



Measurement tools for assessing quality of life, consumer satisfaction and consumer experience across residential and in-home aged care: Summary Report

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Glossary

Acronyms	Terms
15D	15-Dimensional Instrument
ACCOM	Australian Community Care Outcomes Measurement
ACCOM-CM	Australian Community Care Outcomes Measurement-Case Manager
AD-5D	Alzheimer's Disease Five Dimension
ADRQL	Alzheimer's Disease-related Quality of Life
ALFSS	Assisted Living Family Satisfaction Scale
ALSS	Assisted Living Satisfaction Scale
AQoL-6D	Assessment of Quality of Life Instrument – 6 Dimension
AQoL-8D	Assessment of Quality of Life Instrument – 8 Dimension
ASCOT-SCT4	Adult Social Care Outcomes Toolkit four-level self-completion questionnaire
ASCOT-INT4	Adult Social Care Outcomes Toolkit four-level interview schedule
CCI-6D	Consumer Choice Index-6 Dimensions
CEQ	Consumer Experience Questionnaire
CLINT	Client Interview Instrument
COMQOL-A5	Comprehensive Quality of Life Scale-Adult version 5
CPVQ	Consumer Perception of Value Questionnaire
CQI	Consumer Quality Index
CSAT-HC	Client Satisfaction: Home Care
DEMQOL	Dementia Quality of Life Instrument
DEMQOL-Carer	Dementia Quality of Life Instrument – Carer version
DUKE	Duke Health Profile
D-QoL	Dementia Quality of Life Instrument
EQ-5D-3L	EuroQoL 5 Dimensions 3-levels
EQ-5D-5L	EuroQoL 5 Dimensions 5-levels
EQ-HWB	EuroQoL Health and Wellbeing
EQ-HWB-S	EuroQoL Health and Wellbeing short version
GSGL	Good Spirit Good Life
HCSM	Home Care Satisfaction Measure
HUI2	Health Utility Index Mark 2
HUI3	Health Utility Index Mark 3

Acronyms	Terms
ICECAP-O	ICEpop CAPability measure for older people
interRAI-HC	interRAI home care
interRAI-LTCF	interRAI long term care facility
JoLS	Joy-of-Life Scale
LTC-QOL	Long term care quality of life assessment scale
MANSA	Manchester Short Assessment of quality of life
MFSS	Minnesota Family Satisfaction Survey
MIV	My Inner View
MNHFS	Maryland Nursing Home Family Survey
MTRC	Measure of Thriving in Residential Care
NHCAHPS FS	Nursing Home CAHPS Family Survey
NHCAHPS LS	Nursing Home CAHPS Long Stay Survey
NHCR-QOL	Nursing Home Care Related Quality of Life
NHP	Nottingham Health Profile
ONHFSS	Ohio Nursing Home Family Satisfaction Survey
ONHRSS	Ohio Nursing Home Resident Satisfaction Survey
OPQOL-35	Older Peoples Quality of Life-35
OPQOL-Brief	Older Peoples Quality of Life-short version
PGCMS	Philadelphia Geriatric Centre Moral Scale
PQ	Pyramid Questionnaire
PWI-A	Personal Wellbeing Index-Adult
QCE-ACC	Quality of Care-Aged Care Consumers
QOL-ACC	Quality of Life Aged Care Consumer
QoL-AD	Quality of Life in Alzheimer's Disease
QoL-AD-NH	Quality of Life for people with Alzheimer's Disease in a Nursing Home
QOLNHR	Quality of Life Nursing Home Resident
QPP	Quality from the Patients' Perspective
QUALID	Quality of Life in Late-Stage Dementia
QUALIDEM	Dementia specific Quality of Life Instrument
RCSS	Residential Care Satisfaction Scale
RSI	Resident Satisfaction Index
RSQ	Resident Satisfaction Questionnaire

Acronyms	Terms
SERVQUAL (NHS)	SERVQUAL Nursing Home Service Quality Inventory
SF-8	8 item Short Form Survey
SF-12	12 item Short Form Survey
SF-36	36 item Short Form Survey
SNHI	Satisfaction with Nursing Home Instrument
SNHS	Satisfaction with Nursing Home Scale
SWAL	Satisfaction with Assisted Living
SWLS	Satisfaction With Life Scale
USS	User Satisfaction Survey
WHOQoL-100	World health Organisation Quality of Life Scale – 100 items
WHOQoL-AGE	World health Organisation Quality of Life Scale – AGE
WHOQoL-BREF	World health Organisation Quality of Life Scale – BREF
WHOQoL-OLD	World health Organisation Quality of Life Scale – OLD

Executive Summary

This report provides a comprehensive evidence review of validated tools to measure quality of life, consumer experience or consumer satisfaction in aged care, and examines their appropriateness for residential aged care and home care settings for the purposes of incorporation into Australia's National Aged Care Mandatory Quality Indicator Program (QI Program).

The final report of the Royal Commission into Aged Care Quality and Safety recommended the development of a comprehensive suite of quality indicators for aged care. This included implementing 'a comprehensive quality of life assessment tool for people receiving aged care in residential care and at home' [Recommendation 22c] to facilitate continuous improvement and the transparency and accountability of Australia's aged care system.

A comprehensive evidence review of national and international literature on validated tools to measure quality of life, consumer (older person and/or family carer) satisfaction and consumer experience in aged care (including both home recipients or residential aged care) was conducted.

- An evidence-based ranking (based on standardised psychometric and assessment methods and identified strengths and weaknesses) was undertaken.
- Evidence regarding implementation, data analysis and reporting was considered and informed recommendations for embedding the preferred tool/s in the QI Program. Adoption of standardised tools will facilitate national benchmarking, promote consumer choice and increase public accountability and transparency.

Quality of Life

- A total of 46 quality of life tools from 25 countries were identified, including 10 developed in Australia. Most tools focused on health-related quality of life, as opposed to quality of life more broadly, and were developed with adult populations of all ages.
- Eleven quality of life tools developed specifically for application with populations of older people were identified; ICECAP-O (index of capability for older people), OPQOL (older people's quality of life), QOL-ACC (older people aged care specific quality of life), WHOQoL-AGE (older people's quality of life), GSGL (older indigenous people specific quality of life); with 6 focusing on people with dementia, ADRQOL, DEMQOL, D-QoL, QoL-AD, QUALIDEM and QUALID (late stage dementia only).
- Evidence ratings identified the **QOL-ACC (older person aged care specific to home and residential care)** as the highest ranked quality of life tool. The QOL-ACC provides the highest level of psychometric evidence for application with aged care consumers in both home care and residential care settings for Australia's aged care system. The **GSGL (older Indigenous person specific)** tool was identified as providing the highest level of psychometric evidence for application with older indigenous aged care consumers.

