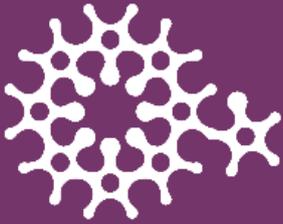


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Evidence Brief

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Quality of life tools to support measurement of aged care quality

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Policy Issue

Ageing is associated with an increase in both dependency and frailty, which in turn places additional demand upon health and aged care services. In Australia, which has for decades been met with an ageing population (AIHW, 2021), this places a significant financial burden on our care systems.

In 2020-21 alone, the Australian government spent over \$23.6 billion on aged care services (Productivity Commission, 2022). This represents steep upwards trajectory, with spending nearly doubling over the last decade (Department of Health and Ageing, 2012).

Despite this increase in spending, demand for aged care services has meant that constrained resources within the aged care sector (Department of Health, 2019a) remains an ongoing policy issue. Despite (and to some extent because of) years of cyclical care reforms for service providers and shifting regulations for national and local commissioning and audit procedures (RCACQS, 2019), aged care services quality and accountability remains a significant concern to both the Government and the Australian public (Productivity Commission, 2022).

To break this cycle and ensure a more efficient and equitable allocation of resources, it is essential that Australia establish a set of long-term and comprehensive indicators of quality in aged care provision. These must not only be both realistic and attainable; they must meet public expectations for high quality, caring, person-centred aged care.

In Australia, maintaining quality of life for older adults is considered an important outcome of aged care services (Cleland et al., 2021a; COTA, 2018). The importance of quality of life as a health outcome is more evident internationally, however, it has increasingly been considered as a potentially more valuable and wholistic indicator of quality in aged care than traditional health indicators alone. Several countries, such as the United Kingdom, Germany, the Netherlands, South Korea and Portugal have either begun directly measuring quality of life in aged care or have developed action plans on ageing (Caughey et al., 2020). This movement reflects a broader recognition of the importance of fostering older people's quality of life, and how the Australian sector can be reformed to improve the provision of aged care.

It has been recommended that the Australian Government Department of Health mandate the collection and publication of quality of life outcomes in aged care to provide a minimum set of standards and provide transparency in aged care quality (COTA, 2018; KPMG, 2017; LASA, 2019). However, substantial variabilities between available wellbeing tools (Linton et al., 2016), a lack of best practice guidance on their use in aged care (Hibbert et al., 2019), and a lack of publicly reported measured outcomes has meant that measuring quality of life and the impact of aged care services on quality of life, consistently and systematically, is a challenge for most aged care providers.

To ensure aged care services track the needs of clients and deliver uniform, transparent care to a high standard, national guidance on how to include, administer, and assess suitable quality of life tools is required.

What does the evidence say?

Clinical Indicators

Measuring clinical quality outcomes against best practice recommendations is one way for providers, governments and consumers to track aged care quality. Clinical quality outcomes can help to improve the standard and quality of care and services, provide measures on safety and effectiveness, and allow participation in systems of quality assurance and improvement (My Aged Care, 2022). Currently, five clinical indicators are used to measure quality of aged care in Australia (Department of Health, 2019b):

- pressure injuries
- use of physical restraint
- unplanned weight loss
- falls and major injury
- medication management

These chosen indicators reaffirm the traditional focus on clinical care and fail to support the broader policy agenda of consumer directed care underpinned by wellness, reablement and restorative approaches to care. Furthermore, clinical outcomes do not provide insight into the experience of care and do not necessarily correlate with levels of consumer satisfaction (Jeon et al., 2019).

Internationally, the use of standardised quality of life measures in the aged care sector have been recognised as a means of ensuring the delivery of person-centred care by firstly measuring the quality of aged care, gain insights into the subjective impact of care services, and to increase consumer choice. These measures are already employed across numerous Organisation for Economic Co-operation and Development (OECD) countries (Table 1).

