will develop a scoring algorithm for the measure which will enable the QOL-ACC to be used to assess the cost-effectiveness of services. Currently, there is no older person specific preference-based measure that is suitable to be used in economic evaluation to produce QALYs. The QOL-ACC will fill this important gap and can be used by policy makers and service providers to make decisions about how best to allocate resources. Resources are scarce in the aged care sector, and it is imperative that existing and new services can be assessed in order to ensure resources are allocated efficiently to maximise the QoL of older people in this sector. The QOL-ACC will be able to be used in economic evaluations to assess the cost-effectiveness of new aged care interventions and also for comparisons between existing services to ensure outcomes are maximised.

9.7 CONCLUSION

The overarching aim of this thesis was to identify the QoL characteristics important to older people in receipt of aged care services in the community and to develop and validate the descriptive system of the QOL-ACC achieved through six objectives. This aim was achieved resulting in the QOL-ACC descriptive system being developed; the first older person specific measure amenable to preference-based scoring that incorporate the values and views of older people receiving aged care in the community of what constitutes QoL from its inception. This unique measure can be used to measure and value QoL as part of quality assessments and in the future, economic evaluations. This thesis outlines the rigorous development stages of the QOL-ACC and makes a significant contribution, providing an important mechanism for measuring the impact of aged care reforms in improving the QoL of older Australians. The research also has the potential for wider impact in other countries, potentially improving the QoL of older people not only in Australia but across the world.

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APPENDICES

Appendix 1: Details of included studies in the quality of care literature review

Author, year, country of study	Aim	Sample and characteristics (where reported)	Methods	Findings
Abbott et al. (2018b) U.S.A	To understand everyday preferences of nursing home residents	Nursing home residents =255 (67.8%: female, male:32.2%) Mean:81 years	Face-to-face interviews using the Preferences for Everyday Living Inventory-Nursing Home version (PELI-NH)	Having staff show respect and taking care of you, contact with family and care of personal belongings were found to be the most important preferences for nursing home residents
Abbott et al. (2018a) U.S.A	To explore barriers to social contact preferences and situations when social preferences change of nursing home residents	Nursing home residents = 255 (67.8%: female, male:32.2%) Mean:81 years	Face to face interviews using 13 social contact items from the PELI-NH	Identified barriers to social interactions such as volunteering, giving gifts, being a member of a club, lack of personal resources and being involved in choosing a roommate
Abbott et al. (2018c) U.S.A	To identify the most important shared preferences of nursing home residents and older adults receiving home and community aged care services	Nursing home residents = 255 (67.8%: female, male:32.2%) Mean:81 years Home and community care recipients = 528 (75.6%: female, 24.4%: male) Mean: 77 years	Face to face interviews using the PELI-NH and the Preferences for Everyday Living Inventory – Home Care (PELI-HC).	Having contact with family was the most important shared preference. Privacy, food choices, self-care and activity choices were also important to both nursing home residents and home

				and community care recipients
Andrew & Meeks (2018) U.S.A	To examine the relationships between preferences and loneliness in nursing home residents	Nursing home residents = 65 (female:65.6%, male: 35.4%) Range: 51 – 90+ years Median:71 years	Face-to-face interviews using 12 preferences taken from the PELI 20-item UCLA Loneliness Scale version 35-item Satisfaction with Life Scale	Person-centred care in particular fulfilling personal care and recreation preferences can help with loneliness amongst residents
Bangerter et al. (2017) U.S.A	To understand nursing home residents' perceptions of choice that they have about their care	Nursing home residents = 39 (female:74,4%, male:25.6%) Mean:79 years	Extended version of the original PELI-NH was used to ask residents about their preferences for everyday living	Understanding nursing home residents' perceptions of choice can enable residents' autonomy and satisfaction with care
Bangerter et al. (2016) U.S.A	To understand how nursing home residents self-define certain preferences of care	Nursing home residents =337 (female:71%, male:29%) Mean:81 years	Face-to-face interviews using 8 open-ended items from the PELI-NH	Residents identified interpersonal interactions, coping strategies, personal care and healthcare discussions as important characteristics of care
Casey et al. (2016) Australia	To describe nursing home residents' perceptions of their social networks	Nursing home residents = 36 (female:61.1%, male:38.9%) Mean:82 years	17-item Barthel Index Global Deterioration Scale (GDS). Cross sectional interviews about social interactions Observation of social interactions	Some residents had friendships, but many reported a lack of social opportunities within the nursing homes to establish close relationships

Cho et al. (2017) South Korea	To explore nursing home residents' perceptions of their daily life	Nursing home residents = 21 (female:52%, male:48%) Range:65-94 years Mean:84 years	Semi-structured interviews about daily life	Enhanced comfort, aspiring to maintain physical and cognitive functions as human beings, desire for meaningful relationships, feelings of confinement and autonomy and acceptance of daily life in the residential facility were identified and highlighted the positive and negative aspects of living in a nursing home
Cooney et al. (2009) Ireland	To identify the important characteristics of quality of life of people living in residential care	Nursing home residents = 101 (female:33%, male:67%) Range:65-90+	Semi-structured interviews about quality of life	Ethos of care, sense of self and identity, connectedness, and activities and therapies were identified as impacting on the quality of life of residents
Cooney et al. (2014) International	A review to examine the meaning of connectedness in regard to its contribution to the quality of life of people living in residential care	Older people living in residential care	Examined 16 sources (14 papers and 2 book chapters)	Key experiences of connectedness for older people in residential care is linked with self-awareness, meaningful relationships, involvement in activities and connections with wider society but many barriers exist to residents fulfilling these experiences

De Boer et al. (2017) Netherlands	To compare quality of life, quality of care in green care farms, small-scale living facilities and nursing homes for people with dementia	Total residents = 115 Green care farm residents:34 Small-scale living facilities:52 Nursing home residents:29 Range:59-97 years Mean:84 years	Data on quality of care such as outcome indictors, structure indicators and process indicators Dementia: Quality of Life-Alzheimer's Disease scale (QoL-AD) and QUALIDEM Social engagement: The Revised Index for Social Engagement (RISE) Behavioural symptoms: Neuropsychiatric Inventory – Nursing Home version (NPI-NH) Agitation: Cohen Mansfield Agitation Inventory (CMAI) Depression: Cornell Scale for Depression (CSDD)	Quality of care was comparable at the facilities but residents at green care farms had a better quality of life than those at traditional nursing homes
Drageset et al. (2017) Norway	To explore aspects promoting nursing home residents experience of meaning and purpose in everyday life	Nursing home residents = 18 (female:61%, male:39%) Range:77-92 years	Qualitative interviews about meaning and purpose in everyday life	Experiences such as physical and mental wellbeing, belonging and recognition, personally treasured activities and spiritual closeness and connectedness were found to promote meaning and purpose to residents
Edvardsson et al. (2010) Australia	To investigate person-centred care as described by people with dementia, their families and residential aged care staff	Aged care staff = 37 Nursing home residents = 11 Family members = 19	Focus groups with aged care staff and family members about person-centred care Qualitative interviews with nursing home residents about person-centred care	Categories such as knowing the person, welcoming family, providing meaningful activities, being in personalised environment and experiencing flexibility

				and continuity contributed to person-centred care
Edvardsson et al. (2014) Sweden	To explore participation of activities by people living in residential care with dementia	Nursing homes residents = 1266 (female:69%, male:31%) Mean:86 years	Cross-sectional questionnaire about activity participation, unit person-centredness and quality of life	Residents who participated in activities had a higher quality of life than residents who did not participate in activities
Gnanamanickam et al. (2018) Australia	To compare quality of care between older people living in homelike clustered domestic models of care and standard models of residential care	Nursing home residents = 541 (female:75%, male:25%) Mean:83 years	Quality of care: Consumer Choice Index–6 Dimension (CCI-6D)	Homelike clustered models of care were associated with better quality of care than standard models of residential care
Goldstein et al. (2019) U.S.A	Investigated the barriers to fulfilling food preferences and why preferences may change over time	Nursing home residents = 255 (female:67.8%, male:32.2%) Mean: 81 years	Interviews using 6 food items from the PELI-NH	Residents expressed a variety of barriers to their food preferences such as facility barriers, health and personal finances
Gordon et al. (2020) Australia	To understand the impact of pastoral care from the perspective of nursing home residents	Nursing home residents = 575 (female:74%, male:26%) Range:53-102 years	Questionnaire with items relating to perceived quality and benefits of pastoral care and subjective psychological well-being	The majority of residents believed they received high quality of care and benefited from the pastoral care they received
Grøndahl et al. (2016) Norway	To identify how nursing home residents perceive their participation in activities relating to food and mealtimes	Nursing home residents = 204 (female:74%, male:26%)	Face-to-face interview questionnaire about food and meal preferences	Residents had limited involvement in activities relating to food and mealtimes

Hall et al. (2014) U.K	To explore and compare the views of residents in care homes for older people, their families and care providers on maintaining dignity	Care home managers = 33 (female:82%, male18%) Range:35-68 years Median:56 years Care assistants = 29 (female:93%, male:7%) Range:23-63 years Median:41 years Care home nurses = 18 (female:94%, male:6%) Range:31-66 years Median:47 years Community nurses = 10 (female:90%, male:10%) Range: 34-59 years Median:47 years Residents = 16 (female:69%, male:31%) Range:56-93 years Median:81 years Resident's family members = 15 (female:80%, male:20%) Range:47-78 years Median:60 years	Semi-structured interviews about dignity	Participants felt that maintaining independence, autonomy, choice and control and privacy were important factors in maintaining dignity for care home residents

Hasson & Arnetz (2010) Sweden	To compare nursing home residents, their families and aged care staff quality of care ratings	Care recipients= 1128 (female:66%, male:33%) Aged care staff = 1739 Relatives =1493 (female:62%, male:38%	Questionnaire to measure quality of care	Care recipients rate quality of care higher than relatives and aged care staff. Low ratings were given to the quality of activities provided to care recipients
Hasson & Arnetz (2011) Sweden	To compare care recipients and their relatives' perceptions of quality of care in nursing homes and home-based care.	Home Care recipients = 342 (female:71%, male:29%) Nursing home residents = 199 (female:70%, male:30%) Home care recipients' relatives = 366 (female:65%, male:35%) Nursing home recipients' relatives = 414 (female:61%, male:39%)	Questionnaire to measure quality of care	Home care recipients rated their access to activities significantly lower than nursing home residents. Staff behaviour was the strongest indicator of care recipient's quality of care rating
Kajonius & Kazemi (2016b) Sweden	To investigate the relationship between person and process related factors in predicting satisfaction with care	Home care recipients = 61,600 Nursing home residents = 33,400	Questionnaire about quality of care	Care process factors such as feeling safe and being treated well by staff are perceived as strong predictors of satisfaction with care over and above person-related factors such as anxiety and health

Kajonius & Kazemi (2016a) Sweden	To investigate the importance of process and structural factors for quality of care	Home care recipients = 61,600 Nursing home residents = 33,400	Questionnaire about quality of care	Quality of care is more strongly associated with process factors such as respect and access to information rather than structural factors
Karlsson et al. (2013) Sweden	To explore care satisfaction in relation to place of living, health-related quality of life, functional dependency and health complaints among people 65 years or older, receiving care	Home Care recipients = 90 (female:54%, male:46%) Range:65-85+ Mean:83 years Nursing home = 76 (female:74%, male:26%) Range:65-85+ Mean:86 years	Standardised interview form Short Form Health Survey (SF-12) Questionnaire about care satisfaction	Care satisfaction was rated higher among older people receiving home care than those in nursing homes. Lower care satisfaction in nursing homes concerned continuity, timing, the staff's personal characteristics and ability to give service while low care satisfaction at home concerned the staff's ability to carry out housework and providing medical care, amount of time and own influence over the care
Kelly et al. (2019) Ireland	To investigate the nursing home residents' perceptions of the person-centred climate of their setting in which they live	Nursing home residents = 56 (female:47%, male:53%) Mean:83 years	Person-centered Climate Questionnaire-Patient (PCQ-P)	Residents considered the setting to be hospitable, welcoming, clean and safe

Li et al. (2013) U.S.A	To investigate the experience of nursing home resident's quality of care	Nursing home residents (1st time point) = 16,448 Nursing home residents (2nd time point)= 20,883 Nursing home residents (3rd time point) = 19,457	Questionnaire about consumer satisfaction	High satisfaction with care was reported. However, it was found that satisfaction was lower for physical and social activities available to residents compared to the physical care
Milte et al. (2014) Australia	To describe the meaning of quality residential care from the perspective of people with cognitive impairment and their families	Nursing home residents = 12 Home care recipients = 3 (female:60%, male:40%) Mean:79 years Family members = 26 (female:69%, male:31%) Mean: 75 years	In-depth interviews Focus groups	Supporting personhood was identified as important to residents and their families for good quality of care. Access to meaningful activities, opportunities to feel valued, connections with family were identified as important characteristics of good quality of care
Netten et al. (2012b) U.K	To explore resident's quality of life and the relationships between quality of care	Nursing home residents = 83 Range:31-104 years Mean:84 years	Adult Social Cares Outcomes Toolkit (ASCOT)	Care homes were more successful in delivering basic domains such as personal cleanliness than higher domains such as social relationships
Ottmann et al. (2013) U.S.A, U.K	A review to identify preferences for and satisfaction with services associated with consumer-directed care programmes for older people	Older people receiving home care or residing in a nursing home	Examined 17 sources (peer-reviewed articles)	Older people want greater involvement in decisions relating to their care.

Poey et al. (2017) U.S.A	To examine whether person-centred care promotes satisfaction with quality of life and quality of care and services among nursing home residents	Nursing home residents (timepoint 1) = 6214 Nursing home residents (timepoint 2) = 5538	Questionnaire about resident satisfaction conducted through face-to-face interviews	Residents in homes that had implemented person-centred care reported higher satisfaction with their care and reported being satisfied with the choices available to them, respect shown to them, privacy needs being met and staff knowing their preferences
Reimer et al. (2009) International	To examine how mealtime practices can be made more person centred		Examined literature from the past 2 decades	Person-centred mealtime care means providing choices and preferences, supporting independence, showing respect and enabling interaction. Residents do not often voice concerns about their meals and staff attitudes and staff levels influence quality of care
Roberts (2018) U.S.A	To describe from the nursing home residents' perspective the types of relationships residents develop with others in the nursing home	Nursing home residents = 15	Unstructured interviews	Few residents had close relationships with other residents or staff. Physical proximity and access to residents with similar interests promoted resident relationships. Carer-resident relationships were fostered with non-care time, treats, treating residents as special and responding to care requests positively by carers

Roberts et al. (2018) U.S.A	To examine nursing home residents' preferences	Nursing home residents = 244,718 (female:65%, male:35%) Mean:81 years	Resident interview version Preference Assessment Tool (PAT) Patient Health Questionnaire-9 (PHQ9)	Residents rated involvement of family in care and personalised daily care and meaningful activities as the most important preferences
Grey Literature				
Australian Aged Care Quality Agency (2019) Australia	To understand what quality outcomes mean to consumers	Nursing home residents = 16,606	Interviews about quality of care	Consumers feedback on quality of care was positive with a large majority stating they were treated with respect and felt safe
COTA Australia (2018) Australia	To measure quality and consumer choice in aged care	Survey: Aged care consumers = 676 Providers of aged care = 416 Focus groups: Aged care consumers = 30 Providers of aged care = 64	Questionnaire Focus groups	There was a need for consumers to be given information so they could make informed choices about their care. Quality of life domains such as dignity and respect, food satisfaction, feeling safe, staff friendliness was important to consumers
Jeon & Forsyth (2016) Australia	To identify aspects that consumers examine prior to moving into residential care and to identify aspects that nursing home residents believe are important to have a good quality of care	Aged care consumers	Examined 47 sources (articles and grey literature)	Aspects that were important for nursing home residents to achieve a good quality of care were choice, respect and dignity, physical environment, social environment, functional environment, staff actions, organisational environment and clinical and personal care

McCallum et al. (2018) Australia	To understand consumer experience of aged care services delivered in the community and home	Home aged care consumers = 4536 (female:43%, male:57%) Range: 50-80+ years Aged care staff = 19	Questionnaire about experience of aged care services (consumers) Interviews (aged care staff)	Older people receiving aged care at home think carers treat them with respect, provide good personal care and support need and are well trained
Wells et al. (2018) Australia	A review to identify key drivers of choice when choosing home or community based aged care services and to examine consumer perceptions and experience of the quality of aged care services	Aged care consumers	Examined 40 sources (articles and reports)	The review identified 8 key themes: control, interpersonal interaction, local residence, affordability, financial literacy, safety and timeliness of services provided