Consumer Experience and Satisfaction

- A total of 29 consumer experience and consumer satisfaction tools (13 experience and 16 satisfaction tools) were identified. Most tools were developed in the USA with 4 tools developed in Australia.
- In contrast to the quality of life tools, most consumer experience and consumer satisfaction tools were developed specifically for application with older people and /or family members in aged care settings, predominantly residential care.

- Two consumer experience tools, **QCE-ACC (generic measure of care experience for both home and residential care)** and the **CCI-6D (residential care specific consumer experience)** and one consumer satisfaction tool the **RSQ (residential and home care consumer satisfaction)** were identified as having the highest level of psychometric evidence and appropriate for Australia's aged care system.

Quality of life and consumer experience/satisfaction tools are not inter-changeable, and are designed to measure different concepts and as such include different dimensions/items.

- If only one concept is to be taken forward this review recommends quality of life as the most important person-centred quality indicator for Australia's aged care system.

Limited guidance is available in the examined literature on sampling and recommended frequency of administration for quality of life, consumer experience and/or consumer satisfaction tools in aged care for the purposes of incorporation within the QI program. This lack of evidence highlights the need for further consultation with the sector, in particular with aged care consumers and providers about how often these types of assessments should be undertaken and the application of results at both local and national levels to facilitate improvements. There is a strong case for pilot studies to provide further evidence related to sampling, frequency of administration and results application prior to widespread implementation.

Recommendations for Implementation:

- It is important to strive for self-assessment of quality of life, care experience or satisfaction using a validated psychometrically robust tool by the older person themselves wherever possible. Where self-assessment is not possible, for example, due to severe physical frailty and/or cognitive impairment, proxy assessment by a family member or close friend who knows the person well and who has regular contact with the person should be sought.
- Preferable modes of tool administration are self-completion using electronic format touch screen technology (tablet) computer or hard copy (paper and pen survey) for the person or proxy respectively. Where self-completion is not possible, interviewer assisted formats should be considered with a prescribed interview script to minimise the possibility of interviewer bias.
- For inclusion within the QI program, all older Australians accessing aged care in Australia in either home or residential aged care settings should be surveyed about their quality of life and/or aged care experience/satisfaction at regular time intervals (every 6-12 months) using a validated assessment tool designed for this purpose.
- Reporting of quality of life, consumer experience and/or consumer satisfaction tools in aged care with relevance to the QI program needs to be case mix adjusted to provide meaningful comparisons. As a consequence of minimal evidence, further consideration needs to be given to the most appropriate methods to summarise and present data for quality of life, consumer experience and/or consumer satisfaction data for different audiences e.g., the general public, aged care consumers and service providers. This also includes stratification of data analyses by aged care recipients with and without dementia and data aggregation by facility, service provider, state or geographical (metropolitan, rural and remote) areas.

1. Aims and Approach

The final report of the Royal Commission into Aged Care Quality and Safety highlighted the need for a philosophical shift to place the people receiving care at the centre of quality and safety regulation and that as part of this the voices of people receiving care must be heard to ensure that the system is relevant and appropriate for the people it is intended to support. It also recommended the development of a comprehensive suite of quality indicators for both residential and home care, including quality of life assessment to facilitate continuous improvement and the transparency and accountability of Australia's aged care system.

- This report summarises the methods and key findings from a comprehensive evidence review of validated tools to measure quality of life, consumer experience or consumer satisfaction in aged care, and examines their appropriateness for residential aged care and home care settings for the purposes of incorporation into Australia's National Aged Care Mandatory Quality Indicator Program (QI Program).
- Validated tools that have been applied in aged care settings in Australia and/or internationally to assess, monitor and evaluate quality of life, consumer experience or consumer satisfaction from the perspective of older people and/or family carers accessing home or residential care were identified. Tools were rated for methodological quality based on standardised psychometric and assessment methods to provide a summary of their respective strengths and weaknesses and an evidence-based ranking of preferred tools.
- Recommendations regarding implementation, data analysis and reporting of the preferred tool/s as an integral component of the QI Program were informed by available evidence on these topics.
- The overall aim was to identify recommended tools able to generate robust, valid data to monitor performance and support continuous quality improvement by service providers. For consumers, these tools should provide an opportunity for them to provide feedback about their lived experiences and, over time, access to information about these aspects of quality in aged care to assist decision-making.

2. Literature Review

Search strategy and data extraction

A comprehensive evidence review was undertaken to identify national and international literature on the measurement of quality of life, consumer (older person and/or family carer) satisfaction and consumer experience in aged care. The review searched the following databases: MEDLINE, EMBASE, PsycINFO, Cochrane Library and CINAHL databases from inception to January 2021. Relevant grey literature was also identified through an online search of published government reports, and other relevant research and policy documents on government and/or regulatory body websites.

Selection criteria

Articles were included in this review if they met the following criteria:

- Published in English language.
- Qualitative and/or quantitative design.
- Study sample of older adults aged ≥ 65 years and/or suitable proxies (e.g., family carers).
- Focused on the development and/or application of quality of life, consumer experience and/or consumer satisfaction tool/s within aged care.

The review focused specifically on the psychometric properties and performance characteristics of tools that have been designed and/or applied in aged care (differentiating residential and in home settings) to measure quality of life, experience and/or satisfaction from the perspective of the older person or proxy assessor. In consultation with our Project Advisory Group (comprising aged care representatives from ECH, Uniting AgeWell, Dementia Alliance International, the Australian Nursing and Midwifery Association and consumer representatives, Appendix) and key representatives from the Department of Health, a set of standardised criteria were developed, refined and applied to systematically compare and rank tools. Criteria included in the review were:

- Design properties including the extent to which tool/s were co-designed with older people and developed in aged care or transferred from another sector e.g., health system, disability care.
- Psychometric testing, psychometric properties and performance characteristics (including practicality, reliability, content and construct validity) in home or residential care settings.
- Applicability and suitability of the identified tools for different aged care populations e.g., culturally, and linguistically diverse (CALD) groups, Aboriginal and Torres Strait Islander peoples, older people with cognitive impairment and dementia.

3. Assessment of Psychometric Properties

The psychometric properties of identified tools were examined according to standardised criteria identified in the COnsensus-based Standards for the selection of health status Toolment INstruments (COSMIN) taxonomy. COSMIN criteria were supplemented by the Food and Drug Administration (FDA) guidelines on the principles for selecting, Developing, Modifying, and Adapting Patient-Reported Outcome Instruments (PROMs) (1-3). All tools were assessed for a range of psychometric properties:

- Content and face validity.
- Acceptability and feasibility.
- Construct validity.
- Reliability.
- Responsiveness.