Table 1. A summary of current quality indicators measured in aged care worldwide (OECD and European Union, 2013)

<u>Country</u>	<u>Pressure Ulcers</u>	<u>Falls and fall-related fractures</u>	<u>Use of physical restraints</u>	<u>Over medications or medication errors</u>	<u>Involuntary weight loss</u>	<u>Depression</u>	<u>Quality of life</u>
Canada	Yes	Yes	Yes	No	No	Yes	No
Finland	Yes	Yes	Yes	Yes	Yes	Yes	No
Iceland	No	Yes	Yes	Yes	Yes	Yes	No
Germany	-	-	-	-	-	-	Yes
Korea	Yes	No	No	No	No	No	Yes
Netherlands	Yes	Yes	Yes	No	Yes	Yes	Yes
Norway	No	No	Yes	No	No	No	No
Portugal	Yes	Yes	Yes	Yes	Yes	No	Yes
United States	Yes	Yes	Yes	No	Yes	Yes	No
Australia	Yes	Yes	Yes	Yes	Yes	No	No

In Australia, the impact of aged care service delivery on quality of life for consumers remains largely unknown, with only one recent paper describing the variation and sociodemographic predictors of wellbeing in home care older adults (Siette et al., 2021a). This absence is largely due in part to a lack of mandatory reporting on this outcome.

From 2011, the United Kingdom has incorporated the Adult Social Care Outcomes Toolkit (ASCOT) in the nation's mandatory national survey to measure social care-related quality of life of aged care consumers (Caughey et al., 2020; Department of Health and Social Care, 2012). Governments of Denmark, Austria, Finland, and the Netherlands have also started measuring the quality of life of aged care users via the periodic administrations of a standardised tool (ASCOT) (OECD & European Union, 2013).

However, accurately measuring the quality of life of aged care populations can be difficult for governments for the following reasons:

Quality of life

An inherently complex and ambiguous concept, making it difficult to measure (Brown et al., 2004). A person's quality of life is influenced by basic and universal factors, such as access to quality food and shelter, but also by higher order needs which may be culturally and biographically specific to individuals (Borges et al., 2021). Subjective experience is also not easily captured by generic questionnaires designed to measure quality of life (Carnell and Paterson, 2017).

Tools to measure quality of life

Despite the number and variety of available tools used to quantify different aspects and interpretations of quality of life (e.g., Linton et al., 2016), most tools do not assess issues relevant to consumers/residents or assess areas that are not appropriate (e.g., experience of care). Further, an over-emphasis on health and physical function might produce a more negative picture of quality of life than experienced (Courtney et al., 2003).

Quality of life: Importance as a quality indicator

The impact of aged care services on quality of life is important to Australians. A recent survey found overwhelming support amongst consumers for the routine assessment and publication of quality of life in aged care (COTA, 2018).

Despite this, very limited information on the subjective experience of consumers using care services is made available.

Australian aged care service providers, even in the absence of mandates, are starting to use quality of life tools to track the quality of care they provide (Siette et al., 2018, 2021). Initial evidence indicates that care staff are receptive to tool utilisation (Siette, et al., 2018; Cardona, 2018). However, no providers currently publicise quality of life outcomes to inform consumer choice.

Review of quality of life tools

A recent systematic appraisal of quality of life tools used in aged care settings was published to guide provider's choice of adoption (Siette et al., 2021b). Using a rigorous review process, 29 quality of life tools covering nine domains were identified. These are summarised below:

- **Physical health:** perceived overall functional and physical status.
- **Mental health:** mental and cognitive health conditions.
- **Emotional state:** experiences of positive and negative emotions.
- **Social connection:** the frequency and quality of social engagement and participation.
- **Spiritual connection:** faith, inner peace; engagement in religious or spiritual customs.
- **Environment:** living conditions.
- **Autonomy:** capacity and satisfaction with one's ability to manage activities of daily living.
- **Overall quality of life:** perceived quality of life in its entirety.
- **Other** (e.g., sociodemographics, employment).

What does this mean for policymakers?

Necessary changes to aged care quality indicators are required to ensure Australians can understand aged care quality, including how care services are provided. Without a national long-term strategy that supports the implementation and use of tools designed to measure quality of life indicators, Australia will remain over-reliant on clinical measures which are unable to provide consumers and policy an accurate picture of aged care quality (Carnell and Peterson, 2017).

To date, the national response to improving the quality of care for older people receiving aged care services has been to provide and refine minimum expectations of care providers, definitions and constitutions of quality, and quality standards for aged care services to meet (COTA, 2018). However, the Aged Care Royal Commission's Final Report has found that the aged care sector continues to lack transparency and is unable to provide care that is adequately aligned with the needs of the people it aims to serve (RCACQS, 2021).

We have developed three policy recommendations which should be considered. These would aid the establishment of comprehensive indicators capable of capturing person-centred outcomes and measuring the success or failure of upcoming reforms.