Appendix 2: Preference-based instruments applications in populations of older people

	ASCOT	AQoL-6D	AQoL-8D	EQ-5D-3L	EQ-5D-5L	HUI2	HUI3	ICECAP-O	QWB-SA	SF-6D	SF-6D (V2)	15D
Mental and behavioural				De Koning et al. (2016) De Sousa et al. (2017) Kwak et al. (2017a) Mountain et al. (2017) Sexton et al. (2017) Van Houwelingen et al. (2015) Adogwa et al. (2014a) Adogwa et al. (2014b) Sarabia-Cobo, et al. (2017)	Lowthian et al. (2018) Harrison et al. (2018) Yi et al. (2021)		Fowler et al. (2014)	Sarabia-Cobo et al. (2017) Davis et al. (2015)				Aalto et al. (2021) Salminen et al. (2019)

	Nielsen et al. (2014) Davis et al. (2015) Kameyama et al. (2016) Akechi et al. (2017) Ali et al. (2015) Han et al. (2020) Lee & So (2019)	
Musculoskeletal system and connective tissue	Imai et al. (2017) Huang et al. (2018) McMurdo et al. (2016) Ozkuk et al. (2018) Cedraschi et al. (2016)	Park et al. (2017)

		Ludwig et al. (2018) Rundell et al. (2015) Giannadakis et al. (2016) Shigematsu et al. (2018) Ulrich et al. (2015) Kwak et al. (2017b) Dilekçi et al. (2019) Hengg et al. (2019)				
Genitourinary system		Wolfgram et al. (2017) Decalf et al. (2017) Arnold et al. (2016)			Shah et al. (2019)	Lee et al. (2016) Shah et al. (2019)
Endocrine, nutritional and metabolic	Wang et al. (2018)	Riedl et al. (2016)	Davies et al. (2019)			

	Turk et al. (2014) Aro et al. (2017) Wang et al. (2018) Liu et al. (2019) Marten et al. (2021)		
Respiratory system	Mangen et al. (2017b) Persson et al. (2020)		
Neoplasms	Delforge et al. (2015) Geessink et al. (2017) Hishii et al. (2018) Lee (2016) Sattar et al. (2019)	Carneiro et al. (2015)	
Circulatory system	Kleczynski et al. (2016)	Tap et al. (2020)	Ojala et al. (2020)

	Seidl et al. (2015) Seidl et al. (2017) Stanska et al. (2017) Blokzijl et al. (2016) Kaier et al. (2016) Muller-Werdan et al. (2014) Ahumada-Canale et al. (2021) Berastegui Garcia et al. (2020) Gavalaki et al. (2020)						
Blood and blood-forming organs	Abdullah et al. (2018)						
Nervous system	McMillan et al. (2015)					McMillan et al. (2015)	
Muscle Mass	Geerinck et al. (2018)	Mijnarends et al. (2018)					

	Kim et al. (2018) Nygard et al. (2018) Fernández-Araque et al. (2021)	Ten Haaf et al. (2018)				
Fractures	Louer et al. (2016) Bartl et al. (2014) Dolatowski et al. (2019) Renerts et al. (2019) Carneiro et al. (2015) Bartha et al. (2019) Williams et al. (2016) Figved et al. (2018) Skoldenberg et al. (2014)	Banierink et al. (2019) Chen et al. (2020b) Feissli et al. (2020) Hassellund et al. (2021) Masters et al. (2021) McMahon et al. (2020) Viberg et al. (2020)		Williams et al. (2016)	Takahashi et al. (2019)	Raittio et al. (2020)

Skoldenberg et al. (2015)
Brouwer et al. (2019)
Lopiz et al. (2016)
Schray et al. (2018)
Robinson et al. (2018)
Kato et al. (2019)
Ju et al. (2019)
Amarilla-Donoso et al. (2020a)
Amarilla-Donoso et al. (2020b)
Gómez-Blasco et al. (2019)
Inose et al. (2020)

	Inose et al. (2021) Kanters et al. (2020) Kelly-Pettersson et al. (20200 Liu et al. (2020) Rommens et al. (2020) Saving et al. (2019)	
Pain	Bernfort et al. (2015)	
	Brandauer et al. (2020) Johansson et al. (2021)	
Multi-morbidities	Parker et al. (2014) Liu et al. (2019) Lutomski et al. (2017) Rodrigues et al. (2018)	Bhadhuri et al. (2020)

			Bhadhuri et al. (2020)								
Functional Implants			Gordon et al. (2014) Chammout et al. (2016) Chammout et al. (2017) Leonardsson et al. (2016) Girgis et al. (2018)			Zwolan et al. (2020)					
Medical procedures			Derrett et al. (2017)	Shimizu et al. (2018) Zimbudzi et al. (2016)							
Frailty	Van Leeuwen et al. (2015b)		Makai et al. (2015) Metzelthin et al. (2015) Ruikes et al. (2018) Sandberg et al. (2015)	Merchant et al. (2017) Kim et al. (2020) Nikolova et al. (2020) Rosenberg et al. (2019)		Ekerstad et al. (2017)	Makai et al. (2015) Van Leeuwen et al. (2015b)		Nikolova et al. (2020)		Perttila et al. (2017) Suikkanen et al. (2019)

	Tarazona-Santabalbina et al. (2016) Van Leeuwen et al. (2015b) Van Leeuwen et al. (2015a) Fairhall et al. (2015) Hu et al. (2020) Li et al. (2020)	Yao et al. (2020)			
Physical disability	Heise et al. (2015) Hagberg et al. (2017)		Hagberg et al. (2017)		Hagberg et al. (2017)
Falls	Cockayne et al. (2014) Davis et al. (2017) Corbacho et al. (2018) Thiem et al. (2014)	Park et al. (2016) Gottschalk et al. (2020)		Davis et al. (2017) Lawler et al. (2019)	

Alvarez Barbosa et al. (2014)
Cockayne et al. (2018)
Lin et al. (2015)
Perez-Ros et al. (2016)
Perez-Ros et al. (2018)
Balsalobre-Fernandez et al. (2018)
Alvarez-Barbosa.et al. (2016)
Bernard et al. (2020)
Davis et al. (2020)
Lawler et al. (2019)
Sapmaz & Mujdeci (2021)

Digestive system	Do & Moon (2020) Cho & Kim (2019)				
Lifestyle behaviour	Kostka et al. (2014) Rasheed.et al. (2014) Husted et al. (2018) Ilhan et al. (2019) Jimenez-Redondo et al. (2014) Cichocki et al. (2015) Esteve et al. (2015) Fernandez-Alonso et al. (2016) Sumukadas et al. (2014)	Deidda et al. (2018) Grede et al. (2021) Heij et al. (2020)		Deidda et al. (2018)	Laussen et al. (2016)

	Amarasena et al. (2018) Cho et al. (2018) Choi et al. (2021)			
Medication	Al Aqqad et al. (2014) Jodar-Sanchez et al. (2014) Jodar-Sanchez et al. (2015) Wallace et al. (2017) Zhang et al. (2018) Cahir et al. (2014) Loffler et al. (2014) Piccoliori et al. (2021) Akkawi et al. (2019)	Verdoorn et al. (2018) Cicero et al. (2021)	Laudisio et al. (2018)	Juola et al. (2016) Romskaug et al. (2017) Romskaug et al. (2020)

		Auvinen et al. (2020) Saqlain et al. (2020) Stuhec et al. (2019)					
General health-related quality of life		Andersson et al. (2014) Botes et al. (2018a) Botes et al. (2018b) Brennan et al. (2018) Ferrer et al. (2015) Franklin et al. (2018) Karampampa et al. (2016) Lee et al. (2018) Luthy et al. (2015)	Engel et al. (2016)		Engel et al. (2016) Franklin et al. (2018)	Pan et al. (2019)	

			Machon et al. (2017) Mangen et al. (2017a) Urosevic et al. (2015) Van Dijk et al. (2016) Chen et al. (2020a) Huang et al. (2019) Ko et al. (2019) König et al. (2020) Wang et al. (2020)			
Survey development/testing/validation	Hackert et al. (2017) Kaambwa et al. (2015)		Kaambwa et al. (2015) Fábrega-Cuadros et al. (2020)	Hackert et al. (2018) Dios-Quiroga et al. (2020) Hackert et al. (2020)		Hackert et al. (2017) Hackert et al. (2018) Gustafsson et al. (2018)

				Marten & Greiner (2021) Skevington et al. (2021) Cleland et al. (2020)					
Aged care services	Towers et al. (2019) Van Leeuwen et al. (2014) Bauer et al. (2017) Malley et al. (2019) Orellana et al. (2020)		Bulamu et al. (2017) Everink et al. (2018) Brettschneider et al. (2015) Dong et al. (2015) Lopez et al. (2019) Wang et al. (2019)	Wichmann et al. (2020)		Bulamu et al. (2017)			Liimatta et al. (2020)
Acute Care			Giannasi et al. (2018) Parlevliet et al. (2016) Lin et al. (2015)						

Other	Lubetkin et al. (2017)

Appendix 3: Participant information sheet for stage one

Project Title: Developing a new Quality of Life instrument with older people

Participant Information Sheet

Description of the study:

People aged 65 and over represent Australia's fastest growing age group and are major users of health and aged care services. The overall aim of the research is to develop a new tool which can be used to measure older people's quality of life. This tool is to be used in economic evaluation and will help decision makers across health and aged care sectors to make efficient decisions about their resources. In order to develop this tool, we need to talk to people aged 65 and over living a good life who are in receipt of aged care about the term 'quality of life' to understand the important characteristics that determine 'quality of life' for older people.

What will I be asked to do?

An ECH Client Advisor has sent you this information on our behalf. They will contact you again in the next week or so to see if you are interested in participating. If you are, they will ask your permission to pass on your contact details to Jenny Cleland from the research team. She will then contact you to discuss the research and answer any questions that you may have. She will then arrange a convenient date and time for the interview to take place. It is expected that the interview will last approximately 60 minutes. Participation is entirely voluntary but if you decide to participate we would seek your consent by asking you to sign a consent form to enable you to participate.

During the interview you will be asked to:

- Answer some questions about what the term ‘quality of life’ means to you and what characteristics you believe are important in determining your ‘quality of life’.
- Complete a brief questionnaire comprising a series of socio-demographic questions and a health related questionnaire.
- Take part in a task involving ranking cards relating to quality of life attributes that are most important to you.

What benefit will I gain from being involved in this study?

It is hoped that the sharing of your views will help us to develop an instrument to measure the quality of life for older people that may be used by decision-makers in

the future. However, we cannot guarantee that you will directly benefit from the participating in the project, therefore the research will have minimal individual benefits.

Will I be identifiable by being involved in this study?

The interview will be audio recorded using a digital recording device. The audio recording will later be transcribed by a professional transcription service and any identifying details removed by the research team. As such, the data will be individually re-identifiable (coded, details of participants kept separate from the digital recordings and transcriptions). All digital recordings will be destroyed once transcribed. Publications from the data will not identify any individual person or stakeholder organisation.

All personal information will be treated in the strictest confidence. Electronic documents will be kept on a Flinders University password protected computer that only the research team will have access to. All records containing personal information will remain confidential and no information which could lead to identification of any individual will be released, unless required by law. Paper records will be stored in a lockable filing cabinet in a secure office at Flinders University. All records will be stored for at least five years from the date of publication, after which time all materials and data will be destroyed.

Are there any risks or discomforts if I am involved?

It is not anticipated that there are any risks to participation in this study beyond those encountered during everyday life. However, if you have any concerns regarding possible or actual risks or discomforts, please raise them with the researcher.

How do I agree to participate?

Participation is entirely voluntary. If you agree to participate in this study you will be asked to complete a consent form before the interview commences. 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 the researcher. The researcher will then discuss with you whether you want to include or exclude any data that has already been collected. If you choose not to participate in the project your relationship with your aged care provider will not be affected.

Will I be able to find out the results of the project?

We will send all participants a summary of project findings once the final report has been prepared at the end of the project.

Funding

This project is funded by a research grant awarded by the Australian Research Council.

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

Chief Researcher

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ruth.walker@flinders.edu.au

Participants or third parties who wish to lodge a complaint about either the study or the way it is being conducted should contact ***the Social and Behavioural Research Ethics Committee Executive Officer on 08 8201 3116 or 08 8201 7938.***

Appendix 4: Participant consent form for stage one

Developing a new Quality of Life instrument for older people

Participant Consent Form

I,………………………………………………………………… in signing this form I confirm that:

- I have read the Participant Information Sheet and the nature and purpose of the research project has been explained to me. Any questions I have asked have been answered to my satisfaction.
- I understand that I may not directly benefit by taking part in this study.
- I understand that I may withdraw from the research project at any stage and that this will not affect my status now or in the future.
- I understand that if I withdraw during the interview, my interview will not be transcribed or included as project data.
- I understand that while information gained during the study may be published, I will not be personally identified.
- I understand that the interview will be audiotaped and transcribed verbatim and will be stored securely on a Flinders University server for 5 years. Once transcribed the recordings will be deleted.
- I understand that any electronic files will be kept on a Flinders University password protected computer that only the research team will have access to. All records containing personal information will

remain confidential and no information which could lead to identification of any individual will be released, unless required by law. Paper records will be stored in a lockable filing cabinet in a secure office at Flinders University. All records will be stored for at least five years from the date of publication, after which time all materials and data will be destroyed.

- I understand that if I decide to withdraw from the study I can choose whether any data already been collected can be included or excluded from the research.
- I understand that my relationship with my aged care provider will not be affected if I choose not to participate in this research.
- I confirm that I am over 18 years of age.

Signed…………………………………..   Date:……………………………

(Participant's Signature)

I have explained the study to subject and consider that he/she understands what is involved.

Signed………………………………   Date:……………………………

(Researcher's Signature)

Appendix 5: Interview schedule for stage one

Developing a new Quality of Life instrument with older people

Interview Schedule

Introduction

Good morning, my name is [name]. I am a researcher from [Flinders University/University of Sydney]. We are interviewing you today to ask you some questions about your quality of life and what is important to you. Your views will help us to understand more about older people's quality of life so we can develop a new measure to assess the quality of life and wellbeing of older people receiving aged care services in the future. All of your responses will be treated in strictest confidence.

TASK 1: Complete consent form

Ask the participant to complete the consent form. Explain that we need the participant's written consent to be interviewed before we commence.

Firstly, I will begin by asking you some questions about your quality of life and what features are important to you in defining your quality of life. Then, I will ask you to complete a ranking exercise that will involve you ranking some cards with different features of quality of life described on them in order of most important to least important. Next, I'll ask you some questions that will involve you using your memory and finally I'll ask you to complete a questionnaire which asks some questions about yourself. The whole process should take no longer than 90 minutes. Please ask if you need to take a break at any time. The interview will be audio-recorded. Do you have any questions to ask me before we start?

Set up digital recorder before commencing the interview.

TASK 2: Interview questions

Let's talk about your quality of life generally. Tell me about what quality of life means to you?

What features or characteristics do you think are important to you to have a 'good quality of life'?

*Do you think that the aged care services you are currently receiving have an impact on your quality of life? (*If respondent answers **yes** – prompt for more information - *In what ways? Could you provide some examples? Can you tell me more about this?)*

We've been talking about quality of life and now I'd like to move on to an exercise about which features of quality of life are most important to you.

TASK 3: Ranking cards exercise

Distribute cards containing quality of life dimensions (e.g. health, social relationships, independence, personal control etc.)

All of these cards describe a different aspect of quality of life. We would like you to rank these cards in order of importance (most importance to least important) on your own.

Please provide an example of ranking the cards to ensure the participant fully understands the task.

Why did you rank this item as most/least important?

Can you talk me through each of the cards and explain why you have placed them in this order?

Do you think any of these items are not important and shouldn't be included when we talk about quality of life? (If **yes** – *why do you think this card should be excluded?)*

Do you think there is anything that is important to your quality of life which is missing from the cards we have given you and that you think should be included?

So, we've talked about what is important to you for your quality of life. Is there anything else you would like to tell me that you haven't already spoken about?

Turn recorder off.

TASK 4. Ask participant to complete the questionnaire and EQ-5D.

OK. Thank you for taking part in the interview today. I really appreciate it and the information you have provided will be very valuable in developing a tool to measure the quality of life for older people.

<u>**Probes**</u>

I'm not sure I understood. Please tell me more about…

I'm not sure what you meant by……. Could you give me some examples?

I think you said……. Did I understand correctly?