Where the psychometric properties of the tools could be identified and extracted, a comprehensive assessment of their quality was conducted by applying these psychometric properties criteria. Psychometric evidence for each tool was assessed and verified by an experienced psychometrician and quality graded as high*, high, medium, low or no evidence available according to the following definitions:

- High*: criteria are achieved with good evidence in the Australian aged care population.
- High: criteria are achieved with good evidence internationally (OECD member countries) but no current Australian evidence.
- Medium: criteria are achieved with good evidence in aged care population from non-OECD countries.
- Low: criteria are not achieved. Limited amount of evidence in small samples and not Australian specific.
- No evidence available (-).

The most important psychometric criteria for any tool to address are content, face and construct validity (1-3):

- Content validity assesses whether the set of items included within a tool comprehensively cover the different components of the underlying construct/s to be measured.
- Face validity is a closely related concept to content validity to assess whether the dimensions or domains included within the tool are sensible, appropriate and relevant to the target population.
- Construct validity assesses whether a tool captures the hypothesised or underlying construct/s it is intended to measure. For this review the underlying constructs were quality of life, consumer experience and/or consumer satisfaction in aged care.

4. Results

Quality of life tools

This literature review identified a total of 46 quality of life tools from 25 countries. Most of the identified tools are focused on health-related quality of life (as opposed to quality of life more broadly) and were developed and applied more commonly in health care settings with adult populations of all ages. Several quality of life tools have been developed specifically for application with populations of older people. This included ICECAP-O (index of capability for older people), OPQOL (older people's quality of life), QOL-ACC (older people aged care specific quality of life), WHOQoL-AGE (older people's quality of life), GSGL (older Indigenous people specific quality of life) and people with dementia e.g., ADRQOL, DEMQOL, D-QoL, QoL-AD, QUALIDEM and QUALID (late stage dementia only).

Most quality of life tools are non-preference based and are scored using simple summative scoring systems whereby individual responses to items/quality of life dimensions are equally weighted to determine an overall total score. Some quality of life tools are preference weighted and this is an important requirement for application of a tool in economic evaluation. Scoring systems for preference based tools are weighted according to the relative importance of individual items/quality of life dimensions in determining the overall quality of life score. For example, the relative importance of physical health in determining overall quality of life may be different to emotional state or autonomy. These differences can be accounted for in a preference weighting.

Preference-based scoring systems are typically derived from large general population samples comprising adults of all ages. Notable exceptions are the ICECAP-O and the QOL-ACC tools which were designed specifically for older populations. The preference based scoring algorithm pertaining to the ICECAP-O was developed with a community based sample (N=255) of older adults in the UK(4). The QOL-ACC scoring system is currently based on a simple summative scoring algorithm. A preference based scoring system for the QOL-ACC tool based on the preferences of aged care consumers is currently in development and will be available for application in early 2022 (5).

The number of included dimensions and the ways in which these are described vary across quality of life tools. The most commonly included quality of life domains describe emotional state, physical health and social connections, followed by personhood and autonomy with mental health (as opposed to emotional state) and spiritual connection less often included.

Quality of life tools: applications in aged care

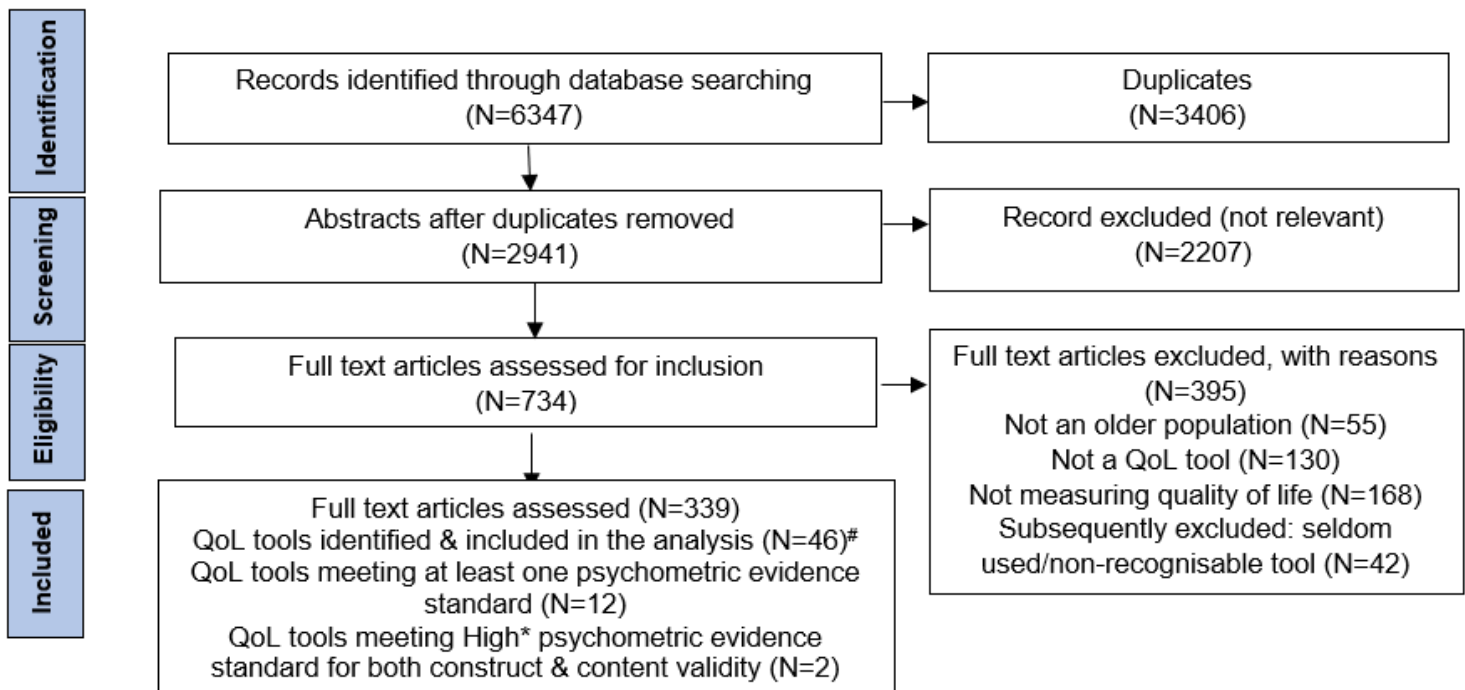
A total of 12 quality of life tools have been applied across Australia in home care settings (ACCOM, AQOL, ASCOT, COMQOL, D-QOL, EQ-5D, GSGL, ICECAP-O, LTQ-QOL, OPQOL-Brief, QOL-ACC, QOL-AD) and ten quality of life tools have been applied in Australian residential care settings (AD-5D, COMQOL, DEMQOL, EQ-5D, GSGL, HUI3, LTC-QOL, QOL-ACC, QOL-AD, QUALID). The size of the populations in which the tools have been applied varies substantially. Most of the identified studies comprised cross-sectional studies assessing the quality of life of older people accessing aged care services at a single time point. Other identified applications included quality of life assessment to measure the effectiveness of an intervention using either a randomised control study design or quasi-experimental methods, longitudinal studies (conducted with people with dementia and applying dementia specific quality of life tools QOL-AD, QUALID and QUAL-DEM) and psychometric assessment studies.