1. Extend existing mandatory reporting requirements of national standards to include quality of life as an outcome measure

Aged care providers should be required to submit quality of life outcomes to the Department of Health on a quarterly basis. To ensure collection is undertaken accurately and in an appropriate manner across populations and aged care contexts, the Department of Health should develop and

distribute a handbook comprised of validated quality of life tools (e.g., EQ-5D, ASCOT, ICECAP-O) for aged care providers.

As an exhaustive repository of information for care providers, the Handbook must be designed to ensure quality of life data collection is conducted accurately in a way that minimises harm and inconvenience to care recipients and staff.

Ideally, this would include:

- Instructions for electronic/online tool use and data submission, including information explaining the interpretation of raw scores and ability to adjust scores.
- National averages and expected outcomes across different aged care setting and population type.
- Best practice guidelines, relating to appropriate tool selection; this should be informed by care settings as well as any diagnosis of respondents. Expectations, responsibilities and legal requirements of aged care staff and providers and consumers in administering, reporting and maintaining quality of life assessments.

We also agree with previous recommendations made by the Australian Council of The Aging (COTA) that, given the diversity of aged care environments, mandated reporting on quality of life maintains a degree of flexibility in terms of tool use and data collection methods (COTA, 2018). Information contained within the handbook should therefore be amendable and responsive to changes in tool quality and availability, best practice guidelines and minimum expected outcomes as aged care standards improve.

We recommend versions of the Handbook be released annually or every two years to allow for these changes. Some aged care services are understaffed, under-funded, or have historically failed to adhere to minimum care standards (RCACQS, 2021). Because of these and other factors, there is a risk that quality of life assessments will be carried out inappropriately or be treated as a checkbox exercise. Additional resources for staff to carry out quality of life assessments should be considered. This would be aimed at ensuring relevant staff are well trained, afforded enough time to discuss and/or report resident concerns, and able discuss sensitive topics in a considered manner.

Based on our evaluation of existing quality of life tools (Siette et al., 2021b), and extant research demonstrating the successful administration (and value) of quality of life tools in community aged care work practices (i.e., Siette et al., 2018), we recommend the ASCOT, ICECAP, EQ-5D for use in residential and community care. **Table 2** provides a summary of why these tools have here been endorsed and how these tools should be utilised. Recommendations for use in the Australian context is based on the available evidence.

Table 2. Select quality of life tools most applicable to the Australian aged care landscape

Tools	Description of tool	Recommendation
ASCOT	<p>Description Examines social care related quality of life and mandated for annual use across several European countries (OECD & European Union, 2013). The tool does not capture health-related quality of life outcomes.</p> <p>Implementation Tool developed in 2010, in response to mounting policy emphases in the UK to deliver cost effective, person centred social care services (Netten et al., 2012). Versions addressing the quality of life of carers (Rand et al., 2015) and adults living in residential care (Towers et al., 2015) have subsequently been developed. An Easy-Read version of the tool is currently being trialled with adults living with dementia (ASCOT Team, personal communication, 24/09/2019).</p> <p>Advantages and Drawbacks A pilot study by KPMG has already demonstrated the suitability of this tool for use in community aged care in Australia (KPMG, 2017); the tool has also been endorsed for use in Australian aged care (COTA, 2018; LASA, 2019).</p>	Strongly recommend
ICECAP-O	<p>Description The ICECAP-O was designed for use with older people (Grewal et al., 2006). The ICECAP-O adopts a capability-based approach to quality of life, capturing the capacity of the respondent to access desired levels of higher and lower order resources associated with life quality, such as love and friendship. The objective physical capacity of respondents is not captured.</p> <p>Implementation A version for end-of-life-care recipients is currently in the latter stages of development (Sutton and Coast, 2013). The ICECAP-O has been deployed most extensively in community care settings, although it has been adopted for residential aged care use. Uniting, a large aged care provider currently uses ICECAP-O to track the impact of their community care services (Siette et al., 2018). ICECAP-O was not designed specifically for adults living with dementia, although the tool has been used to assess the quality of life of this population (Makai et al., 2014; Sarabia-Cobo et al., 2017).</p> <p>Advantages and Drawbacks Like the ASCOT, the ICECAP-O is relatively short and logistically easy to use, has strong psychometric properties, and can be used to conduct economic and cost benefit analysis (Makai et al., 2014).</p>	Strongly recommend