Appendix 6: QoL cares ranking exercise for stage one

SLEEP Being able to sleep without difficulty most of the time	**INDEPENDENCE** Being able to spend your time as you want, doing things you value and enjoy
PHYSICAL MOBILITY Being able to get around your home and community by yourself without difficulty	**MENTAL HEALTH** Not feeling anxious, worried or depressed
CONTROL Having as much control over your daily life as you would want	**SELF-CARE** Feeling that you are able to present yourself in the way that you like and take care of yourself

PAIN Having no pain or discomfort	**Vision** Being able to see normally
HEARING Being able to hear normally	**SAFETY** Feeling as safe as you want
SOCIAL-RELATIONSHIPS Having as much social contact as you want with people you like	**DIGNITY** Being treated by others with respect and in ways that which make you think and feel better about yourself

Appendix 7: EQ-5D-5L

Removed due to copyright restrictions

Available online from: https://euroqol.org/

Appendix 8: Socio-demographic questionnaire for stage one and stage three

Flinders UNIVERSITY

THE UNIVERSITY OF SYDNEY

Project Title: Developing a new Quality of Life instrument for older people

QUESTIONNAIRE

We would be grateful if you could provide a few details about yourself. All of the

information you provide will be treated in strictest confidence and used for the research only.

1a. What is your date of birth? ………… Day ……….. Month 19……. Year

1b. How old are you? ……… Years

2. What is your gender? Male ☐ Female ☐ Prefer not to

define ☐

3a. Were you born in Australia? Yes ☐ No ☐

3b. If *no*, what country were you born in?

……………………………………………………………

4. What is the usual language spoken in your home?

……………………………..

5. What is your post-code? …………

6. What is the highest educational qualification you have? (Please tick).

No qualifications	
Completed high school	
Undergraduate degree or professional qualification	
Post-graduate qualification	
Other (*please specify*)……………………….…	

7. Do you live alone, with a spouse or other relative? (Please tick).

Living alone	
Living with spouse/partner	
Living with other relatives	
Living with other(s) - not relatives	
Living in an aged care home	

8. Do you have someone who helps you and acts as your informal carer (e.g. a family member or friend) with day-to-day tasks?

Yes ☐ No ☐

9. What level of Home Care Package are you receiving? (Please tick).

Commonwealth Home Support Program (e.g once-off and intermittent low level assistance)	
Home Care Level 1	
Home Care Level 2	
Home Care Level 3	
Home Care Level 4	
Unsure	

10. Approximately how many hours of support per week are you currently receiving?

…………hours per week

11a. Are you approved for a higher level of care than you are currently receiving?

Yes ☐ No ☐ Unsure ☐

11b. If *Yes* how long have you been waiting for?

…………………………………………….

12. Do you currently pay for the care you receive? (Please tick).

No, I don't make a contribution	
Yes, I pay a small contribution	
Yes, I pay a large contribution	
Yes, I pay for all of my care	

13. What types of services are you currently receiving? (Please tick all that apply).

Meals or help with cooking	
Cleaning	
Personal Care (e.g. showering)	
Home nursing	

Group Social Activities	
Respite Care in the Home	
Other (e.g. gardening, shopping) Please specify ………………………………..	

14a. In general, would you say your health is: (Please tick)

Excellent	
Very Good	
Good	
Fair	
Poor	

14b. Please provide a reason for your response

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

Thank you for taking the time to complete this questionnaire.

Appendix 9: Participant information sheet for stage three

Project Title: Developing a new Quality of Life instrument with older people

Participant Information Sheet – Telephone Interview

Description of the study:

People aged 65 and over represent Australia's fastest growing age group and are major users of health and aged care services. The overall aim of the research is to develop a new tool which can be used to measure older people's quality of life. This tool is to be used in economic evaluation and will help decision makers across health and aged care sectors to make efficient decisions about their resources.

We have talked to older people receiving Home Care Packages across four states (SA, VIC, NSW and TAS) to find out what is important for them to feel like they have a good quality of life. From these 40 interviews we have now developed some draft questions and we are now looking for feedback on these questions. We will be talking to some people we interviewed before (who have said we may contact them again) as well as some new participants who are helping us for the first time.

What will I be asked to do?

If you are interested in taking part in the research, a member of the research team will contact you to discuss the research and answer any questions that you may have. The researcher will then arrange a convenient date and time for a telephone interview. It is expected that the interview will last between 30 and 60 minutes. The materials to be discussed during the interview will be sent to you in advance. Participation is entirely voluntary but if you decide to participate, we will seek your consent by asking you to sign a consent form to enable you to participate. This will be sent to you with a reply paid envelop.

During the interview you will be asked to:

- Look at some draft questions and response categories
- Answer some questions so we can find out what you think about each option
- Complete a brief questionnaire comprising a series of socio-demographic questions and a health-related questionnaire.

What benefit will I gain from being involved in this study?

It is hoped that the sharing of your views will help us to develop an instrument to measure the quality of life for older people that may be used by decision-makers in the future. However, we cannot guarantee that you will directly benefit from the participating in the project, therefore the research will have minimal individual benefits.

Will I be identifiable by being involved in this study?

The interview will be audio recorded using a digital recording device. The audio recording will later be transcribed by a professional transcription service and any identifying details removed by the research team. As such, the data will be individually re-identifiable (coded, details of participants kept separate from the digital recordings and transcriptions). All digital recordings will be destroyed once transcribed. Publications from the data will not identify any individual person or stakeholder organisation.

All personal information will be treated in the strictest confidence. Electronic documents will be kept on a Flinders University password protected computer that only the research team will have access to. All records containing personal information will remain confidential and no information which could lead to identification of any individual will be released, unless required by law. Paper records will be stored in a lockable filing cabinet in a secure office at Flinders University. All records will be stored for at least five years from the date of publication, after which time all materials and data will be destroyed.

Are there any risks or discomforts if I am involved?

It is not anticipated that there are any risks to participation in this study beyond those encountered during everyday life. However, if you have any concerns regarding possible or actual risks or discomforts, please raise them with the researcher.

How do I agree to participate?

Participation is entirely voluntary. If you agree to participate in this study, you will be asked to complete a consent form before the interview commences. 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 the researcher. The researcher will then discuss with you whether you want to include or exclude any data that has already been collected. If you choose not to participate in the project your relationship with your aged care provider will not be affected.

Will I be able to find out the results of the project?

We will send all participants a summary of project findings once the final report has been prepared at the end of the project.

Funding

This project is funded by a research grant awarded by the Australian Research Council.

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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Participants or third parties who wish to lodge a complaint about either the study or the way it is being conducted should contact Flinders University Social and Behavioural Research Ethics Committee on 08 8201 3116 or 08 8201 7938.

Appendix 10: Participant consent form for stage three

Developing a new Quality of Life instrument for older people

Participant Consent Form

I,………………………………………………………………… in signing this form I confirm that:

- I have read the Participant Information Sheet and the nature and purpose of the research project has been explained to me. Any questions I have asked have been answered to my satisfaction.
- I understand that I may not directly benefit by taking part in this study.
- I understand that I may withdraw from the research project at any stage and that this will not affect my status now or in the future.
- I understand that if I withdraw during the interview, my interview will not be transcribed or included as project data.
- I understand that while information gained during the study may be published, I will not be personally identified.
- I understand that the interview will be audiotaped and transcribed verbatim and will be stored securely on a Flinders University server for 5 years. Once transcribed the recordings will be deleted.
- I understand that any electronic files will be kept on a Flinders University password protected computer that only the research team

will have access to. All records containing personal information will remain confidential and no information which could lead to identification of any individual will be released, unless required by law. Paper records will be stored in a lockable filing cabinet in a secure office at Flinders University. All records will be stored for at least five years from the date of publication, after which time all materials and data will be destroyed.

- I understand that if I decide to withdraw from the study I can choose whether any data already been collected can be included or excluded from the research.
- I understand that my relationship with my aged care provider will not be affected if I choose not to participate in this research.
- I confirm that I am over 18 years of age.

Signed…………………………………. Date:……………………………

(Participant's Signature)

I have explained the study to subject and consider that he/she understands what is involved.

Signed……………………………… Date:……………………………

(Researcher's Signature)

Appendix 11: Cards for telephone interviews for stage three

Response Categories

A Always Mostly Sometimes Occasionally Not at all	B Most of the time Often Some of the time Only occasionally None of the time
C Most of the time Often Sometimes Seldom Never	D Always Most of the time Sometimes Rarely Never
E All of the time Most of the time Some of the time A little of the time None of the time	

Card 1: Independence – Items

Definition: Living the life you choose and making your own decisions.

Consider your quality of life TODAY…..

1.	I live the life I choose and make my own decisions
2.	I feel that I can live the life I choose and make my own decisions
3.	I am in charge of my own life
4.	I have as much independence as I want

Card 2: Mobility – Items

Definition: Being able to get to the places you need or want to go to (indoors and outdoors), using mobility aids if you use them.

Consider your quality of life TODAY…..

If you use mobility aids (wheelchair, walker, stick), please answer the following question/s assuming you are using them.

1. I am mobile
2. I am able to get around as much as I need to
3. I am able to get around as much as I want to
4. I find it easy to move around
5. I am able to move around
6. I am physically mobile
7. I am physically mobile and can get out and about

Card 3: Emotional Well-being – Items

Definition: Living your life without sadness, worry or stress.

Consider your quality of life TODAY…..

1.	I feel happy and free from worry
2.	I am generally stress free / free of stress
3.	I am generally happy
4.	I am free from worry (and stress)
5.	I am generally happy and stress free

Card 4: Social Connectedness – Items

Definition: Having social relationships e.g. with family and/or friends and connections to the community

Consider your quality of life TODAY…..

1.	I have as many social connections as I need
2.	I have as many social connections as I would like
3.	I have good social relationships with family and friends
4.	I enjoy close relationships with family and friends
5.	I am happy with my close relationships
6.	I have as much contact as I like with family and friends

Card 5: Activities – Items

Definition: Spending time doing things you enjoy, whether alone or with other people

Consider your quality of life TODAY…..

1.	I have enough (leisure) activities / hobbies to keep me busy
2.	I am as busy as I would wish with my leisure activities
3.	I am as busy with my leisure activities as I like to be
4.	I feel that I have enough leisure activities to keep me busy
5.	I feel that I have enough leisure activities to keep me occupied
6.	I have leisure activities / hobbies I enjoy

Appendix 12: Interview schedule for telephone interviews for stage three

Flinders UNIVERSITY

THE UNIVERSITY OF SYDNEY

Developing a new Quality of Life instrument for older people

INTERVIEW SCHEDULE

1. Introduction

We are working on a project to develop a new quality of life instrument with older people. This instrument will be used for quality assessments and for economic evaluations.

We have already interviewed 40 people receiving Home Care Packages across 4 states (SA, NSW, VIC, TAS) to ask them about what having a good quality of life means to them.

From these interviews we have identified five areas that are the most important to the older people we have spoken to. We have now developed some draft questions for each of these five areas and are now talking to people to find out what they think of these draft questions and response options.

First, I need to get your formal consent to participate in the research. Then I will go through the draft questions and response options with you. At the end I will ask you a few basic questions about you, the services you received and your health. If we interviewed you previously, you have given this information to us before but, as each interview was anonymous, we will need to ask you again. Thanks for your understanding.

2. Consent Process

Go through consent form with participant and answer any questions they have. If they do not provide consent, end the session.

Are you ready to get started? [comfortable, need glasses?]

[Start audio recording]

3. Draft items and response categories

I am going to go through 5 sets of questions and response options with you. For each set, the draft questions are on one card and the response options are on another card.

We are looking for feedback on whether the items are clear and understandable, appropriately worded and whether your preferred answer is available.

Let's get started. Here is the first set of draft questions and responses….***[go through all sets]***

Let the participants give their initial thoughts unprompted. Based on what they say, you can use the following prompts as appropriate:

- How do you interpret the question?
- Is the item clear and understandable?
- Is the wording appropriate for older people?
- Would you be prepared to answer this question?
- Do they think other people with understand the question / find it acceptable?
- Is your preferred response available? If not, what would your preferred response be?
- What do you think about the definitions? Do they help? Are they clear?
- Which of the options available do you like the best and why?
- Is there anything that is important to your quality of life that isn't capture in these questions?
- Are there any questions that you don't think are important to your quality of life?

4. Socio demographic questionnaire & EQ-5D

Thank you for participating. We appreciate your feedback and help with refining the questions for the quality of life measure.

Appendix 13: Participant information sheet for stage four

Survey – Information for Participants

Purpose of the survey

This survey aims to find out what aspects of quality of life are most important for people aged 65 and over receiving aged care services in the community.

Who is this survey for?

This survey is for:

1) people who are aged 65 and older, and;

2) receiving a Commonwealth Home Support Programme or a Home Care Package.

Are there any risks or adverse effects to participating?

This survey includes questions about your quality of life. If you feel particularly worried, sad or anxious following completion of this survey, help is available to you from a number of free counselling services including:

Lifeline
Phone - 13 11 14
Website – www.lifeline.org.au

Beyond Blue
Phone – 1300 22 4636
Website - www.beyondblue.org.au

What benefit will I gain from being involved in this study?

It is hoped that your answers given will help us to develop an instrument to measure the quality of life for older people that may be used by decision-makers in the future. However, we cannot guarantee that you will directly benefit from the participating in the project, therefore the research will have minimal individual benefits.

Participation and withdrawal from the survey

Your participation in this survey is entirely voluntary. The survey is confidential and anonymous. This means that once you have completed the survey you will not be able to withdraw your data because we will not be able to identify you. However, if you decide to withdraw before you have fully completed the survey your data will not be included. You can choose to withdraw from the survey by closing the survey at any point.

Confidentiality

All of the information you provide will remain confidential and will not be used in any way in which you can be identified.

Informed Consent

By completing this survey, you will be giving your informed consent to take part in this research and for your data to be used for the purpose of this project and future related research projects. Completing the survey will signify that you have read and understood the information provided above.

Will I be able to find out the results of the project?

A summary of findings will be available on the project website (https://www.qol-acc.org/) once the final report has been prepared at the end of the project.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 2201). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 08 8201 3116, or by email human.researchethics@flinders.edu.au

Appendix 14: Screening questions and online survey for stage 4 and stage 6

Screening questions

S1. Are you aged 65 years or over? Yes / No

If no, terminate survey.

If yes, go to S2

S2. Are you receiving either a Commonwealth Home Support Programme or a Home Care Package? Yes/No

If no, terminate survey.

If yes, proceed with survey

You will be asked to answer 5 sets of questions about your current quality of life. We will then ask a few questions to find out a bit more about you (age, gender, type of homecare package you receive etc.).

Section A

Questions A1. to A13. below contain a series of questions about your quality of life.

Please click on one answer from each question below.

Consider your quality of life TODAY

A1. I feel that I can live the life I choose and make my own decisions

	Please click one
All of the time	☐
Most of the time	☐
Some of the time	☐
A little of the time	☐
None of the time	☐

A2. I am in charge of my own life

	Please click one
All of the time	☐

Most of the time	☐
Some of the time	☐
A little of the time	☐
None of the time	☐

A3. I have as much independence as I want

	Please click one
All of the time	☐
Most of the time	☐
Some of the time	☐
A little of the time	☐
None of the time	☐

A4. I am physically mobile and can get out and about *(with the use of mobility aids, e.g. wheelchair, walker, stick, if you use them)*

	Please click one
All of the time	☐
Most of the time	☐
Some of the time	☐
A little of the time	☐
None of the time	☐

A5. I am able to get around as much as I want to *(with the use of mobility aids, e.g. wheelchair, walker, stick, if you use them)*

	Please click one
All of the time	☐
Most of the time	☐
Some of the time	☐
A little of the time	☐

None of the time	☐

A6. I am generally happy

	Please click one
All of the time	☐
Most of the time	☐
Some of the time	☐
A little of the time	☐
None of the time	☐

A7. I am generally happy and stress free

	Please click one
All of the time	☐
Most of the time	☐
Some of the time	☐
A little of the time	☐
None of the time	☐

A8. I have as many connections to the community as I would like

	Please click one
All of the time	☐
Most of the time	☐
Some of the time	☐
A little of the time	☐
None of the time	☐

A9. I have good social relationships with family and friends

	Please click one
All of the time	☐

Most of the time ☐

Some of the time ☐

A little of the time ☐

None of the time ☐

A10. I enjoy close relationships with family and friends

Please click one

All of the time ☐

Most of the time ☐

Some of the time ☐

A little of the time ☐

None of the time ☐

A11. I have leisure activities / hobbies I enjoy

Please click one

All of the time ☐

Most of the time ☐

Some of the time ☐

A little of the time ☐

None of the time ☐

A12. I feel that I have enough leisure activities to keep me occupied

Please click one

All of the time ☐

Most of the time ☐

Some of the time ☐

A little of the time ☐

None of the time ☐

A13. I am as busy with my leisure activities as I like to be

	Please click one
All of the time	☐
Most of the time	☐
Some of the time	☐
A little of the time	☐
None of the time	☐

Section B

Questions B1. to B6. below contain a series of questions about the quality of the aged care services you receive. Thinking about these services please read each statement carefully and then click on the response category which best reflects your current situation.