Quality of life tools: psychometric assessment

The results from each stage of the quality of life tool literature review are presented in the PRISMA diagram (Figure 1). From the 46 quality of life tools identified in this evidence review, 12 tools were found to meet at least one psychometric evidence standard with 2 of these tools (QOL-ACC and GSGL) meeting the highest psychometric evidence standard for both construct and content validity.

Figure 1: PRISMA diagram for quality of life

PRISMA = Preferred Reporting Items for Systematic Review and Meta analysis
 (#1 tool identified through grey literature search)



A summary table ranking preferred quality of life tools according to standardised psychometric assessment criteria is presented in Table 1. As previously stated, tools were ranked according to the quality grading of the available evidence pertaining to the psychometric criteria with a higher ranking applied to tools presenting evidence of content, face and construct validity (followed by evidence of responsiveness and reliability) in the Australian aged care population. The top three

tools based on the highest level of psychometric evidence for older Australians accessing aged care services, for at least one of the psychometric criteria were:

1. QOL-ACC, 2. GSGL, 3. DEMQOL.

[1] Quality of Life–Aged Care Consumers (QOL-ACC)

The QOL-ACC instrument was developed in 2020 from a research study funded by the Australian Research Council and led by the Caring Futures Institute, Flinders University, in collaboration with researchers from the University of Sydney and Australian National University (ANU) and partner organisations ECH, Helping Hand, Uniting AgeWell, Uniting ACT NSW, Presbyterian Aged Care and Dementia Alliance International (6). The QOL-ACC is the first quality of life tool, developed from its inception with older Australians accessing aged care in both home and residential care settings. It has been designed specifically for quality assessment and economic evaluation in aged care to capture consumer (older person and family carer) focused quality of life outcomes from their own perspective (7). The QOL-ACC consists of six dimensions: mobility, emotional wellbeing, social connections, independence, activities, and pain management with five response levels attached to each dimension. These final six dimensions were confirmed by the QOL-ACC project aged care provider partners as both relevant to and highly influenced by the care and services provided to the older person in either home or residential care settings. There are self-complete, interviewer administered and proxy versions of the QOL-ACC available.

[2] Good Spirit, Good life (GSGL)

The GSGL tool is a non-preference-based tool developed in 2020 that measures the quality of life of older Aboriginal Australians aged 45 years and over (8). The GSGL consists of twelve dimensions: family and friends, country, community, culture, health, respect, elder role, supports and services, safety and security, spirituality, future planning, and basic needs. Each dimension consists of five response levels. There is also a carer version of the GSGL tool available. It is the first instrument of its kind developed from its inception with older Aboriginal people and was designed to be applied with this population.

[3] Dementia Quality of Life (DEMQOL/DEMQOL-Proxy/DEMQOL PROXY-U/DEMQOL-PROXY-U)

The DEMQOL instruments measure the health-related quality of life of individuals with dementia and were developed in the mid-2000s (9). DEMQOL is a self-report non-preference-based measure completed by the person with dementia, and the DEMQOL-Proxy is completed by a caregiver (proxy reported by the caregiver). The DEMQOL has 28 items, and the DEMQOL-proxy has 31 items that both cover five dimensions: health and well-being, cognitive functioning, social relationships, daily activities, and self-concept. Both versions have four response levels. The DEMQOL-U and the DEMQOL-Proxy-U were developed in 2012 based on the DEMQOL and the DEMQOL-Proxy as preference based tools to enable the DEMQOL to be used in economic evaluation (10).

Table 1: Quality of Life Tools

Rank	Instrument	Country of origin	Primary focus	Development population	Respondent	Dimensions	Residential care	Home care
1	QOL-ACC	Australia	Aged care specific QoL	Older adults and family carers, home and residential care	Self-completion; interviewer administered; proxy	Physical health; Emotional state; Social connection; Personhood; Autonomy	✓	✓
2	GSGL	Australia	QoL older Indigenous people	Aboriginal Australians ≥45 years	Interviewer administered; proxy	Physical health; Social connection; Environment; Spiritual feeling	✓	✓
3	DEMQOL	UK	Health Related QoL people with dementia	Older adults with dementia	Interviewer administered	Emotional state; Mental health; Social connection; Environment; Overall question	✓	-
4	EQ-5D-5L	UK	Health Related QoL	Adults	Self-completion; interviewer administered; telephone interview; proxy	Physical health; Mental health; Personhood; Overall question	✓	✓
5	SF-36	USA	Health-related QoL	Adults	Self-completion	Physical health; Emotional state; Mental health; Social connection; Autonomy	✓	✓
6	ICECAP-O	UK	Capability	Adults aged 65 and over	Self-completion	Emotional state; Social connection; Personhood; Autonomy	✓	✓
7	ACCOM	Australia	Social Care Related QoL	Older adults who receive home care packages	Self-completion; interviewer administered	Social connection; Environment; Personhood; Autonomy	✓	-
8	LTC-QOL	Australia	Long Term Care aged 55+	Nursing home residents	Interviewer administered (carer/proxy and person)	Emotional state; Social connection; Environment	✓	✓
9	EQ-5D-3L	UK	Health Related Quality of Life	Adults	Self-completion; interviewer administered; telephone interview; proxy	Physical health; Mental health; Personhood; Overall question	✓	✓
10	AD-5D	Australia	Health Related Quality of Life	Older adults and family carers of	Self-completion; interviewer administered (carer/proxy and person)	Physical health; Emotional state; Social connection; Environment; Personhood; Autonomy; Overall question	✓	-

Rank	Instrument	Country of origin	Primary focus	Development population	Respondent	Dimensions	Residential care	Home care
			for people with dementia	people with dementia				

Consumer experience and consumer satisfaction tools

This literature review identified 13 consumer experience and 16 consumer satisfaction tools. Most of these tools were developed in the USA with four tools developed in Australia. Most tools were developed specifically for application with older people and/or family members in aged care settings, predominantly residential care. The frequency, characteristics and descriptions of included dimensions and items varies markedly across tools some common over-arching themes are evident regardless of whether the tool is classified as having a consumer experience or consumer satisfaction focus and the care setting (home or residential care) in which it has been applied.