<p>EQ-5D</p>	<p>Description The EQ-5D, developed by the EuroQoL group (1990), is a simple health-related quality of life measure consisting of five items exploring mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The EQ-5D has been used extensively across community and aged care settings. The EQ-5D is suitable for use alongside either the ASCOT SC4 or the ICECAP-O.</p> <p>Implementation The combined use of ICECAP-O and the EQ-5D to conduct performance monitoring, including economic analysis of long-term care services has been recommended elsewhere (Zorginstituut Nederland, 2016). The combined use of the EQ-5D and the ASCOT-SC4 have also been recommended for quality assessments of older people (Makai et al., 2014).</p> <p>Advantages and Drawbacks Ensuring optimal physical health may not be possible or the sole aim of some aged care services, yet evidence indicates Australian aged care users and older adults generally regard physical health as primary factor associated with quality of life (Milte et al., 2014; van Leeuwen et al., 2019). Capturing health related quality of life may therefore be necessary to the delivery of care which maximises quality of life, however poorer health may not necessarily indicate poorer care quality. We recommend the EQ-5D over the similar tool SF-8, as the latter captures domains already covered by the ICECAP-O and ASCOT SC4 tools.</p>	<p>Strongly recommend (tandem with ASCOT or ICECAP-O)</p>
<p>QOL-ACC</p>	<p>Description QOL-ACC was created from the perspectives of older Australians accessing aged care services (in both home and residential care settings) and designed to be suitable for quality assessment and economic evaluation (Hutchinson et al., 2021). The tool assesses six key quality of life dimensions including mobility, pain management, emotional well-being, independence, social connections, and activities.</p> <p>Implementation The QOL-ACC has recently been developed and to date the tool has been implemented with over 1,000 older Australians. The QOL-ACC is currently being trialled by the Australian Government Department of Health for inclusion as a new Quality Indicator for residential aged care (QOL-ACC Team, personal communication, 21/03/2022).</p> <p>Advantages and Drawbacks The QOL-ACC is a preference-based instrument of quality of life for informing quality assessment and economic evaluation in Australian community and residential aged care. It has the potential to become widely adopted and used. Early psychometric testing has demonstrated practicality and validity. Further psychometric testing to establish responsiveness over time and minimal important difference statistics is required and this work is on-going (QOL-ACC Team, personal communication, 21/03/2022).</p>	<p>Tentatively recommend.</p>

<p>QoL-AD</p>	<p>Description QoL-AD was designed for use by people living with dementia (Logsdon et al., 2002). The first section of the tool is completed via interview with the person living with dementia. A second section is via interview with (or by) a family or professional carer familiar with the person being assessed.</p> <p>Implementation Based on a recent review of domains factors impacting the quality of life of adults living with dementia (O’Rourke et al., 2015), the QoL-AD captures the most suitable domains. Of existing dementia-specific tools, the QoL-AD is most widely used. It is not as psychometrically sound as some other tools like the QULIDEM (Hughes et al., 2019); however other relevant tools were health-oriented and/or covered fewer domains.</p> <p>Advantages and Drawbacks The QoL-AD is not wholly suitable for use in the Australian aged care context as it is not capable of performing economic and analysis of care services (Comans et al., 2018). Furthermore, due to its lengthy administration, the QoL-AD may be logistically difficult for use. It is likely that the AD-5D – a tool currently being developed – will be more suitable for use than existing dementia specific tools (Comans et al., 2018). The AD-5D has been designed specifically for Australian aged care settings and can perform economic analysis (Comans et al., 2018).</p>	<p>Tentatively recommend.</p> <p>Note: Barriers associated with use. Should be replaced by the AD-5D when the latter is made available.</p>
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The timely evaluation and deployment of tools designed specifically for the Australian aged care context, such as the AD-5D (Comans et al., 2018) and the QOL-ACC (Cleland et al., 2021b) could be considered as these may more readily reflect and accurately measure the psychosocial needs of Australians compared with tools currently in existence. However, further validation of these tools is warranted prior to definitive implementation within aged care.

2. Establish standardised scores reflecting accurate quality of life outcomes across aged care settings

Different aged care populations are likely to experience varied life quality. For example, it is evident that irrespective of care quality, recipients receiving community care are likely to experience greater life quality than residential care recipients (Olsen et al., 2016). Therefore, the range of quality of life outcomes expected to be observed for each tool will need to be established across applicable aged care settings and risk-adjusted for other variables that may impact on the results (Siette et al., 2021a). Establishing and setting population-sensitive expected quality of life scores for multiple tools will require funding for research purposes and ongoing aged care staff training. This approach to standardising quality of life scores for consumers and providers will be necessary to maintain data accuracy and should be provided by the Department of Health.