Please click on one answer from each question below.

B1. I am treated with respect and dignity and can maintain my identity

	Please click one
Always	☐
Mostly	☐
Sometimes	☐
Rarely	☐
Never	☐

B2. I am supported to make informed choices about the care and services I receive and to live the life I choose

	Please click one
Always	☐
Mostly	☐
Sometimes	☐

Rarely ☐

Never ☐

B3. I receive care and support from aged care staff who have the appropriate skills and training

Please click one

Always ☐

Mostly ☐

Sometimes ☐

Rarely ☐

Never ☐

B4. I receive the services and supports for daily living that are important for my health and wellbeing

Please click one

Always ☐

Mostly ☐

Sometimes ☐

Rarely ☐

Never ☐

B5. I am supported to maintain my social relationships and connections with the community

Please click one

Always ☐

Mostly ☐

Sometimes ☐

Rarely ☐

Never ☐

B6. I am encouraged and supported to give feedback and make complaints and I have confidence that appropriate action will be taken

	Please click one
Always	☐
Mostly	☐
Sometimes	☐
Rarely	☐
Never	☐

Section C

Questions C1. to C9. below contain a series of simple questions about your quality of life and well-being. These questions form the Adult Social Care Outcomes Toolkit, which is an established instrument for assessing social care-related quality of life of adults in the community.

Please click on one answer from each question below.

C1. Which of the following statements best describes how much control you have over your daily life?

By 'control over daily life' we mean having the choice to do things or have things done for you as you like and when you want.

	Please click one
I have as much control over my daily life as I want	☐
I have adequate control over my daily life	☐
I have some control over my daily life but not enough	☐
I have no control over my daily life	☐

C2. Thinking about keeping clean and presentable in appearance, which of the following statements best describes your situation?

	Please click one
I feel clean and am able to present myself the way I like	☐

I feel adequately clean and presentable ☐

I feel less than adequately clean or presentable ☐

I don’t feel at all clean or presentable ☐

C3. Thinking about the food and drink you get, which of the following statements best describes your situation?

Please click one

I get all the food and drink I like when I want ☐

I get adequate food and drink at OK times ☐

I don’t always get adequate or timely food and drink ☐

I don’t always get adequate or timely food and drink, and I think there is a risk to my health ☐

C4. Which of the following statements best describes how safe you feel?

By feeling safe we mean how safe you feel both inside and outside the home. This includes fear of abuse, falling or other physical harm.

Please click one

I feel as safe as I want ☐

Generally I feel adequately safe, but not as safe as I would like ☐

I feel less than adequately safe ☐

I don’t feel at all safe ☐

C5. Thinking about how much contact you’ve had with people you like, which of the following statements best describes your social situation?

Please click one

I have as much social contact as I want with people I like ☐

I have adequate social contact with people ☐

I have some social contact with people, but not enough ☐

I have little social contact with people and feel socially isolated ☐

C6. Which of the following statements best describes how you spend your time?

When you are thinking about how you spend your time, please include anything you value or enjoy including leisure activities, formal employment, voluntary or unpaid work and caring for others.

	Please click one
I'm able to spend my time as I want, doing things I value or enjoy	☐
I'm able to do enough of the things I value or enjoy with my time	☐
I do some of the things I value or enjoy with my time but not enough	☐
I don't do anything I value or enjoy with my time	☐

C7. Which of the following statements best describes how clean and comfortable your home is?

	Please click one
My home is as clean and comfortable as I want	☐
My home is adequately clean and comfortable	☐
My home is not quite clean or comfortable enough	☐
My home is not at all clean or comfortable	☐

C8. Which of these statements best describes how having help to do things makes you think and feel about yourself?

	Please click one
Having help makes me think and feel better about myself	☐
Having help does not affect the way I think or feel about myself	☐
Having help sometimes undermines the way I think and feel about myself	☐
Having help completely undermines the way I think and feel about myself	☐

C9. Which of these statements best describes how the way you are helped and treated makes you think and feel about yourself?

Please click one

The way I’m helped and treated makes me think and feel better about myself ☐

The way I’m helped and treated does not affect the way I think or feel about myself ☐

The way I’m helped and treated sometimes undermines the way I think and feel about myself ☐

The way I’m helped and treated completely undermines the way I think and feel about myself ☐

Section D

Questions D1. to D5. below contain a series of questions about your health followed by a scale in which we ask you to mark an X on to indicate your health today and to write the number of the scale marked in the corresponding empty box. These questions form the EQ-5D-5L, which is an established instrument to describe and value health.

Please click on one answer from each question below.

Under each heading, please click the ONE box that best describes your health TODAY.

D1. MOBILITY

I have no problems with walking around ☐

I have slight problems with walking around ☐

I have moderate problems with walking around ☐

I have severe problems with walking around ☐

I am unable to walk around ☐

D2. PERSONAL CARE

I have no problems with washing or dressing myself ☐

I have slight problems with washing or dressing myself ☐

I have moderate problems with washing or dressing myself ☐

I have severe problems with washing or dressing myself ☐

I am unable to wash or dress myself ☐

D3. USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ☐

I have slight problems doing my usual activities ☐

I have moderate problems doing my usual activities ☐

I have severe problems doing my usual activities ☐

I am unable to do my usual activities ☐

D4. PAIN / DISCOMFORT

I have no pain or discomfort ☐

I have slight pain or discomfort ☐

I have moderate pain or discomfort ☐

I have severe pain or discomfort ☐

I have extreme pain or discomfort ☐

D5. ANXIETY / DEPRESSION

I am not anxious or depressed ☐

I am slightly anxious or depressed ☐

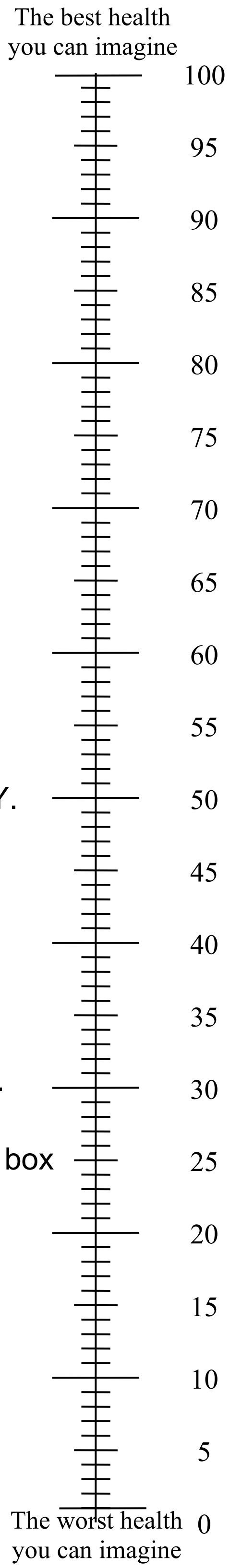
I am moderately anxious or depressed ☐

I am severely anxious or depressed ☐

I am extremely anxious or depressed ☐

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the <u>best</u> health you can imagine.
  0 means the <u>worst</u> health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = ☐



Section E

Questions E1. to E9. below contain a series of questions about your satisfaction with aspects of your quality of life. These questions form the Personal Wellbeing Index Scale, which is an established instrument for assessing personal wellbeing.

The following questions ask how satisfied you feel, on a scale from zero to 10. **Zero** means you feel no satisfaction at all and **10** means you feel completely satisfied.

Please click on one answer from each question below.

E1.Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole?

No satisfaction at all										Completely satisfied
0	1	2	3	4	5	6	7	8	9	10

E2. How satisfied are you with your standard of living?

No satisfaction at all										Completely satisfied
0	1	2	3	4	5	6	7	8	9	10

E3. How satisfied are you with your health?

No satisfaction at all										Completely satisfied
0	1	2	3	4	5	6	7	8	9	10

E4. How satisfied are you with what you are achieving in life?

No satisfaction at all										Completely satisfied
0	1	2	3	4	5	6	7	8	9	10

E5. How satisfied are you with your personal relationships?

No satisfaction at all										Completely satisfied
0	1	2	3	4	5	6	7	8	9	10

E6. How satisfied are you with how safe you feel?

No satisfaction at all										Completely satisfied
0	1	2	3	4	5	6	7	8	9	10

E7. How satisfied are you with feeling part of your community?

No satisfaction at all										Completely satisfied
0	1	2	3	4	5	6	7	8	9	10

E8. How satisfied are you with your future security?

No satisfaction at all										Completely satisfied
0	1	2	3	4	5	6	7	8	9	10

E9. How satisfied are you with your spirituality or religion?

No satisfaction at all										Completely satisfied
0	1	2	3	4	5	6	7	8	9	10

Section F

We would now like to ask you some questions about you.

F1. Are you:

☐ Female

☐ Male

☐ Prefer not to define

F2. How old are you?

☐ **Years**

F3a. Were you born in Australia?

☐ Yes

☐ No

F3b. If *no*, what country were you born in?

☐

F4. What is the usual language spoken in your home?

☐

F5. What is your post-code?

☐

F6. What is the highest educational qualification you have?

☐ No Qualifications

☐ Completed High School

☐ Undergraduate degree or professional qualification

☐ Post-graduate qualification

☐ Other (please specify)

☐

F7. Do you live alone, with a spouse or other relative?

☐ Living alone

☐ Living with spouse/partner

☐ Living with other relatives

☐ Living with other (s) – not relatives

☐ Living in an aged care home

F8. Do you have someone who helps you and acts as your informal carer (e.g. a family member or friend) with day-to-day tasks?

☐ Yes

☐ No

F9. What level of Home Care Package are you receiving?

☐ Commonwealth Home Support Program

☐ Home Care Level 1

☐ Home Care Level 2

☐ Home Care Level 3

☐ Home Care Level 4

☐ Unsure

F10. Approximately how many hours of support per week are you currently receiving?

☐ **Hours**

F11a. Are you approved for a higher level of care than you are currently receiving?

☐ Yes

☐ No

☐ Unsure

F11b. If *Yes* how long have you been waiting for?

☐

F12. Do you currently pay for the care you receive?

☐ No, I don’t make a contribution

☐ Yes, I make a small contribution

☐ Yes, I make a large contribution

☐ Yes, I pay for all of my care

F13. What types of services are you currently receiving? (please select all that apply)

☐ Meals or help with cooking

☐ Cleaning

☐ Personal care (e.g. showering)

☐ Home Nursing

☐ Group Social Activities

☐ Respite care in the home

☐ Shopping

☐ Gardening

☐ Transport

☐ Other (please specify)

☐

F14. In general, would you say your health is:

☐ Excellent

☐ Very Good

☐ Good

☐ Fair

☐ Poor

F15. In general, would you say your quality of life is:

☐ Excellent

☐ Very Good

☐ Good

☐ Fair

☐ Poor

Thank you for taking the time to complete this survey

Appendix 15: Publications arising from this thesis

Applied Health Economics and Health Policy (2019) 17:781–801
https://doi.org/10.1007/s40258-019-00512-4

REVIEW ARTICLE

A Review of the Development and Application of Generic Preference-Based Instruments with the Older Population

Jenny Cleland[1] · Claire Hutchinson[1] · Jyoti Khadka[1,2] · Rachel Milte[1] · Julie Ratcliffe[1]

Abstract

Older people (aged 65 years and over) are the fastest growing age cohort in the majority of developed countries, and the proportion of individuals defined as the oldest old (aged 80 years and over) living with physical frailty and cognitive impairment is rising. These population changes put increasing pressure on health and aged care services, thus it is important to assess the cost effectiveness of interventions targeted for older people across health and aged care sectors to identify interventions with the strongest capacity to enhance older peoples' quality of life and provide value for money. Cost-utility analysis (CUA) is a form of economic evaluation that typically uses preference-based instruments to measure and value health-related quality of life for the calculation of quality-adjusted life-years (QALYS) to enable comparisons of the cost effectiveness of different interventions. A variety of generic preference-based instruments have been used to measure older people's quality of life, including the Adult Social Care Outcomes Toolkit (ASCOT); Health Utility Index Mark 2 (HUI2); Health Utility Index Mark 3 (HUI3); Short-Form-6 Dimensions (SF-6D); Assessment of Quality of Life-6 dimensions (AQoL-6D); Assessment of Quality of Life-8 dimensions (AQoL-8D); Quality of Wellbeing Scale-Self-Administered (QWB-SA); 15 Dimensions (15D); EuroQol-5 dimensions (EQ-5D); and an older person specific preference-based instrument—the Investigating Choice Experiments Capability Measure for older people (ICECAP-O). This article reviews the development and application of these instruments within the older population and discusses the issues surrounding their use with this population. Areas for further research relating to the development and application of generic preference-based instruments with populations of older people are also highlighted.

1 Introduction

In the majority of developed countries, people aged 65 years and over represent the fastest growing age cohort, and the proportion of individuals defined as the oldest old (aged 80 years and over) living with physical frailty and cognitive impairment is rising [1, 2]. Older adults living with physical needs, frailty and/or cognitive impairment are frequent health system and aged care service users. Recently, in Australia, as in many other countries, initiatives have been introduced that aim to build partnerships between health and aged care services and promote cost effectiveness by breaking down traditional boundaries in care settings (e.g. through increased use of multidisciplinary aged care health teams and mechanisms to allow some services traditionally provided in a hospital setting to be provided in the community in an older person's home or within aged care facilities). This has resulted in a corresponding increase in the need for data on the relative benefits of interventions for application within economic evaluation across both health and aged care sectors. In a world of increasing resource constraints, the viability of new innovations in health and aged care will be highly dependent on their demonstrated cost effectiveness. Government expenditures in these areas are rising commensurate with the aging of the population, and thus it is important to assess the cost effectiveness of interventions targeted for older people to identify those interventions with the strongest capacity to enhance older peoples' quality of life and provide value for money [3, 4].

Electronic supplementary material The online version of this article (https://doi.org/10.1007/s40258-019-00512-4) contains supplementary material, which is available to authorized users.

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Key Points for Decision Makers

Older people aged 65 years and over represent the fastest growing age cohort for many countries and are major users of health and social care.

Preference based measures of quality of life are routinely applied in economic evaluation, however their application to date with populations of older people are relatively rare in comparison with the general adult population.

This review highlights the importance of incorporating older people's preferences for quality of life into the methodology of economic evaluation for assessing the relative value of interventions targeted for older people across health and social care sectors.

Cost-utility analysis (CUA) is a type of economic evaluation that facilitates comparisons of the cost effectiveness of different interventions through the calculation of a generic outcome measure, the quality-adjusted life-year (QALY). A QALY is a multidimensional measure of health outcome that encompasses both quality-of-life and quantity-of-life (survival) gains. Quality-of-life gains are represented by health state utilities generated on the QALY scale, which ranges from zero (equivalent of being dead) to one (full health). In some cases, negative utility values (worse than dead) can also be calculated and represented. QALYs are endorsed by the Pharmaceutical Benefits Advisory Committee (PBAC) and Medical Services Advisory Committee (MSAC) in Australia, and are also recommended by regulatory authorities internationally, e.g. the National Institute for Health and Care Excellence (NICE) in the UK and the Canadian Agency for Drugs and Technologies in Health (CADTH) in Canada [5–7]. Despite the label of quality of life, to date QALYs have typically focused more narrowly on health status and have tended to incorporate the views and preferences of predominantly younger people rather than older people. Many interventions accessed by older people in aged care have an impact beyond health status. For example, rehabilitation, reconditioning and reablement interventions for older people may lead to significant improvements in an individual's broader quality of life or well-being [8].

Our previous research conducted with a large community-based sample of older (aged 65 years and above) and younger (aged 18–64 years) Australians ($N = 1000$) to empirically compare, via ranking and best–worst tasks, the relative importance of key dimensions of quality of life for younger and older people found some important differences [8]. For older people, the ability to be independent and to have control over their daily lives were particularly important for their overall quality of life, whereas, for younger people, mental health was considered most important. The findings from our previous research indicated that a focus on broader aspects of quality of life may be more consistent with the preferences of older people themselves as to what constitutes quality of life from their perspective [8].