Commonly identified themes include:

- the skills and knowledge of professional nursing and personal care staff
- staff knowledge of and interactions with consumers
- opportunities for social engagement
- participation in meaningful activities.

For residential care this also included:

- dining experience and food quality
- environmental characteristics including homeliness, garden space and the cleanliness of the facility.

Most of the identified consumer experience and consumer satisfaction tools are non-preference based and are scored using simple summative scoring systems whereby individual responses are equally weighted to determine an overall total score. Notable exceptions are the CCI-6D and the QCE-ACC. Both tools were developed in Australia for application in economic evaluation in addition to quality assessment and hence both have preference based scoring systems available (11,12).

Consumer experience and consumer satisfaction tools: applications in aged care

Relatively few tools have been applied in Australia with most applications in residential care in other countries. Four consumer experience tools have been applied in Australia (CCI-6D, CEQ, PQ, QCE-ACC). Three of these tools were developed specifically for application in residential care and have therefore been applied only in this setting (CCI-6D, CEQ, PQ) whereas the QCE-ACC was developed for generic application across both home and residential care and has been applied in both settings. Two consumer satisfaction tools have been applied in Australia (CPVQ, RSQ). The CPVQ is specific to residential care whereas the RSQ has been applied in both residential and home care settings.

Consumer experience and consumer satisfaction tools: psychometric assessment

The results from each stage of consumer experience and consumer satisfaction tool literature review are presented in PRISMA diagrams (Figures 2 & 3). From the 13 consumer experience tools identified in this evidence review, 3 tools were found to meet at least one psychometric evidence standard with 2 of these tools (QCE-ACC and CCI-6D) meeting the highest psychometric evidence standard for both construct and content validity. From the 16 consumer satisfaction identified in this evidence review, 2 tools were found to meet at least one psychometric evidence standard with 1 of these tools (RSQ) meeting the highest psychometric evidence standard for both construct and content validity.

Summary table rankings of preferred consumer experience and consumer satisfaction tools respectively according to standardised psychometric assessment criteria are presented in

Tables 2 and 3. As previously indicated, tools were ranked according to the quality grading of the available evidence pertaining to the psychometric criteria with a higher ranking applied to tools presenting evidence of content, face and construct validity (followed by evidence of responsiveness and reliability) in the Australian aged care population. The tools for which a high level of psychometric evidence was available for at least one of the psychometric criteria were the QCE-ACC, CCI-6D and CEQ (consumer experience tools) and the RSQ and CVPQ (consumer satisfaction tools). When considering consumer satisfaction tools, it is important to be aware of the possibility of 'satisfaction bias', the tendency to report positive responses that often do not equate to true satisfaction levels. Long-standing evidence from health system settings indicates that consumer satisfaction tools may not be as reliable as consumer experience tools as a measure of quality due to the potential for satisfaction bias (13,14).

[1] Quality of Care-Aged Care Consumers (QCE-ACC)

The QCE-ACC is a preference-based measure of aged care specific quality of care experience designed to be applicable across both home and residential aged care settings (11). The QCE-ACC has six dimensions (respect and dignity, services and supports, decision-making, staff skills and training, social relationships, and feedback) rated across five response options ('all of the time' to 'none of the time').

[2] Consumer Choice Index – 6 Dimensions (CCI-6D)

The CCI-6D was developed in Australia in 2015 as a preference based measure to evaluate the quality of care received in long term care facilities from the perspective of the consumer (12). The CCI-6D contains six questions, each of which focus on a quality of care dimension identified by older people with cognitive decline as being important to their quality of care (care time, spaces, own room, outside and gardens, meaningful activities, and care flexibility). There are three levels of response for each question and the tool is preference based.

[3] Consumer Experience Questionnaire (CEQ)

The CEQ is a non-preference based tool developed in Australia with aged care residents and their families, with the intent to capture consumers' experience of care (15). The tool covers ten dimensions of care which are important to the consumer's experience of care (dignity, autonomy and choice, assessment and planning, care, lifestyle, service, feedback, human relations, governance, food, and independence). There are twelve questions in the tool. Ten of the questions are dedicated to capturing the consumer's experience of care relevant to one of the dimensions and each question has four or five response levels. The final two questions are open-ended and ask the resident for general comments about the best aspect of their care and general feedback to improve their experience of care.

[4] Resident Satisfaction Questionnaire (RSQ)

The RSQ was developed in 1998 in Australia to measure aged care residents' level of satisfaction with their care (16). It was developed in conjunction with aged care residents, and it covers ten dimensions that were identified as important to their satisfaction with care (overall level of satisfaction, care by staff, individual needs, your room, residential centre, social life and involvement in the aged care centre, links with the community, chaplaincy services, resident services, and resident involvement and feedback). The original residential care version of the tool has 50 questions with a 24 item short form version also available. The original RSQ has since been adapted with an updated residential care version developed in 2012 comprising 86 questions and an extension of the tool into home care comprising 62 questions (16).

[5] Consumer Perception of Value Questionnaire (CPVQ)

The CPVQ was developed in Australia in 2008 to capture residential aged care residents' level of satisfaction with the care and services provided to them (17). There are two versions of the tool – one that captures the level of satisfaction with care from the resident's perspective (64 questions), and one that captures the level of satisfaction with care from the family member's perspective (67 questions). Each question has six levels of responses and both versions of the CPVQ cover nine dimensions (welcome, delivery of care, spiritual life, meals, cleanliness, laundry, activities, facilities, and overall satisfaction).