Quality of life outcomes must be made accessible to the public if consumer choice is to be improved. However, understanding the significance and meaning of raw quality of life scores derived from standardised tools requires specialised knowledge and methods. Score interpretation and presentation should be carried out by existing organisation operating under Government initiatives (e.g., Ageing and Aged Care Engagement Hub). In order to engage consumers' raw scores obtained from quality of life tools, measurements should be adjusted into an easily understandable and comparable format and piloted for its use. This means that quality of life results could be used to inform facility and provider ratings that are suitable to the general public. For example, the star rating, currently used in the United States through the Nursing Home Compare program (Centers for Medicare & Medicaid Services, 2019), or the Overall Rating feature for social care services (Care Quality Commission, 2019) used in the UK, could be adapted for use in Australia and launched on the My Aged Care website.

3. Re-evaluate quality in aged care

Understanding the quality of life of aged care users will be essential to delivering person-centred care. Publicised quality scores of aged care facilities and providers also contribute to our understanding of aged care quality and should be determined by a suite of multiple outcomes, including care quality, and other clinical and physical outcomes to suitably capture all facets of care received. The overall ratings or scores to be informed by sub-ratings, including quality of life scores, will be critical to addressing different aspects of care quality and help consumers choose care most suited to their needs.

The introduction of a comprehensive, easily understandable rating feature based on several quality indicators will be important to incentivising aged care providers and policy makers to address otherwise unnoticed care deficits. Indeed, it has been reported that if the American rating standards were applied to the Australian context, more than half of all residential care residents would be living in facilities with staffing levels rated only one or two stars out of five (Eagar et al. 2019). This implies that, in 2019, half of all Australian residential aged care facilities had inadequate staffing ratios.

Establishing sound and meaningful quality indicators will require (Mainz, 2003):

- establishing standards and indications of quality in aged care;
- designing measurement specifications and procedures; and
- performing pilot tests.

Usually, these steps are performed by a delegated team or body comprised of stakeholders and/or experts appointed by a relevant regulatory and/or governmental body (Mainz, 2003) and appears to be underway (e.g., Ageing and Aged Care Engagement Hub).

In this brief we have summarised our review of available quality of life tools used for older adults accessing aged care and contributed to existing consensus concerning the importance measuring quality of life in Australian aged care (COTA, 2018; KPMG, 2017; LASA, 2019).

Further pilot testing and consultation with stakeholders are now required to establish tool suitability in the aged care setting, the feasibility of producing a handbook that standardises the administrative and logistical components associated with quality of life tools, and to establish baseline quality of life evaluations in aged care.

Now, more than ever, capturing quality of life metrics in older adults receiving aged care services is essential. The COVID-19 pandemic resulted in drastic changes towards care provision in home and residential care settings, with staff and regulatory bodies attempting to balance effective infection control and ensuring wellbeing of residents (Giebel et al., 2020; Giebel et al., 2021). Yet, immediate collateral consequences of the COVID-19 outbreak have shown an adverse impact on quality of life for home care older adults (Siette et al., 2021c). The optimal implementation and measurement of quality of life tools can therefore guide efforts to preserve and promote older adults' well-being during our crisis recovery period, and to inform strategies to mitigate potential harm during future pandemics.

Key reading

- Siette J, Knaggs GT, Zurynski Y, Ratcliffe J, Dodds L and Westbrook J. (2021b). Systematic review of 29 self-report instruments for assessing quality of life in older adults receiving aged care services. *BMJ Open*. 11: e050892. <https://doi.org/10.1136/bmjopen-2021-050892>

This review provides the first quantified demonstration of how self-reported measures of quality of life have developed over the past 40 years nationally and internationally and represents a first step in supporting choice of suitable instruments to be used for monitoring and evaluating quality of care in aged care.

- RCACQS: Royal Commission into Aged Care Quality and Safety. (2021). Final Report: Care, Dignity and Respect. RCACQS, Australian Government, Canberra, Australia. Viewed 17 March 2022: https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-1_0.pdf

The Final Report calls for fundamental and transformational reform of the aged care system and present 148 recommendations including a focused plan to deliver, measure and report on quality of aged care, as achieved by a comprehensive approach to quality measurement, reporting and star ratings

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