Generic preference-based instruments take into consideration the relative importance of different quality-of-life dimensions and are generally deemed suitable for CUA as they can be used to generate QALYs. One notable exception is the Investigating Choice Experiments Capability measure (ICECAP) family of instruments, which measure outcomes in terms of capabilities. Generic preference-based instruments consist of two common features: a descriptive system and a scoring algorithm. The descriptive system consists of various dimensions of quality of life (e.g. mobility, pain, usual activities), with different response options typically self-completed by the participant. The responses are converted into a utility score using a scoring algorithm. Responses are typically based on general population preferences for the health states defined by the descriptive system using valuation methods such as visual analogue scale (VAS), time trade-off (TTO), standard gamble (SG), discrete choice experiment (DCE) or best–worse scaling (BWS).

This article provides an overview of the use of generic preference-based instruments with populations of older people. An exhaustive list of generic preference-based instruments applicable for the older population were initially developed. These were extracted from the seminal textbook by Brazier and colleagues on the measurement and valuation of health for economic evaluation [9]. The descriptive systems and the scoring algorithms of the preference-based instruments that have been applied with older populations are summarised. An overview and classification of the recent application (during the preceding 5 years) of generic preference-based instruments with populations of older people is then provided. Finally, several key methodological issues surrounding the applicability and practicality of generic preference-based instruments for the economic evaluation of interventions across health and aged care sectors targeted for older people, along with recommendations for further research directions, are also presented.

2 Use of Preference-Based Instruments with the Older Population

Currently, only one preference-based instrument has been developed from its inception to be applied specifically with older populations—the ICECAP for older people

(ICECAP-O) (see Sect. 2.8). Several other generic preference-based instruments have also been used with populations of older people. The following section provides a summary of these instruments (see Sects. 2.1–2.7).

2.1 3-Level EuroQol-5 Dimensions (EQ-5D-3L)/5-Level EQ-5D (EQ-5D-5L)

The EuroQol-5 dimensions (EQ-5D) is a widely applied generic preference-based instrument consisting of five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. The 3-level EQ-5D (EQ-5D-3L) was the first version to be developed in 1990 and comprises three levels for each dimension [10]. The EQ-5D-5L was later developed in 2009 as a 5-level version to improve reliability and sensitivity of the instrument and to increase the number of health states generated [11].

2.2 Adult Social Care Outcomes Toolkit (ASCOT)

The Adult Social Care Outcomes Toolkit (ASCOT) was developed in 2010 and evaluates the impact of social services on an individual's quality of life (referred to as Social Care-Related Quality of Life [SCRQoL]). The toolkit consists of eight dimensions: control over daily life, personal cleanliness and comfort, food and drink, personal safety, social participation and involvement, occupation, accommodation cleanliness and comfort, and dignity. Each dimension comprises of four levels (ideal, no unmet needs, some unmet needs, high unmet needs) devised from Sen's theory of capabilities [12].

2.3 Health Utility Index (HUI) 1/2/3

There are three versions of the Health Utility Index (HUI): HUI1, HUI2 and HUI3. The HUI1 was originally developed in the 1970s to evaluate health-related quality of life in low birthweight babies in neonatal intensive care [13]; the HUI2 was developed in the early 1990s to be used in childhood cancer research, but more recently has also been widely applied within the general adult population; and the HUI3 was developed in the early 2000s for application within the general adult population. The instrument consists of eight dimensions (vision, hearing, speech, ambulation, dexterity, emotion, cognition and pain), with five to six levels of disability/functional ability for each dimension [14].

2.4 Short-Form-6 Dimensions (SF-6D)

The Short-Form-6 Dimensions (SF-6D) was developed in the late 1990s from the Short Form 36 Health Survey (SF-36). The SF-36 is a generic tool comprising eight dimensions (physical health, physical role functioning, social role functioning, emotional role functioning, mental health, pain, vitality and general health perceptions) but it is unable to be used in economic evaluation in its original form as it lacks a preference-based scoring system. The SF-6D scoring algorithm was developed from the SF-36 to enable the instrument to be used in CUA. There are two versions: one version created from the 12-item SF-12 and one version created from the 36-item SF-36. Recently, the SF-6D version 2 was developed with a new scoring system to increase the utility score range [15].

2.5 Assessment of Quality of Life (AQoL)-6 Dimensions (AQoL-6D)/AQoL-8 Dimensions (AQoL-8D)

Four Assessment of Quality of Life (AQoL) instruments have been developed to measure health-related quality of life: AQoL-4D, AQoL-6D, AQol-7D and AQoL-8D. The original AQoL-6D was developed in the early 2000s and consists of 20 items that cover six dimensions: independent living, relationships, mental health, coping, pain and senses. The AQoL-8D is the most recent instrument and was developed in 2011. It builds upon the previous AQoL instruments by adding further psychosocial dimensions. The AQoL-8D has 35 items that create eight dimensions (happiness, mental health, coping, relationships, self-worth, pain, senses and independent living). Each item has four to six response levels [16].

2.6 Quality of Wellbeing (QWB)

The Quality of Wellbeing (QWB) scale measures status and wellbeing and was developed in the 1970s to be used in health policy for the allocation of resources [17]. The QWB scale required a trained interviewer to administer the instrument to the participant. The QWB Scale-Self-Administered (QWB-SA) was introduced in 1996 for ease of use and is a self-completed version of the QWB [18]. The instrument consists of four sections: chronic symptoms, physical symptoms, mental health symptoms, and behaviours, and has three dimensions (mobility, physical activity and social activity).

2.7 15 Dimensions (15D)

15 dimensions (15D) was developed in Finland in the early 1990s to measure health-related quality of life, and comprises a self-administered tool consisting of 15 dimensions: mobility, vision, hearing, breathing, sleeping, eating, speech, usual activities, elimination, mental function, discomfort and symptoms, depression, distress, vitality and sexual activity. Each dimension has five levels and the instrument defines billions of health states [19].

2.8 Investigating Choice Experiments Capability Measure for Older People (ICECAP-O)

The ICECAP-O is a relatively new instrument, designed from its inception for application with older people, that focuses on capabilities with respect to broader quality of life and wellbeing rather than just health. The instrument is based on Sen's capability theory [20], which is reflected in the ICECAP-O instrument with the items using 'able to' or 'can'; for example, 'I can have all', 'I can have a lot', 'I can have a little', 'I cannot have any'. The instrument has five dimensions (attachment, security, role, enjoyment and control), with four levels for each dimension. The instrument produces a measure of capability and the values range from 0 (no capability) to 1 (full capability). Currently, the ICECAP-O is the only older-person-specific preference-based instrument in existence. The ICECAP for Adults (ICECAP-A) was developed later for application with the general adult population rather than specifically with the older population. It is not possible to calculate QALYs using the ICECAP-O. Consequently, some commentators have raised concerns about the instrument's applicability for application in CUA, where QALYs are typically the main outcome measure [20]. The ICECAP-O instrument developers have indicated that the ICECAP-O may be used within the framework of economic evaluation using a capability scale for the assessment of outcomes [21].

2.9 Comparisons of Preference-Based Instruments Descriptive Systems

Table 1 presents a comparison of the preference-based instruments, the majority of which are suitable to be applied in the general adult population; the ICECAP-O is the only older population-specific instrument. Most instruments adopt 'present' as the recall period, except for the QWB-SA, which uses a 3-day recall period; the AQoL-6D and AQoL-8D, which use 'past week' as the recall period; and the SF-6D (emanating from responses to the SF-36 and SF-12), which uses a standard recall period of 4 weeks. However, the HUI1 and HUI2 have three other standard options in addition to the present recall period: 'past 1 week', 'past 2 weeks' and 'past 4 weeks'. The instruments vary in the number of dimensions, items and response levels. The EQ-5D-3L and EQ-5D-5L have the least number of dimensions (five) compared with the 15D, which comprises 15 dimensions. The number of dimensions does not always directly correlate to the number of items in an instrument. For example, the EQ-5D-3L and EQ-5D-5L both comprise five items that produce five dimensions, but the AQoL-8D, for example, consists of 35 items that form eight dimensions. The response options for each instrument's items range between two and six levels. The different number of dimensions, items and response levels produce varying numbers of health states. The 15D and the AQoL-8D define the most health states, while the EQ-5D-3L defines the least.

It is important to recognise that instruments with large numbers of items may not always be practical to administer in older people due to respondent burden and/or cognitive overload, particularly where physical frailty and/or cognitive impairments are present [22, 23].

The dimensions of each instrument were categorised into those associated with both physical and psychosocial health using the classifications developed by Richardson et al. in their original review of preference-based instruments (see Table 2) [24]. Overall, the physical health dimensions are more prevalent in the instruments than the psychosocial health dimensions. The most widely used dimensions are the physical health dimensions of bodily function/self-care (adopted in all instruments apart from the ICECAP-O) and mobility/physical activity (present in all instruments except the ASCOT and the ICECAP-O). The physical health dimensions dexterity and fertility are the least adopted dimensions, with only the HUI3 covering dexterity and the HUI2 covering fertility (fertility is an optional dimension that can be excluded if measuring generic health status). The psychosocial health dimensions of meaning/achievement, safety/security and family are the least captured, with only the ICECAP-O covering meaning/achievement and the AQoL-6D and AQoL-8D covering family and intimacy dimensions. The EQ-5D-3L, EQ-5D-5L, HUI2, HUI3, AQoL-6D and 15D consist of predominantly physical health dimensions, whereas the ASCOT, SF-6D, AQoL-8D and ICECAP-O consist mostly of psychosocial health dimensions. QWB-SA focuses more on symptoms and therefore mainly covers physical dimensions.

Table 3 describes the scoring algorithms, predicted utilities and valuation methods used to produce the algorithms. VAS is the most common valuation method and has been used with the AQoL-8D, EQ-5D-3L, HUI2, HUI3, QWB-SA and 15D. The algorithms for the ASCOT, AQoL-6D, AQoL-8D, and both the EQ-5D-3L and EQ-5D-5L were produced using TTO. Other valuation methods include SG (used with the HUI2, HUI3 and SF-6D), BWS (used with the ASCOT and ICECAP-O) and DCE (used with the EQ-5D-5L and SF-6D v2). It is notable that more than one valuation method has been used to create utility scores for six of the instruments. The preference-based instruments, i.e. AQOL-8D, EQ-5D-3L, EQ-5D-5L, HUI2, HUI3 and SF-6D v2, can produce negative utility scores representing health states considered worse than being dead. The SF-6D v2 is the preference-based instrument that generates the lowest (all worst state) utility score (-0.718).

Table 1 Descriptive systems for preference-based instruments

	ASCOT	AQoL-6D	AQoL-8D	EQ-5D-3L	EQ-5D-5L	HUI2	HUI3	ICECAP-O	QWB-SA	SF-6D	SF-6D (V2)	15D
Country of origin	UK	Australia	Australia	Netherlands, UK, Sweden, Finland, and Norway	Netherlands, UK, Sweden, Finland, and Norway	Canada	Canada	UK	USA	UK	UK	Finland
Population	Adults	Adults	Adults	Adults	Adults	Adults, children	Adults	Adults aged 65 years and over	Adults	Adults	Adults	Adults
Respondent	Self-completion Interviewer administered Proxy	Self-completion	Self-completion	Self-completion Interviewer administered Proxy	Self-completion Interviewer administered Proxy	Self-completion Interviewer administered Proxy	Self-completion Interviewer administered Proxy	Self-completion	Self-completion Interviewer administered Proxy	Self-completion	Self-completion	Self-completion
Length of health-status recall period	Present	Past 1 week	Past 1 week	Present (today)	Present (today)	Usual (present) Recall (past 1 week, past 2 weeks, past 4 weeks)	Usual (present) Recall (past 1 week, past 2 weeks, past 4 weeks)	Present	3 days	Present	Present	Present
Primary focus	Social care	Health states and psychometric scores	Health states and psychometric scores	Health states	Health states	Health states, health-related quality of life	Health states, health-related quality of life	Capabilities	Health outcomes	Health states	Health states	Health states
Dimensions	8	6	8	5	5	7	8	5	3 (and 58 symptoms)	6	6	15
Items	8	20	35	5	5	7	8	5	76	11 (SF-36) 7 (SF-12)	11	15
Levels	4	4–6	4–6	3	5	3–5	5–6	4	2–4	4–6	4–6	5
Health states		5.4×10^{13}	2.43×10^{23}	243	3125	24,000	972,000		945	18,000 (taken from SF-36) 7500 (taken from SF-12)	18,750	31 billion

Table 1 (continued)

	ASCOT	AQoL-6D	AQoL-8D	EQ-5D-3L	EQ-5D-5L	HUI2	HUI3	ICECAP-O	QWB-SA	SF-6D	SF-6D (V2)	15D
Other versions of instruments	CH3 (for care homes) CH3-INT-Res CH3-INT-FS CH3-INT-QUAL CH3-Obs CH3-ratings	AQoL-4D AQoL-7D AQoL-8D	AQoL-4D AQoL-6D AQoL-7D	EQ-5D-5L EQ-5D-Y	EQ-5D-3L EQ-5D-Y	HUI HUI3	HUI HUI2	ICECAP-A CES ICECAP-SCM	QWB	SF-6D v2	SF-6D	16D 17D
Website	https://www.pssru.ac.uk/ascot/	https://www.aqol.com.au	https://www.aqol.com.au	https://euroqol.org/	https://euroqol.org/	http://www.healthutilities.com/	http://www.healthutilities.com/	www.birmingham.ac.uk/icecap	https://hoap.ucsd.edu/qwb-info/	https://www.sheffield.ac.uk/scharr/sections/heds/mvh/sf-6d	https://www.sheffield.ac.uk/scharr/sections/heds/mvh/sf-6d	http://www.15d-instrument.net/15d/

ASCOT adult social care outcomes toolkit, *AQoL-6D* Assessment of Quality of Life-6 Dimensions, *AQoL-8D* Assessment of Quality of Life-8 Dimensions, *EQ-5D-3L* 3-Level EuroQol-5 dimensions, *EQ-5D-5L* 5-Level EuroQol-5 dimensions, *HUI2* Health Utility Index Mark 2, *HUI3* Health Utility Index Mark 3, *ICECAP-O* Investigating Choice Experiments Capability Measure for older people, *QWB-SA* Quality of Wellbeing Scale-Self-Administered, *SF-6D* Short-Form-6 Dimensions, *SF-6D (V2)* Short-Form-6 Dimensions version 2, *15D* 15 Dimensions, *SF-36* 36-Item Short Form Health Survey, *SF-12* 12-Item Short Form Health Survey, *CH3* Care Home Three-Level Mixed Methods Tool, *CH3-INT-Res* Care Home Resident Structured Interview Schedule, *CH3-INT-FS* Care Home Family and Staff Structured Interview Schedule, *CH3-INT-QUAL* Care Home Resident Qualitative Interview Schedule, *CH3-Obs* Care Home Observation Schedule, *CH3-ratings* Care Home Ratings Schedule, *AQoL-4D* Assessment of Quality of Life-4 Dimensions, *AQoL-7D* Assessment of Quality of Life-7 Dimensions, *EQ-5D-Y* EuroQol-5 dimensions-Youth, *HUI* Health Utilities Index, *ICECAP-A* Investigating Choice Experiments Capability Measure for Adults, *CES* Carer Experience Scale, *ICECAP-SCM* Measure of capability for use in end-of-life care (under development), *QWB* Quality of Wellbeing Scale, *16D* 16 Dimensions, *17D* 17 Dimensions

Table 2 Preference-based instrument dimensions

Dimension type	ASCOT	AQoL-6D	AQoL-8D	EQ-5D-3L	EQ-5D-5L	HUI2	HUI3	ICECAP-O	QWB-SA	SF-6D	SF-6D (V2)	15D
Physical												
Mobility/physical activity		3	2	1	1	1	1		7	1	1	1
Bodily function/self-care	1	2	1	1	1	1	1		13	1	1	3
Dexterity							1					
Coping		1	1									
Pain/discomfort		2	2	1	1	1	1		14	1	1	1
Senses		2	2			1	2		5			2
Usual activities/work role related to physical health			4	1	1				12	1	1	1
Communication		1	1			1	1		2			1
Vitality		1	1						1	1	1	1
Fertility						1						
Psychosocial												
Sleeping			1						1			1
Wellbeing/depression/anxiety		5	7	1	1	1	1		4	1	1	2
Autonomy/control/dignity	1		1					1	1			
Self-esteem/identity	1		2									
Meaning/achievement								1				
Safety/security	1											
Cognition/memory						1	1		1			1
Usual activities related to psychosocial health	1		4	1	1			1	12	1	1	1
Relationship/social functioning	1	1	6					1	2			
Family		1	1									
Intimacy		1	1						1			