Figure 2 PRISMA diagram for consumer experience
 (#1 tool identified through grey literature search)

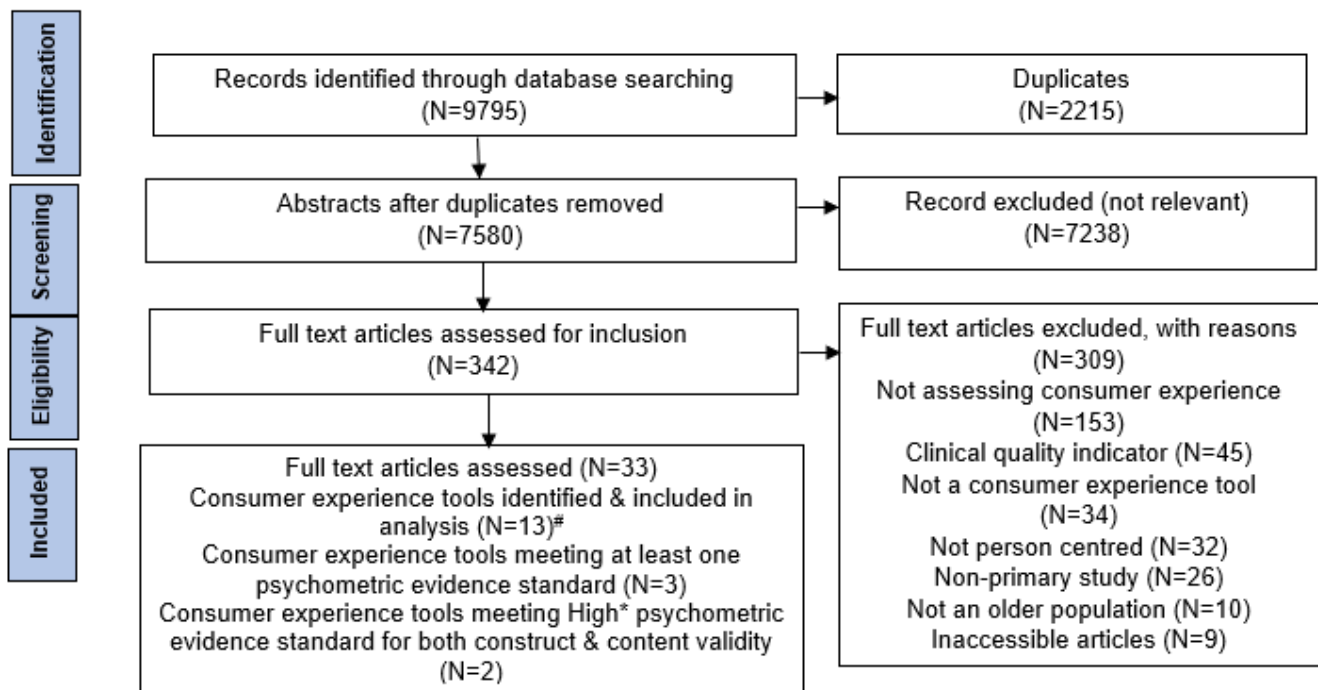


Figure 3 PRISMA diagram for consumer satisfaction
2 tools identified through grey literature search)

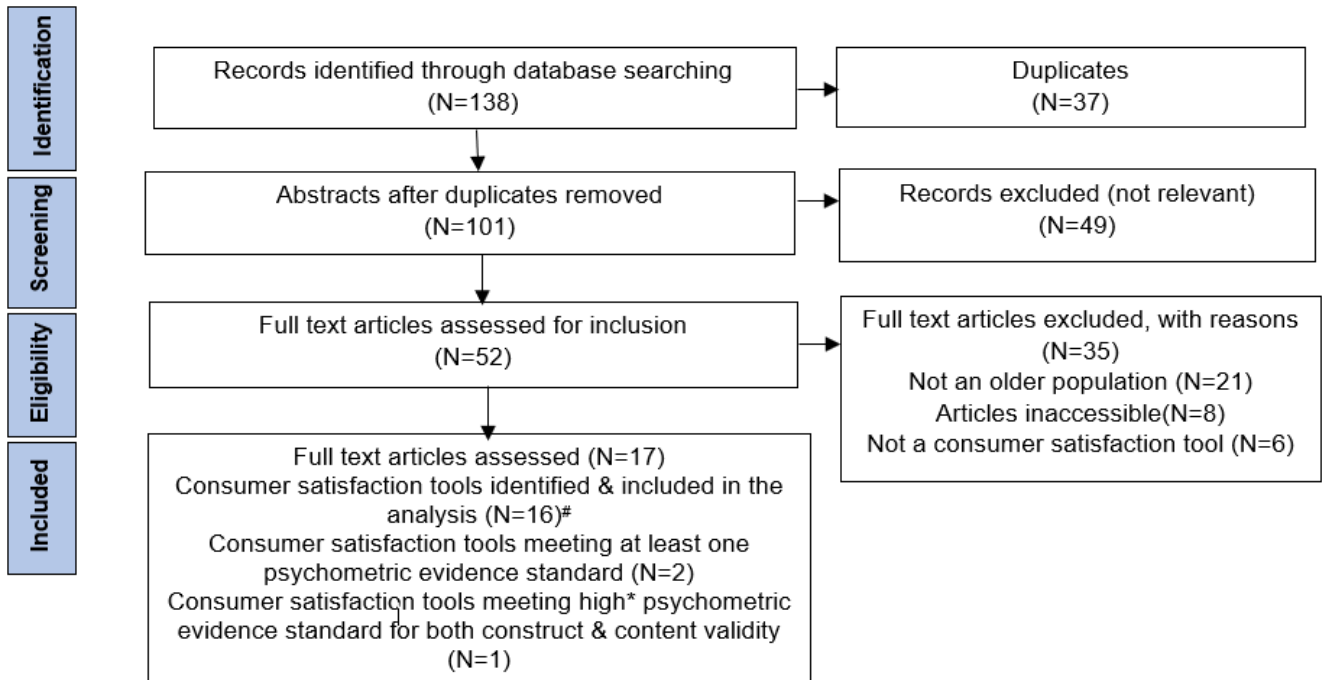


Table 2 Consumer Experience Tools

Rank	Tool	Country of origin	Primary focus	Development population	Respondent	Dimensions	Residential care	Home care
1	QCE-ACC	Australia	Consumer experience of care	Older adults and family carers, home and residential care	Self-completion; interviewer administered; proxy	Treated with respect and dignity; Supported to make own decisions; Staff with appropriate skills and training; Supported in aspects of daily living that are important; Social relationships and connections	✓	✓
2	CCI-6D	Australia	Consumer experience: Quality of care residential care	Residents and family members	Self-completion; interviewer administered	Caregiving staff time; Feel at home in shared spaces; Feel at home in own room; Access to outside and gardens; Feel valued in facility; Flexibility of care routines	✓	-
3	CEQ	Australia	Consumer experience: residential care	Residents and family members	Interviewer administered	Dignity, autonomy and choice; Assessment and planning; Care; Lifestyle; Service; Feedback; Human relations; Governance; Food; Independence; Open ended (best things about the home)	✓	-