ASCOT Adult Social Care Outcomes Toolkit, *AQoL-6D* Assessment of Quality of Life-6 Dimensions, *AQoL-8D* Assessment of Quality of Life-8 Dimensions, *EQ-5D-3L* 3-Level EuroQol-5 dimensions, *EQ-5D-5L* 5-Level EuroQol-5 dimensions, *HUI2* Health Utility Index Mark 2, *HUI3* Health Utility Index Mark 3, *ICECAP-O* Investigating Choice Experiments Capability Measure for older people, *QWB-SA* Quality of Wellbeing scale-Self-Administered, *SF-6D* Short-Form-6 Dimensions, *SF-6D (V2)* Short-Form-6 Dimensions version 2, *15D* 15 Dimensions

Table 3 Properties of the preference-based instrument scoring algorithms and their predicted utilities

	ASCOT	AQoL-6D	AQoL-8D	EQ-5D-3L	EQ-5D-5L	HUI2	HUI3	ICECAP-O	QWB-SA	SF-6D	SF-6D (V2)	15D
Original source of population weights	General adult population in the UK	General adult population in Australia	Mental health patients and the general adult population in Australia	General adult population in Europe (Finland, Germany, The Netherlands, Spain, Sweden and the UK)	General adult population in the UK	General adult population in Canada	General adult population in Canada	Adults aged 65 years and over in the UK	Adults from primary care clinics and college campuses in San Diego, USA	General adult population in the UK	General adult population in the UK	General adult population in Finland
Valuation	BWS TTO	TTO	VAS transformed into TTO	TTO VAS	TTO DCE	VAS SG	VAS transformed into SG	BWS	VAS	SG	DCE	VAS
Best health	1	1	1	1	1	1	1	1	1	1	1	1
Worst health	−0.17	0	−0.04	−0.56	−0.208	−0.03	−0.36	0	0.09	0.301	−0.718	0.11
Scoring algorithms developed in other countries				Several other countries such as Japan, Singapore, USA, Australia, China, Poland	Several other countries such as Australia, France, Philippines, Poland, USA, Singapore	UK	UK, France			Japan, Hong Kong, Portugal, Brazil, Australia, Singapore, Spain	USA, Canada, Australia, Portugal and Brazil	

ASCOT Adult Social Care Outcomes Toolkit, *AQoL-6D* Assessment of Quality of Life-6 Dimensions, *AQoL-8D* Assessment of Quality of Life-8 Dimensions, *EQ-5D-3L* 3-Level EuroQol-5 dimensions, *EQ-5D-5L* 5-Level EuroQol-5 dimensions, *HUI2* Health Utility Index Mark 2, *HUI3* Health Utility Index Mark 3, *ICECAP-O* Investigating Choice Experiments Capability Measure for older people, *QWB-SA* Quality of Wellbeing scale-Self-Administered, *SF-6D* Short-Form-6 Dimensions, *SF-6D (V2)* Short-Form-6 Dimensions version 2, *15D* 15 Dimensions, *15D* 15 Dimensions, *BWS* Best–Worse Scaling, *TTO* Time Trade-Off, *VAS* Visual Analogue Scale, *DCE* Discrete Choice Experiment, *SG* Standard Gamble

3 Applications of Preference-Based Instruments in the Older Population

A literature review was conducted to identify applications of preference-based instruments in the older population during the preceding 5 years (January 2014 to May 2019). A 5-year review period was chosen for pragmatic reasons, coupled with the observation that the two most recently developed generic preference-based instruments included in this review (ICECAP and ASCOT) would be more likely to have been applied in economic evaluations during this period than in earlier time periods during which they were still in development and undergoing psychometric testing. The review was conducted by first searching the websites pertaining to each instrument to identify published studies. Second, a literature search was conducted using the PubMed and Google Scholar electronic databases. The search terms for the older population included ‘older people’, ‘elderly’, ‘aged’ and ‘geriatric’. These terms were combined with the keywords ‘ASCOT’, ‘AQoL-6D’, ‘AQoL-8D’, ‘EQ-5D’, ‘HUI2’, ‘HUI3’, ‘ICECAP-O’, ‘QWB’, ‘SF-6D’, ‘15D’, ‘preference-based instrument’, ‘preference-based measure’, ‘multi-attribute utility’, ‘health utility’ and ‘cost utility’. The search was limited to studies published in English in the last 5 years and studies that had applied the instruments exclusively with the population of interest (older people aged 65 years and over).

Figure 1 provides a flowchart of the selection process and the identification of the relevant papers for inclusion in the review. The titles and abstracts of the 981 studies initially identified were screened against the eligibility criteria by the lead review author (JC). Of these, 816 records were excluded as they did not meet the selection criteria, as detailed in Fig. 1. At this stage, the full texts of 165 articles were first assessed by JC, followed by two other reviewers (CH and JR) who independently assessed all of the articles. Overall agreement (interrater reliability) was calculated using Cohen’s kappa. An average kappa statistic of 0.95 was obtained, which indicated almost perfect interrater reliability [25]. Differences were resolved by discussion and consultation with the authorship team.

Table 4 presents an overview of the application of the generic preference-based instruments previously identified within different contexts across the health and aged care sectors in the older adult population. Further details of the identified studies are presented in Appendix 1. Studies were classified using the WHO International Classification of Diseases, Tenth Revision (ICD-10), with extensions into broader areas of social and aged care as dictated by the application areas for the generic preference-based instruments identified [26]. The review highlighted the wide variety of settings in which the preference-based instruments have been applied. In general, the instruments were most frequently applied in studies in the areas of mental and behavioural, fractures, falls, lifestyle behaviours and general health-related quality of life. The most common instrument applied in the older population is the EQ-5D, which was used in a wide range of health contexts. A recent review has shown the EQ-5D

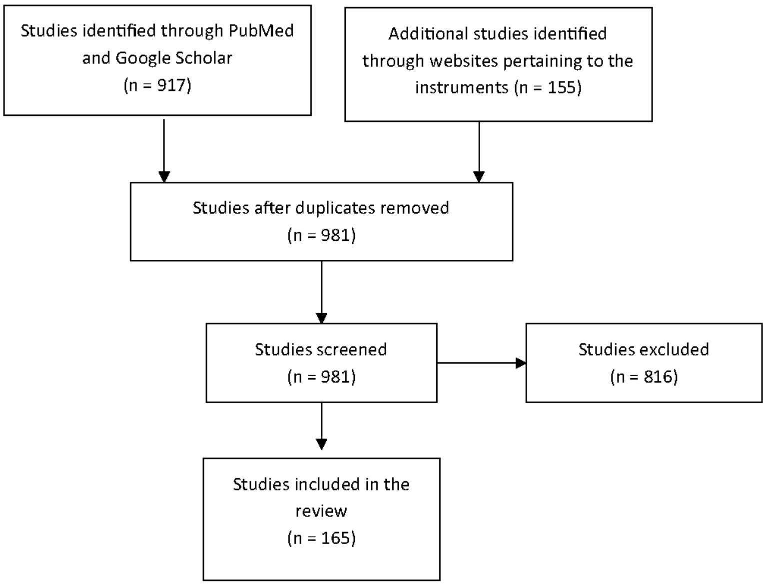

Fig. 1 Study identification process

Table 4 Number of preference-based instrument applications in populations of older people

	ASCOT	AQoL-6D	AQoL-8D	EQ-5D-3L	EQ-5D-5L	HUI2	HUI3	ICECAP-O	QWB-SA	SF-6D	SF-6D (V2)	15D
Mental and behavioural				14	2		1	2				
Musculoskeletal system and connective tissue				11	1							
Genitourinary system				3						1		
Endocrine, nutritional and metabolic		1		3	1							
Respiratory system				1								
Neoplasms				5	1							
Circulatory system				7								
Blood and blood-forming organs				1								
Nervous system				1						1		
Muscle mass				3	2							
Fractures				15				1		1		
Pain				1								
Multimorbidities				4								
Functional implants				5								
Medical procedures				1	2							
Frailty	1			8	1		1	2				1
Physical disability				2			1			1		
Falls				11	1			1				
Lifestyle behaviour				12	1			1	1			
Medication				7	1		1					2
General health-related quality of life				13	1			2				
Survey testing/validation	2			1	1			3				
Aged care services	3			5				1				
Acute care				2								
Other				1								

ASCOT Adult Social Care Outcomes Toolkit, *AQoL-6D* Assessment of Quality of Life-6 Dimensions, *AQoL-8D* Assessment of Quality of Life-8 Dimensions, *EQ-5D-3L* 3-Level EuroQol-5 dimensions, *EQ-5D-5L* 5-Level EuroQol-5 dimensions, *HUI2* Health Utility Index Mark 2, *HUI3* Health Utility Index Mark 3, *ICECAP-O* Investigating Choice Experiments Capability Measure for older people, *QWB-SA* Quality of Wellbeing scale–Self-Administered, *SF-6D* Short-Form-6 Dimensions, *SF-6D (V2)* Short-Form-6 Dimensions version 2, *15D* 15 Dimensions, *15D* 15 Dimensions to be the most widely used preference-based instrument to date, and it has been validated in many countries and across numerous health conditions [24]. One reasonable explanation for this instrument's prevalence is that agencies around the world recommend its use in economic evaluations for the measurement and valuation of health-related quality of life. For example, NICE has mandated the EQ-5D as its preferred instrument, and it is also recommended by the Australian PBAC, CADTH in Canada, the Health Information and Quality Authority in Ireland and PHARMAC in New Zealand [20].

The HUI2 was not applied in any of the identified studies, and the HUI3, AQoL-6D, QWB-SA and SF-6D instruments were applied in a relatively small number of studies in comparison with the EQ-5D. Despite being a relatively new instrument, the ICECAP-O had been applied in a variety of areas, including mental and behavioural, fractures, frailty, falls, lifestyle behaviour and general health-related quality of life. The ASCOT, which also represents a relatively new instrument that has been designed principally for application in a social care context, has been applied in several economic evaluation studies, including frailty and the aged care sector.

4 Key Methodological Issues

The application of generic preference-based instruments in the older population raises several key methodological issues, which are discussed in the following sections.

4.1 Applicability of the Content of Descriptive Systems to Older People

Within health economics, older peoples' quality of life has been measured using preference-based instruments to generate QALYs; however, QALYs typically measure health status and to date have not tended to focus on the broader dimensions of quality of life that are important to older people, particularly within the aged care and social services sectors [8, 21, 27]. For example, dimensions such as independence, control, safety, dignity and social relationships are imperative to older people's overall quality of life and these are not routinely captured in existing instruments suitable for economic evaluation [8, 27, 28].

Research acknowledging that generic preference-based instruments need to go beyond the traditional concept of health has resulted in the development of the ICECAP-O and the ASCOT. The ICECAP-O currently represents the only older-person-specific generic preference-based instrument in existence and was developed exclusively from its inception to measure and value older peoples' broader concept of quality of life. The items in the descriptive system were elicited from previous qualitative research with older people that identified the salient quality-of-life attributes for this population group [28]. The instrument focuses on quality of life influenced by an individuals' capabilities (based on Sen's capability theory) [21]. Therefore, the index scale is not compatible with the QALY scale as it reflects levels of capability, i.e. 1 (full capability) to 0 (no capability) [20].

The ASCOT was designed to be used to evaluate social care and focuses on broader concepts of quality of life; however, the instrument does not include specific items that relate to physical health and emotional wellbeing. Therefore, the instrument developers recommend that it should be used alongside other generic preference-based instruments designed to capture these dimensions, e.g. the EQ-5D [11]. Furthermore, the ASCOT was not designed to be used specifically within the older population, hence it does not isolate the views and preferences relevant to this specific population group.

4.2 Proxy Completion

Cognitive impairment and dementia are more prevalent in populations of older people than younger populations. Presently, 10% of people aged 65 years and over and one-third of people aged 85 years and over in Australia are living with a diagnosis of dementia, and estimates are predicted to rise markedly in the next three decades [29–31]. The DEMQOL-U and DEMQOL-Proxy-U are dementia-specific preference-based scoring algorithms derived from the DEMQOL family of instruments. While not designed to be applied in a generic context (and hence not directly included in this review), several studies applying these instruments in populations of older people have highlighted that, with appropriate assistance and support, older people with mild cognitive impairment and mild dementia are typically able to accurately report their own quality of life; however, this is often not the case for older people with moderate to severe cognitive impairment and dementia [8, 32–34].

In many countries, it is not possible to collect self-reported quality-of-life data directly from people with moderate to severe cognitive impairment and dementia as they have limited capacity to consent, and, in these types of instances, proxy completion is the only possible method of data collection [35]. These observations have led to debates surrounding proxies assessment of quality of life on behalf of older people living with cognitive impairment or dementia. Indeed, a literature review conducted by Rand and Caiels discussed the methodological challenges and issues with using proxies to assess quality of life [36]. The review found that proxy assessors tended to rate quality of life lower than self-reported assessments and this gap was often attributable to the personal characteristics of the proxy. This has also been found in research using proxies to assess quality of life with older people with dementia where proxy bias has been reported [37, 38]. However, a recent systematic review found that despite discrepancies between self-reporting and proxy reporting, validation studies have demonstrated overall good validity and reliability for proxy reporting in studies with older people with mild cognitive impairment rather than moderate and severe impairment [39].

Proxy assessment using the existing generic preference-based instruments highlighted in this review has tended to involve a proxy assessor completing the original instrument (designed principally for self-completion) on behalf of the respondent. Specific proxy versions of the existing generic preference-based instruments have tended not to be produced by instrument developers. The possibility of proxy assessment in this context raises important issues relating to the applicability (or otherwise) of an original instrument for application in proxy assessment and the level of cognitive impairment beyond which the person's assessment of their own quality of life may be considered unreliable and therefore proxy assessment should be sought.

Cognitive screening tools, e.g. the Psychogeriatric Assessment Scales-Cognitive Impairment Scale (PAS-Cog), are often used in research with older people to establish cognitive impairment threshold levels beyond which self-assessment of quality of life is no longer sought and proxy assessment is pursued [40]. An alternative approach that may be helpful for the more general development of instrument guidelines in relation to self versus proxy completion is to apply qualitative approaches, e.g. 'think aloud' in methodologically focused studies that may provide insights into the identification of cognition thresholds [41, 42]. The 'think aloud' approach involves participants verbalising what they are thinking, doing, seeing and feeling during data collection. This approach can allow the researcher to have a good understanding of the decision-making processes of the participant and provide an insight into their cognition levels and therefore their ability to accurately self-assess their own quality of life [43]. Another potential approach to inform the development of instrument guidelines in relation to self versus proxy completion is eye tracking. Eye tracking involves the observation of a participant's eye movements to identify how the individual is processing information [44]. A recent review by Eckstein et al. on eye tracking measures concluded that eye tracking is a useful method to gain insight into an individual's cognition level [45]. For large-scale routine collection of quality-of-life data, a more conventional interviewer-based approach to self versus proxy assessment of quality of life may be more appropriate, where the interviewer has the discretion to prematurely end the interview and seek an appropriate proxy response if the respondent is obviously distressed and/or struggling.

When seeking a proxy assessor, it is important to consider who is appropriate. Research has shown that the selection of a proxy assessor can result in different levels of quality of life being reported [46, 47]. Coucill et al. argue the use of different proxies leads to varying results, and their findings highlight the issue of who is an ideal proxy assessor [47]. Research by Bryan et al. assessing the quality of life in people with dementia using the EQ-5D with family members and clinicians also emphasised the variations in proxy reporting. The study found clinicians may be more suited to report on the participants' physical dimensions, and family members may report more accurately on the psychological dimensions [46]. Thus, the variations found between proxy assessors highlights the importance of considering the relationship of the proxy assessor to the participant when using proxy instruments to gather data.

4.3 Valuation of the Preference-Based Instruments

Several commentators have noted that if interventions aimed at the older population are to be accurately evaluated, older people's quality-of-life preferences need to be incorporated when validating instruments to accurately reflect the older populations' preferences [8, 21, 48]. However, with the notable exception of the ICECAP-O, the scoring algorithms pertaining to the preference-based instruments discussed in this review were generated based on preferences drawn from the general adult population. As mentioned previously in Sect. 4.1, there is evidence to suggest that older people interpret quality of life differently to the general adult population [8, 21, 27]. Therefore, the preferences elicited across dimensions of quality of life to develop the scoring algorithms of the instruments are unlikely to accurately represent older peoples' preferences. The scoring algorithm pertaining to the ICECAP-O instrument was developed from a sample of community-dwelling older people aged 65 years and over in the UK, using BWS, a form of DCE [21].

4.4 Comparability of Preference-Based Instruments

The quality-of-life domains included in the preference-based instruments highlighted in this review are varied and there is very little commonality to the ways in which quality-of-life domains or attributes are described between instruments, which makes it hard for the outcomes of different instruments to be compared across interventions. For example, both the ASCOT and ICECAP-O have a domain that measures 'control'; however, the ASCOT measures control by identifying the participants' 'control' over their daily life, whereas the ICECAP-O measures 'control' through identifying the participants' level of independence, leading to disparity between the instruments [48].

A recent study by Richardson et al. comparing six preference-based instruments, highlighted the differences both in the content and scale of the instruments, leading to different utilities representing the same health states [49]. The study found the instruments vary in their descriptive systems to measure quality of life, which, coupled with the different measurement scales, leads to the incomparability of the preference-based instruments. This is an issue for decision makers when attempting to compare outcomes generated from different preference-based instruments across different interventions.

4.5 Health Spillovers in Economic Evaluation

Interventions across health and aged care may have an impact that goes beyond the benefits experienced by the older person; for example, family members, friends and carers may also benefit from the intervention. Research by Bobinac et al. highlighted the wider benefits experienced by caregivers when reducing their burden of informal care, and improvements to family members' health resulting from decreased anxiety and stress related to the individual [50]. Economic evaluations typically focus on the outcomes and benefits in relation to the individual, and often neglect the wider impact that the intervention may have, e.g. on close family members and informal carers [51]. A recent systematic review by Bulamu et al. of economic evaluations conducted in the community aged care sector found that none of the included studies considered the possible wider impact of interventions for the older person on informal carers, nor did they include in the economic evaluation the time spent providing care [52]. Informal carers are a key component of care delivery, and therefore informal care costs and outcomes should be considered in economic evaluations [51, 52]. Thus, recent research has demonstrated the importance, within economic evaluations, of recognising these health and quality-of-life spillovers, in addition to the individuals' benefits, for the full effect of the intervention to be captured.

5 Limitations

There are several limitations to this review that are important to highlight. While the review was exhaustive in terms of providing a comprehensive list of the available generic preference-based instruments applicable for the older population, due to resource limitations it was not possible to gather evidence relating to the application of these instruments using a systematic review approach. It is therefore possible that some studies conducted within the relevant time period, e.g. appearing in the grey literature, were not included in this review. Similarly, for practical purposes, the literature search was limited to published studies presented in the English language within the last 5 years, as well as studies that had applied the identified instruments exclusively to the population of interest (older people aged 65 years and over). Despite these limitations, this review provides unique insights. It provides a detailed overview of the development and application of generic preference-based instruments with populations of older people to date, and discusses the issues surrounding their use with this population. Areas for further research relating to the development and application of generic preference-based instruments with populations of older people are also highlighted.

6 Conclusions

This review has highlighted the preference-based instruments (ASCOT, HUI2, HUI3, SF-6D, AQoL-6D, AQoL-8D, QWB-SA, 15D, EQ-5D-3L, EQ-5D-5L, ICECAP-O) that have been applied to date within populations of older people. The key differences between the instruments in terms of their descriptive systems, the included dimensions and the development of the respective scoring algorithms pertaining to the descriptive systems of each instrument have been highlighted.

In order to accurately assess the cost effectiveness of interventions within the older population, it is imperative that older people's views of what constitutes quality of life are considered. Thus, further research needs to be undertaken to more fully incorporate older people's views and preferences for quality of life into the methodology of economic evaluation for assessing the relative value of interventions targeted for older people across health and aged care sectors. This includes a more detailed consideration of the myriad of issues surrounding self versus proxy assessment of quality of life, and the potential for the development of proxy-specific versions of established instruments. If economic evaluations conducted in aged care are to accurately assess the value of competing interventions, it is important that older people's preferences in relation to the defining characteristics of quality of life are adequately captured within QALY calculations. Therefore, in the longer term, the development of a new older-person-specific preference-based instrument developed from its inception with older people, for application in economic evaluation in aged care and designed to measure and value quality-of-life outcomes from their perspective, should be considered.

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Compliance with Ethical Standards

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Developing dimensions for a new preference-based quality of life instrument for older people receiving aged care services in the community

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Abstract

Purpose To identify the salient quality of life characteristics relevant to older people in receipt of community aged care services in order to develop dimensions for a draft descriptive system for a new preference-based quality of life instrument.

Methods Forty-one in-depth semi-structured interviews were undertaken with older people (65 years and over) receiving community aged care services across three Australian states to explore quality of life characteristics of importance to them. The data were analysed using framework analysis to extract broader themes which were organised into a conceptual framework. The data were then summarised into a thematic chart to develop a framework matrix which was used to interpret and synthesise the data. Care was taken throughout to retain the language that older people had adopted during the interviews to ensure that appropriate language was used when identifying and developing the quality of life dimensions.

Results The analysis resulted in the identification of five salient quality of life dimensions: independence, social connections, emotional well-being, mobility, and activities.

Conclusion This research finds that quality of life for older people accessing aged care services goes beyond health-related quality of life and incorporates broader aspects that transcend health. The findings represent the first stage in a multiphase project working in partnership with older people to develop a new preference-based instrument of quality of life for informing quality assessment and economic evaluation in community aged care. In future work, draft items will be developed from these dimensions and tested in face validity interviews before progressing to further psychometric testing.

Keywords Quality of life · Older people · Aged care services · Preference-based instrument · Economic evaluation

Introduction

The policy and practice landscape for the Australian aged care sector, in common with the aged care sectors of many other countries, is changing with a significant increase in recent years in the incidence of older people accessing community aged care services [1]. In Australia, the home care packages (HCP) programme is the fastest growing sector of the aged care system with 116,800 people receiving a HCP in 2017–2018 compared to 97,200 in 2016–2017 [2]. This sector is predicted to increase markedly in the coming decades due to increasing numbers of people living at home with frailty, cognitive decline and dementia [3]. In Australia, the aged care sector is currently the subject of a Royal Commission that is placing an international spotlight on the shortfalls of the system and which is likely to highlight the need for significant policy reform to drive improvements in quality and efficiency when it issues its final recommendations at the end of this year [4]. A suite of recent systematic reviews have identified the paucity of economic evaluation evidence internationally, [5–8] yet economic evaluation forms a much needed component for policy reform to drive

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quality improvements and ensure that resources allocated across the aged care sector are targeted to services and programmes which maximise the quality of life (QoL) of older people [6, 7, 9].

Cost-utility analysis is a widely applied economic evaluation framework which synthesises costs and outcomes into a cost-utility ratio, whereby outcomes are most often assessed through the calculation of quality-adjusted life-years (QALYs). QALYs measure and value QoL on the zero (equivalent of being dead) to one (full health) QALY scale and are typically generated through the application of preference-based QoL measures. A recent review of the development and application of generic preference-based instruments with the older population across health and social care sectors by Cleland et al. [10] highlighted the EQ-5D-3L [11] and EQ-5D-5L [12] as the most widely used measures applied with the older population to date. These measures that focus on health-related QoL were applied in 137 studies. The Adult Social Care Outcomes Toolkit (ASCOT), [13] a preference-based measure of social care related QoL and the Investigating Choice Experiments Capability Measure for older people (ICECAP-O), [14] a measure of capability for older people, have also been applied in a number of studies (6 and 13, respectively). Research conducted by Van Leeuwen et al. [15] exploring the content validity and feasibility of the EQ-5D-3L, ASCOT and ICECAP-O with older adults found that some of the dimensions in these measures were not deemed to be relevant and none of the measures captured all the dimensions that older people thought were important to their quality of life. The most important aspect of an instrument is its content relevance. None of the existing preference-based measures are specific to older people accessing aged care. Previous work by Ratcliffe and colleagues [16] published in this journal found that the preferences of younger and older people in relation to the relative importance of dimensions of QoL are not the same. Whilst this research found some importance differences in preferences between younger and older adults the study did not collect any qualitative data to further explore and examine why these differences existed. A need for further research to be undertaken to explore the concept further and to develop a preference-based measure for older people accessing aged care were the main recommendations from this previous study. Ratcliffe's work and that of others has highlighted that older people's views and preferences about what encapsulates QoL from their perspective goes beyond health status incorporating wider dimensions such as independence, control, social relationships, and dignity [17, 18]. If economic evaluations conducted in aged care are to accurately assess the value of competing interventions, it is important that the defining characteristics of QoL for older people are adequately captured within QALY calculations. Our research aims to address this gap by developing an older person-specific preference-based QoL measure for application in quality assessment and economic evaluation in aged care.

Most of the existing preference-based QoL and patient-reported outcome (PRO) measures more generally have been developed using a professional-centred approach based upon the literature and/or the views of experts [19]. However, the involvement of the population of interest using a person-centred approach from inception has recently been encouraged in developing PRO measures [20]. This approach has also recently been incorporated in the development of a new preference-based QoL measure for paediatric populations [21] and was utilised in the development of the ICECAP suite of measures for assessing capabilities in adult and older populations [17, 22]. Whilst the ICECAP-O was developed for application with older people using a similar approach to the one adopted here, it is a measure of capability developed with older people living in the community in the UK and has Sen's capability approach as its fundamental theoretical foundation [23, 24]. In contrast, this study sought to partner more specifically with aged care organisations and older people in Australia receiving community aged care services to develop a new preference-based measure of QoL. A person-centred approach was applied to directly facilitate the use of appropriate language and content relevant to older people receiving community aged care services, thereby increasing its content validity and relevance [25–27]. This paper reports on the first stage of our multiphase research project to develop an older person-specific preference-based QoL measure for application in aged care. This phase involved identifying the salient QoL dimensions relevant to older people in receipt of community aged care services to develop the draft descriptive system for the measure.

Methods

Recruitment

Participants were recruited from five aged care organisations providing community aged care services to older people in metropolitan and rural areas across three Australian states (South Australia, Victoria, and New South Wales). Eligibility to participate in the research was based on the following criteria: aged 65 years and over; in receipt of a government HCP; ability to communicate in English; normal cognitive functioning through to mild cognitive impairment/mild dementia (assessed by the aged care organisation using the Psychogeriatric Assessment Scale Cognitive Impairment Scale (PAS-Cog [28])); and ability to provide informed consent. Purposive sampling was utilised to ensure a representative sample of older people receiving HCPs participated in the study. The research team provided the eligibility criteria and an overview of the demographics of participants in Australia receiving HCPs to the aged care organisations who recruited using this criterion enabling our sample to be broadly representative.

The aged care organisations approached potential participants in the first instance and provided them with a letter detailing the research and a participant information sheet. After one week, the organisations re-contacted the participant to ask if they were interested in taking part and to gain verbal consent for the researcher to approach the participant. If consent was gained, the organisation gave the contact details of the older person to the research team. The researcher then contacted the participant via telephone to confirm their willingness to participate, answer any questions, and to arrange a face-to-face interview.

In total, 41 qualitative interviews were undertaken with participants who were receiving community aged care services in South Australia, New South Wales, and Victoria. The participants were interviewed in their choice of setting with all the participants choosing to be interviewed in their own home. The interviews were conducted by two researchers with prior experience of interviewing older people in this context. On arrival, the researcher discussed the participant information sheet, explained the interview process, answered any questions, and gained written consent. The interview duration ranged from 21 to 69 min (mean = 33 min).

Interviews

The in-depth semi-structured interviews consisted of three stages. The researchers followed an interview schedule to ensure the interviews were conducted in the same manner. At the first stage the researcher began the interview by asking the participant ‘What does QoL mean to you?’ to initiate a discussion. This question was then followed by open-ended questions about QoL in general to explore the meanings around the term and characteristics that were important to the older person. These open-ended questions enabled the participant to initiate discussion about the issues relating to QoL which were most pertinent to them, and for the interviewer to then probe further to understand the factors and issues relating to QoL. The participant was then asked questions about the aged care services they were receiving to understand how their support impacted upon their QoL. The second part of the interview consisted of the presentation of a series of 12 cards reflecting different dimensions of QoL. The card labels and descriptors are based on the content of the descriptive systems of the EQ-5D, the Assessment of Quality of Life (AQoL) and the ASCOT instruments and were developed and employed in the previous study by Ratcliffe and colleagues to ascertain older and young person preferences for attributes of QoL [16]. Each participant was presented with the 12 cards, each card displaying a single QoL dimension (independence, safety, social relationships, hearing, vision, mental health, sleep, physical mobility, self-care, dignity, control, pain) with a brief description to explain its meaning. The cards were used to probe the participant about the different dimensions of QoL that they deemed important to promote further discussion on the impact of the dimensions on their quality of life. Participants were also provided with the opportunity to discuss any other aspects of QoL that may not have already been discussed in the interview. The final stage involved the participant completing the EQ-5D-5L (self-complete version) and a short questionnaire that included questions about the participant’s socio-demographics and their care. The EQ-5D-5L and the socio-demographic questionnaire were printed in large font size to accommodate participants with visual impairment.

Analysis

The analysis was guided by the purpose of the research which was to understand the QoL characteristics important to older people in order to identify salient candidate dimensions for the development of a descriptive system for a new preference-based QoL measure for older people in receipt of aged care. The dimensions were developed from stage one of the interviews with stage two providing further data to illustrate the impact of the dimensions on participant’s quality of life. Data saturation was assessed by the two researchers through conducting their own interviews and reading each other’s interview transcripts as the data collection progressed to establish when no new themes were emerging. Saturation was reached prior to the 41 interviews being conducted but it was decided that all the interviews would still be carried out to increase confidence in the data.

Interviews were transcribed verbatim by a Flinders University approved transcriber and the data were analysed using framework analysis [29–31]. Framework analysis as a technique was initially developed in the 1980′s in a social policy context for large-scale policy research as a response to the growth of qualitative research being undertaken [31]. However, it has now been used extensively in analysing qualitative data in health services research, [32, 33] including in QoL research [34–38], in the development of the CHU9D, a preference-based HrQoL measure for children [21, 39] and in the ICECAP-O, a preference-based measure of capability for older people [23]. The software package NVivo version 12 [40] was used to manage the qualitative data and analysis.

Framework analysis is a structured and vigorous approach to analysing qualitative data and consists of several stages. The first stage of familiarisation involved reading and re-reading the interview transcripts to become familiar with the data. The two authors who conducted the interviews (JC and CMB) read all transcripts whilst the other authors read a subsample of transcripts each. In the second stage, two independent coders (JC and CMB) analysed all the transcripts and developed an initial set of codes. At stage three, all members of the authorship team attended a workshop where the initial codes and quotes were examined, discussed, and collated into broader themes to form an agreed analytical framework.

In stage four, known as *indexing,* the two initial coders applied the analytic framework, collating participants' quotes under the agreed themes. Stage five involves a process known as *charting* and is a unique aspect of framework analysis. In this stage, the coders develop a framework matrix which consists of rows (participants) and themes (columns) with each cell containing data summaries, thereby reducing the data whilst retaining the original perspectives of participants. In this way, the research team could examine the data at different levels of abstraction to aid synthesis and interpretation at a second workshop of the authorship team where the charts were reviewed. The framework approach therefore assisted in maintaining an analytical trail. Throughout the analysis, care was taken to retain the language that older people had adopted during the interview to ensure that appropriate language was used when developing the dimensions and which can subsequently be drawn upon to develop the draft items for the QoL measure.

Statistical analysis

Summary statistics for the sample were generated as simple frequencies and percentages using SPSS, version 25.0 [41] and are presented in Table 1. Health state utility values for the EQ-5D-5L were generated from a pilot scoring algorithm based on a DCE approach in an Australian general population sample [42]. A final Australian general population scoring algorithm for the EQ-5D-5L is currently in development but is not yet publicly available. Utility scores range from − 0.676 to 1 where health states with a score less than 0 are considered worse than death.

Results

Participant characteristics

Forty-one interviews were completed with older adults aged 68 to 95 years old. Four participants chose to have a family member present during the interview. These individuals did not formally participate in the research or influence the participant's response in any way. Approximately three-quarters of the sample were female (73%). Most of the older adults lived alone (63%) with just under a third (29%) living with

Table 1 Participant characteristics (n = 41) and Australian home care population [1, 43]

Study participants	*N* (%)	Australian home care population	%
Sex		Sex	
Male, *n* (%)	11 (27)	Male, %	36
Female, *n* (%)	30 (73)	Female, %	64
Age		Age	
65–79, %	12 (29)	65–79, %	35
80–89, %	21 (51)	80–89, %	47
> 90, %	8 (20)	> 90, %	18
Living arrangements			
Living Alone, *n* (%)	26 (63)		
Living with spouse/partner, *n* (%)	12 (29)		
Living with other relatives, *n* (%)	2 (5)		
Living with others (not relatives), *n* (%)	1 (2)		
Home care package level		Home care package level	
Level 1 (basic care needs), *n* (%)	2 (5)	Level 1 (basic care needs), %	9
Level 2 (low care needs), *n* (%)	19 (46)	Level 2 (low care needs), %	44
Level 3 (intermediate care needs), *n* (%)	8 (20)	Level 3 (intermediate care needs), %	19
Level 4 (high care needs), *n* (%)	12 (29)	Level 4 (high care needs), %	28
Self-reported health			
Excellent, *n* (%)	2 (5)		
Very Good, *n* (%)	4 (10)		
Good, *n* (%)	20 (49)		
Fair, *n* (%)	12 (29)		
EQ-5D-5L Score, mean (SD)	0.56 (0.28)		
EQ-VAS Score, mean (SD)	66.88 (18.46)		

their spouse or partner. Five percent were receiving a level 1 HCP, nearly half (46%) a level 2 HCP, a fifth (20%) a level 3 HCP, and just under a third (29%) a level 4 HCP. The sociodemographic characteristics (age and sex data only available for comparison) and the distribution of HCP levels across our study sample are broadly representative of the population of older people currently receiving HCPs in Australia [1, 43]. Participant's health-related QoL as approximated by the EQ-5D-5L using the Australian general population-specific scoring algorithm was on average significantly lower (mean 0.56, SD 0.28) than for the general population of similar age range (mean 0.85, SD 0.16) [44]. This finding was not unexpected given that the sample comprised dependent older people in the community receiving aged care services (Table 1).