Table 3 Consumer Satisfaction Tools

Rank	Tool	Country of origin	Primary focus	Development population	Respondent	Dimensions	Residential care	Home care
1	RSQ	Australia	Consumer satisfaction: Care recipients' and friends/family members	Care recipients' and friends/family members	Care recipients' and friends/family members	Residential care (overall); Care by staff; Individual needs and preferences; Your room; Residential centre; Social life and involvement in the centre; Links with the community; Chaplaincy services; Resident services; Resident involvement and feedback. Home care (overall); Care by staff; Individual needs and preferences; Care co-ordination; Clients rights; Spiritual support; Social support; Support services; Client involvement and feedback; Day centre activities	✓	✓

Rank	Tool	Country of origin	Primary focus	Development population	Respondent	Dimensions	Residential care	Home care
2	CPVQ	Australia	Consumer satisfaction: Resident satisfaction with care and services	Residents and family members	Interviewer administered (resident); Self-completion (family members)	Welcoming; Assessing and delivering care; Spiritual life; Meals; Cleanliness; Laundry; Activities; Facilities; Overall satisfaction	✓	-

5. Recommendations for implementation, data analysis and reporting

This review has highlighted that quality of life and consumer experience/satisfaction tools are not inter-changeable and that tools designed for each purpose measure different concepts. Therefore, in implementing quality of life, consumer experience and/or consumer satisfaction tools as important person-centred quality indicators and complements to clinical indicators of care quality it is important to be aware of the differences between tools in terms of their overarching concept and the dimensions included and hence being measured by each tool.

Little evidence is currently available in the literature on sampling and recommended frequency of administration for quality of life, consumer experience and/or consumer satisfaction tools in aged care for the purposes of quality assessment. This lack of evidence highlights the need for further consultation with the aged care sector, with aged care consumers and providers about how often these types of assessments should be undertaken.

There is a strong case for pilot studies to provide further evidence related to sampling and frequency of administration prior to widespread implementation. Recommendations for each element to be taken forward in piloting and subsequently embedding the preferred tool/s as an integral component of the QI Program are provided in the summary table below and described in the following sections (5.1-5.4).

Summary of Implementation Recommendations

Implementation Recommendations	Summary
Sampling and frequency of tool administration	<ul style="list-style-type: none"> • All older Australians accessing aged care in home or residential care settings surveyed every 6-12 months commencing with the ACAT assessment <i>or</i> • Representative sample of older Australians accessing aged care in home or residential care settings surveyed as above. Representative sample to be independently determined using robust probability sampling technique • Where aged care staff are involved in recruitment and/or administration of quality of life and/or aged care experience/satisfaction tools a brief education and training package should be provided to assist aged care staff in better understanding the purpose and value of quality of life and/or aged care experience/satisfaction tools and to support the QI program data collection activities
Mode of administration	<ul style="list-style-type: none"> • Preferable modes of tool administration are self-completion using electronic format touch screen technology (tablet) computer or hard copy (paper and pen survey) for the person or proxy respectively • Where assistance is required independently administered interviewer assisted formats should be considered. A prescribed interview script should be used to reduce the possibility of interviewer bias

Implementation Recommendations	Summary
Guidance on self and proxy assessment	<ul style="list-style-type: none"> Self-assessment of quality of life and/or aged care experience/satisfaction using a validated assessment tool designed for this purpose should be undertaken through self-completion or interviewer assisted formats Proxy assessments should be undertaken only where self-assessment is not possible e.g., due to severe physical frailty, disability and/or cognitive impairment and dementia
	<ul style="list-style-type: none"> The proxy assessor should be a person who knows the older person well, preferably a family member or close friend
Data analysis and reporting	<ul style="list-style-type: none"> Data analysis and reporting of quality of life, consumer experience and/or consumer satisfaction tools in aged care with relevance to the QI program needs to be case mix adjusted to provide meaningful comparisons Little evidence is available and further consideration needs to be given to how quality of life, consumer experience and/or consumer satisfaction data should be presented for different audiences e.g., the general public, aged care consumers and service providers. Consideration of data stratification e.g., older people with and without dementia and data aggregation e.g., by facility, service provider, state or geographical (metropolitan, rural and remote) areas

5.1 Sampling and frequency of tool administration

For inclusion in the QI program all older Australian's accessing aged care in Australia in either home or residential care settings should be surveyed about their quality of life and/or aged care experience/satisfaction at regular time intervals (every 6-12 months) with a preference for self-assessment and inclusion of proxy assessment only where self-assessment is not possible e.g., due to severe physical frailty, disability and/or cognitive impairment and dementia. If aged care staff are involved in recruitment and/or administration of quality of life and/or aged care experience/satisfaction tools a brief education and training package should be provided to assist aged care staff in better understanding the purpose and value of quality of life and/or aged care experience/satisfaction tools and to support the QI program data collection activities

5.2 Mode of administration

Preferable modes of tool administration are self-completion using electronic format touch screen technology (Tablet) computer or hard copy (paper and pen survey) for the person or proxy respectively. Where self-completion is not possible interviewer assisted formats should be considered. Preferably all interviews should be independently administered by an interviewer external to the aged care provider. Where this is considered not practically possible (e.g., where all older Australian's accessing aged care in Australia in either home or residential care settings are surveyed) an aged care staff member who is not directly

responsible for providing direct care and support to the older person may administer interviews using a validated quality of life and/or aged care experience/satisfaction tool. In all instances, a prescribed interview script should be utilised to reduce the possibility of interviewer bias.

5.3 Self and proxy assessment

Assessments should be from the person themselves wherever possible (self-completion or interviewer administered). A proxy assessor (ideally a family member or close friend who knows the person well) should be used only where self-assessment is not possible e.g., due to severe physical frailty, disability and/or cognitive impairment and dementia.

5.4 Data analysis and reporting

Reporting of quality of life, consumer experience and/or consumer satisfaction data in aged care with relevance to the QI program needs to be case mix adjusted to account for key socio-demographic and clinical characteristics at an individual level. Appropriate case mix adjustment will enable quality of life and consumer experience scores to be attributed to the care and services provided in home or residential care settings and facilitate meaningful comparisons. QI program quality of life and consumer experience/ satisfaction data should be securely stored and presented in an anonymous format (to preserve consumer confidentiality). Consideration should be given to compatibility with other administrative data-sets e.g., electronic health record for facilitating data linkage between the health and aged care systems.

Little evidence is available and further consideration needs to be given to a range of issues including how quality of life, consumer experience and/or consumer satisfaction data should be presented for different audiences e.g., the general public, aged care consumers and service providers; data stratification e.g., older people with and without dementia and data aggregation e.g., by facility, service provider, state or geographical (metropolitan, rural and remote) areas. Attention should also be placed on how results can be used at both local and national levels to inform service enhancements to drive measurable improvements in quality of life, consumer experiences and satisfaction.