Dimensions

The analysis produced five salient dimensions that were consistently identified: independence, social connections, emotional well-being, mobility, and activities. Each of these dimensions will be discussed in more detail below. Relevant quotes illustrating the themes are presented in Table 2.

Independence

The importance of being independent was discussed by all participants as a key attribute of their QoL. Most participants spoke about their desire to retain their own independence during the ageing process by continuing to do as much as possible for themselves including making their own decisions. This was of particular importance to participants as they wanted to retain control over their own lives and minimise their reliance on other people. In addition, some participants noted how much they valued the support they received from aged care services to help them to remain living at home independently. Whilst some participants receiving high-level HCPs acknowledged they would not be able to remain at home without the support they currently received, others receiving lower level HCPs were also grateful for help with various daily tasks and activities of daily living that they recognised that they had difficulties undertaking and/or were no longer able to do.

Social connections

Almost all participants spoke about being connected to family and friends and how good relationships with those close to them were important for them to experience a good quality of life. Family was especially important to many participants and they looked forward to contact with family and valued their support. Relationships with friends were also important for many participants. Contact with friends was experienced face to face and via the telephone. Several participants also discussed being disconnected from family and friends due to health restrictions, death of loved ones, and family disagreements. These social disconnections often caused participants to worry and become anxious, and in some cases were a cause of great upset. For some participants, contact with their paid carers was the only social connection they experienced, and they looked forward to their visits. Some participants expressed that they had developed close bonds with these carers and considered them as friends. The three relationships (carers, friends, and family) were incorporated into one dimension because the manner in which participants spoke about these relationships impacting upon their quality of life was fundamentally the same.

Emotional well-being

A large majority of participants spoke about how their emotional well-being such as general feelings of worry, 'feeling down' and anxiety, often associated with everyday experiences affected their quality of life. For some participants, these feelings were linked to the fear of having to leave their own homes and move into residential care. Other participants spoke about experiencing depression as a result of their physical decline which meant they were no longer able to participate in activities or hobbies that they previously enjoyed. Other instances of depression amongst participants were related to family disagreements and fallouts which for some had resulted in complete disconnection from family members which had caused great distress.

Mobility

Almost all participants spoke about their physical mobility and the limitations they experienced which impacted upon their quality of life. For many participants, these changes meant they had to find ways of adapting to continue to do everyday tasks or activities that they had previously enjoyed. However, some participants experienced major restrictions as a result of their decline in mobility which prevented them entirely from doing what they previously had enjoyed. In general, participants were accepting of changes to their mobility and accepted physical mobility limitations as a normal and inevitable part of the ageing process. However, some participants indicated that they often still felt frustrated by their lack of ability to do what they wanted to do. Many participants discussed the importance of their mobility aids such as scooters, wheelchairs, walking frames and walking sticks to help them get around and carry on doing the things they enjoyed.

Table 2 QoL Dimensions illustrated by quotes

Dimension	Quote
Independence	*Quality of life? Well, that means to me that I still have independence. I like to be able to do things for myself* (Female, 91 years)
	The worst thing about getting old, is your lack of independence. (Female, 87 years)
	Well, I like to be independent. I like to be able to look after myself as much as possible, but it is nice to have the help when you feel that you can't (Female, 83 years)
	Well, I think quality of life to me means everything. It means independence, to be in charge of yourself. Yeah, that probably just sums it up in a couple of words, you know, to have that total independence really… just be in control; that's really, really important to me. Not to have other people make decisions. I make the decisions where it relates to me (Female, 76 years)
	Well, I like having control over what I do. I don't want to have people telling me what to do (Male, 78 years)
Social connections	*You need a few good friends and you need good family, supportive family, and also neighbours are important when you're so much at home. I'm very fortunate, I have nice neighbours and I have friends and family who are very, very supportive* (Female, 76 years)
	One girl comes in and does the cleaning, two hours, and we have a little bit of a chatter and cup of tea. The other girl comes in and we go shopping and have a cup of coffee out so that's my enjoyment as far as the week's concerned. It breaks up the week. (Female, 95 years)
	I don't have social relationships with people except for the people who come here, carers (Male, 82 years)
	I've just lost a very dear friend. Seventy-five years we've been friends. That was only two weeks ago. It's hard to watch them go, you know (Female, 85 years)
	I think [Names], they are simply fantastic friends. I tell them what I do. I tell them my life history; they tell me their life history and I've never had such good friends…Normally I would see them on a daily basis (Male, 78 years)
Emotional well-being	*When I first lost my sight I went into depression and being a bright person that was disastrous but it took me two years to accept that I couldn't – I was a dressmaker, I was a china painter, I did all sorts of fine crafts, taught fine crafts and then not to be able to do any of it, that was very – it took a lot out of me.* (Female, 93 years)
	I do suffer with the anxieties and I do get worried. Last year I became very depressed, just through other family members that tried to make our lives very difficult (Female, 76 years)
	I do sometimes feel, not depressed but I feel a bit anxious about things (Female, 84 years)
	I have the horrors about going into care… I don't know how I'd cope with that (Female, 91 years)
	I'm happy and happy is quality of life (Male, 78 years)
Mobility	*One quality of life that I miss is my mobility. That's being unable to walk very far. It's lack of ability that's the greatest lack that I have. I am constrained from doing what I want to do, you know, because physically I'm constrained, not mentally but physically.* (Female, 87 years)
	That's [physical mobility] a little bit difficult at the moment. Apart from the ankle I could get around all right but it's just a bit awkward now. As I say, I used to walk around the village every day. I can't walk properly now without pain (Male, 84 years)
	I can't get around very much on my feet. I have a stick and my walker so that's very important to me (Male. 81 years)
	Physically when you go to do it you no longer can do it. Now, up until a couple of years ago I could walk around and do all different things, just took it for granted (Female, 76 years)

Table 2 (continued)

Dimension	Quote
Activities	*Well, this probably might attribute to some people but I go to what's called [name]here and we don't learn craft because that's behind us now, we all know knitting, crocheting, cross stitch, all that sort of thing, and that is my happiest day of the week, Wednesday morning. We have so much fun, we just talk to one another and laugh* (Female, 84 years) *I'm a person that likes to be doing something…I like to be active. I like to – I paint as a hobby… I like to have interest in things. I'm a member of the jazz club. I don't always get there as often as I'd like to…I just like to keep busy* (Female, 85 years) *I do lots of crosswords and I watch quiz shows. I've got to keep my mind busy. I think that's a really important thing when you're getting older, to keep your brain moving, you know, keep it going.* (Female, 80 years) *I think there's things I want to do now that I haven't done for many, many years. I want to get back to singing. My voice has gone, and I want to get it back so I'm going to be getting back on the keyboard to keep my voice going. That's important to me because I was a singer, you see* (Female, 80 years) *I like to get out and – with my volunteering job at the library and relationships [at the] keep fit class and all those sorts of things* (Male, 81 years)

Activities

Involvement in group activities, for example singing groups, craft classes and in independent activities, for example, crosswords, sewing were important to every one of the participants for their quality of life. There were several reasons why they chose to participate. For example, some participants enjoyed the social connections that activities facilitated and their main reason for participating was the social contact they experienced with close friendships often being developed. Other participants spoke about taking part in activities to keep busy as a way of passing time, so the day went quicker. Several participants discussed how doing activities to keep their mind and brain active was particularly important to them as they got older. Role continuity was also raised by some participants with activities linked to previous roles and hobbies helping to maintain their identity. There were also some participants that spoke about their loss in participating in activities, mostly as a result of physical decline, and the upset they experienced from this loss (Table 2).

Discussion

The QoL dimensions identified in this research are similar to those included in some of the preference-based measures that have been applied within the older population previously [10]. For example, the ICECAP-O has a control dimension similar to the concept in this study identifying levels of independence but uses 'I am able' in the item wording reflecting the capability scale it adopts. Our dimension is similar identifying independence through decision-making and control over lives. The ASCOT includes a social connections and participation dimension which aligns with our social connections dimension identifying levels of social contact people experience. Similarly, the EQ-5D covers depression and anxiety, identifying the extent of depression and anxiety individuals experience. Our concept of emotional well-being is similar as it includes happiness and feelings of stress and worry but is described in different terms to the EQ-5D dimension as it does not use the words 'depression' or 'anxiety' as older people tended to not regularly adopt these during the interview when talking about emotional well-being. Furthermore, feelings of stress and worry amongst older people were often expressed as being related to the fear of moving into residential care which is unique to this population.

Whilst the draft dimensions developed from this research share some similarities with dimensions in existing measures, there are some important differences. For example, the ASCOT consists of a control dimension which is linked to independence but is described in different terms as it identifies levels of control over daily life rather than general feelings of independence and being able to make one's own decisions. Similarly, the ICECAP-O consists of the dimension attachment which is related to social connections but is different to our dimension as it includes the concept of love in addition to friendships. Whilst the concept of love is no less relevant to people of an older age, it may not reflect the real-life experiences of older people as many are widowed during their later life. This is particularly relevant to older females who on average live longer than males [45]. Our social connections dimension has a broader focus incorporating social relationships with family and friends and connections to the community. The ICECAP-O also includes a security dimension which is partially related to the concept of emotional well-being as it focuses on concerns when thinking about the future. Likewise, the ASCOT includes a dignity dimension identifying if the way in which individuals are treated impacts on how they feel about themselves. However, our concept of emotional well-being is dissimilar to these two dimensions as it covers a generic concept of emotional well-being; specifically identifying feelings of happiness, stress and worry.

Although mobility is included in the EQ-5D, the wording used for the mobility dimension is not age appropriate. Many older people in our study discussed mobility in relation to their ability to get out and about (including with the use of mobility aids if they regularly used them), and these issues are not encapsulated in the way that mobility is described within the EQ-5D instrument as it does not make reference to mobility aids which are often used by older people receiving aged care services. An activities dimension is included in the EQ-5D which focuses on ability to perform usual activities. Likewise, the ICECAP-O has two dimensions that are related to activities, one concentrating on doing things that make you feel valued and the other on enjoyment and pleasure. These activity dimensions are different to our dimension as our dimension focuses more on spending time doing things for enjoyment alone or with other people and therefore has a unique concept of older people's needs in relation to activities.

Whilst the qualitative approach adopted in this study to identify draft dimensions share some similarities with the development of the ICECAP-O descriptive system there are some important differences. Importantly, the ICECAP-O is a measure of capability and has Sen's capability approach as its fundamental theoretical foundation. The scoring system for ICECAP-O is anchored upon an absence of capability to full capability scale rather than anchoring on being dead and full health as is usual for generic preference- based measures which generate QALYs [46]. Research investigating the relationship between capability and functioning is in its infancy. However, there are some early indications that whilst these concepts are related, they are separate. Research conducted by Van Leeuwen et al. [47] exploring measurement properties of the EQ-5D-3L, ASCOT and ICECAP-O with older adults found that responses to the EQ-5D-3L were more strongly associated with physical health than were responses to the ICECAP-O and ASCOT instruments.. Conversely, mental health status was more strongly associated with responses to the ICECAP-O, whilst self-perceived QoL and mastery was associated more strongly with responses to the ASCOT. Al-Janabi [48] in his study of 943 family members of meningitis patients, similarly identified that whilst a large proportion of responses indicated that capability equalled functioning (86%) across the dimensions of the ICECAP-A questionnaire, a proportion of responses (12%) demonstrated higher capability than functioning. Participants were more likely to report a difference between their capability and their functioning when their health status was impaired (as indicated by a EQ-5D-5L index score less than 1) as compared to those with unimpaired health status, or if they had caring duties, both groups of people who are likely to be reflected in aged care users. Previous empirical studies have also identified discrepancies between capability and functioning. For example, Bulamu et al. [49] reported relatively high capability in older adults using community aged care services (ICECAP-O mean score 0.76) in comparison with quality of life (EQ-5D mean score 0.47). These identified differences highlight the importance of developing a new measure of quality of life from inception with older people suitable for the aged care context that uses the content and language most often expressed by older people themselves.

Our findings generally concur with those of several previous studies which have demonstrated that the concept of QoL for older people goes beyond health status incorporating broader dimensions of QoL. For example, Ratcliffe et al.'s [16] study comparing the preferences of younger and older people in relation to QoL indicated that older people valued being independent, physically mobile and being in control. Similar research conducted with older adults in a day rehabilitation centre in South Australia found that although older people valued health as important in relation to their QoL, wider dimensions such as independence, control and social relationships were also important [18]. Other research has also highlighted independence and control as key dimensions of QoL amongst older people [13, 17].

Strengths and limitations

The main strength of this research is the person-centred approach adopted. This method enables the language used by older people to be retained throughout the development of the QoL dimensions which we expect to ultimately result in greater content and face validity, and additionally, making the measure user-friendly. Furthermore, the dimensions have been developed directly from older people receiving community aged care services which means they are of greater relevance to this population. A diverse socio-demographic population broadly representative of older people accessing community aged care services in Australia were recruited across three different Australian states, thus strengthening the validity of the results.

The current study was also designed to be inclusive for older adults living with minor cognitive impairments and/or mild dementia which is a strength of this research as this group are important users of aged care services. Older people living with cognitive impairment and dementia have traditionally been excluded from research of this nature and the development of new preference-based QoL instruments.

The use of one-to-one interviews in a private setting enabled older people to discuss sensitive issues that they may not have felt comfortable discussing in a focus group setting. Most of the language and terminology used by the participants was consistent when describing QoL dimensions but more work will need to be done to establish appropriate wording to ensure the measure is suitable for all older people accessing aged care and to determine the generalisability of the QoL dimensions beyond this context e.g. for older people living independently in the community.

A potential limitation of this study is that the use of cards in the second stage of the interview may have had the potential to influence participant's responses. The cards were used to initiate further discussion around the dimensions participants had raised in stage one of the interviews. A very small number ($n = 2$) when reading the cards identified a QoL dimension from the cards that was important to them that they had not discussed in the first stage of the interview. However, these data were analysed separately to ensure the dimensions were developed from stage 1 of the interview and therefore any possible influence would be minimal in this respect.

Although a diverse sample of participants was recruited, we recognise that hard to reach older adults may have been excluded from this study. The study does not include respondents who could not communicate in English. Interviewing older adults whose first language was not English was unfortunately outside the scope of this project due to resource limitations. However, it is recognised that, in common with many other developed nations, Australia's population is culturally and linguistically diverse (CALD). Therefore, future research is planned to identify the extent to which older people from CALD backgrounds value the same QoL dimensions as older people from Anglo/English-speaking populations. It is therefore expected that the QoL measure developed from the current research may be further developed to make it meaningful, acceptable, and suitable to assess the QoL of older people whose first language is not English.

Conclusion

This study has identified the key QoL dimensions articulated by older people in receipt of community aged care services about what is important to them to experience a good QoL. The five key dimensions identified will be used to inform the development of a new preference-based measure of QoL specific for older people in the aged care context. The dimensions have been developed directly from older people adopting a person-centred approach and therefore have not been influenced by existing literature or other individuals such as carers, family members, or aged care providers. Further work will focus on developing a draft descriptive system to test face validity and psychometric testing to further refine and generate the final descriptive system. The study findings represent a crucial first stage in a multiphase project working in partnership with older people to develop a new preference-based QoL measure for informing quality assessment and economic evaluation in community aged care.

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Data availability Not applicable.

Code availability Not applicable.

Compliance with ethical standards

Conflicts of interests The authors declare that they have no conflicts of interest.

Ethical Approval Ethics approval for this study was granted from Flinders University Ethics Committee (Project no. 8399). All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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