6. Conclusions

Using evidence-based psychometric criteria and assessment, tools to assess, monitor and evaluate quality of life, consumer experience or consumer satisfaction from the perspective of older people (and/or family carers) accessing home or residential aged care services in Australia have been identified.

This includes two quality of life tools:

1. QOL-ACC (older person aged care **specific to both home and residential aged care**) and
2. GSGL (older Indigenous person specific).

Two consumer experience tools:

1. QCE-ACC (generic measure of care experience for both home and residential care and
2. CCI-6D (residential care specific consumer experience)

One consumer satisfaction tool:

1. RSQ (residential and home care consumer satisfaction).

In practice, no perfect tool exists, and all tools have their own purported advantages and disadvantages. Furthermore, this review has highlighted that quality of life and consumer experience/satisfaction tools are not inter-changeable. Tools classified under each category have in general been designed to measure these different concepts with different dimensions/items.

Like health system settings where both patient reported outcomes measures (PROMs) and patient reported experience measures (PREMs) are increasingly being recognised as important in both primary care and hospital settings, ideally quality of life and consumer experience should be measured as important and complementary quality indicators for Australia's aged care system in both home and residential care. Appropriate case mix adjustment to account for key socio-demographic and clinical characteristics at an individual level will enable quality of life and consumer experience scores to be attributed to the care and services provided in home or residential care settings. This will support aged care providers through access to robust, valid data to measure and monitor performance and support continuous quality improvement and, over time, provide consumers with transparent information about quality in aged care to assist decision making.

If only one concept is to be taken forward, in response to and in accordance with the Royal Commission recommendations [Rec no 22c], this review recommends quality of life as the most important person-centred quality indicator for Australia's aged care system in both residential and home care settings.

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Appendix

Acknowledgements

The research team would like to express their gratitude to the members of our Project Advisory Group for their input to the development of the evidence tables, psychometric assessment criteria and helpful comments on an earlier version of this report.

Project Advisory Group Members

Nina Bowes: Nina is the Director Strategy and Innovation at Uniting AgeWell. An experienced professional with a decade of experience in aged care policy, advocacy, research, project management, and organizational capacity building, Nina has a detailed understanding of aged care reform development, and policy design from her roles at both the Council of the Ageing (COTA), and the National Aged Care Alliance (NACA). Nina has also represented Victorian Public Hospitals, Health Services and Community Health Organisations during her time at the Victorian Healthcare Association (VHA). She has a strong track record of creating and sustaining partnerships with industry stakeholders and universities to successfully complete a diverse range of projects to benefit health and aged care services and consumers.

Megan Corlis: Megan is the Associate Director - Aged Care at the Australian Nursing and Midwifery Federation (SA Branch). Megan's role is to work with the aged care sector and other stakeholders creating relationships and seeking synergy related to projects and research related directly to building workforce capability and capacity. Megan also works with the University of South Australia as the Academic Liaison in Aged Care. This role allows her to promote tertiary sector activities such as research and the benefits of student engagement.

Megan has worked in a diverse range of roles across the acute and aged care sector – including as the Executive Manager of R&D in a large, aged care organisation. Her expertise is research and practice translation resulting in a positive impact both on older people and the workforce who provide services to them.

Victoria Cornell: Victoria is the Research Manager at ECH, one of the largest providers of independent living and aged care services in South Australia. Victoria manages ECH's active research programme— a role that straddles academic and service-based research and development, giving her a unique insight into translating research to action. Victoria's research and engagement in the area of social gerontology has been recognised in national and international journal article publications, conference presentations and media interviews. Victoria is a Board Director of the Australian Association of Gerontology and the Chair of the Southern Fleurieu Positive Ageing Taskforce, a network of aged care service providers, government and councils in the Southern Fleurieu and Kangaroo Island region.

Marjorie Schulze: Marjorie brings an experienced consumer voice to the project. Her knowledge and interest include making a positive contribution to the translation and accessibility of the research to older people, providers, carers and policy makers with the goal of ensuring improved services and outcomes for older people in both public and private aged care services. As a consumer representative on the Register for Older Senior Australians (ROSA) committees Marjorie knows the value and impact the contribution of consumers with lived experience can have on the focus and outcomes of research. Marjorie is a former Pharmacist with tertiary qualifications in Public Policy and Management. She has many years lived experience as a member of Boards in various NFP Health and Human Service organisations, of relevance 15 years' experience as a Director of The ACH Group, a major provider of residential aged care and independent living support in South Australia.

Anna Sheppard: Anna brings an experienced consumer voice to the project. Anna's professional background is in physiotherapy and she has worked in UK, NZ and Australia. Working with older people has been Anna's special interest and she became an APA (Australian Physiotherapy Assoc) Titled Gerontological Physiotherapist in 2010. For 25 years Anna worked in Community and Residential Care as a Clinician and Allied Health team leader. She was also a Staff trainer in Manual handling particularly in the use of dementia friendly techniques to maintain mobility and reduce falls. She spent 5 years caring for her father who suffered with mobility issues and dementia. He remained in his own home until he died at 101 years in 2013. The experience of caring for her father were pivotal in Anna undertaking consumer advocacy. She has acted as a consumer representative on the Register for Older Senior Australians (ROSA) committees since 2018.

Kate Swaffer: Kate is a humanitarian, and an independent scholar and author. She is an award-winning campaigner for the rights of people with dementia and older persons in Australia and globally and was named 2017 Australian of The Year in South Australia, 2018 Global Leader 100 Women of Influence in Australia, and won the Emerging Leader in Disability award in Australia in 2015. Kate is an Ambassador for the Australia Day Council (SA) and for Step Up For Dementia Research in Australia. Kate has a Master of Science in Dementia Care, a Bachelor of Psychology, a BA, a graduate Diploma in grief counselling, and is a retired chef, and a retired registered nurse. Her incomplete PhD research focuses on dementia stigma, using an autoethnographic approach. She is an activist for human rights and disability rights, and a highly published author and poet, and the past Chair, and current CEO and a co-founder of Dementia Alliance International.

Declarations

Julie Ratcliffe is the lead investigator on an ARC funded project to develop and validate the QOL-ACC and she was a member of the research team for the development of the AD-5D, CCI-6D, GSGL and the QCE-ACC. She has led published studies applying the DEMQOL, EQ-5D, ASCOT, ICECAP-O, PWI and the OPQoL in Australian aged care populations in both home and residential care settings.

Jyoti Khadka was the lead investigator for the development of the QCE-ACC tool and a member of the research team for the development of the QOL-ACC.

Johanna Westbrook has led published studies applying the ICECAP-O in Australian aged care populations in home care settings and she is currently the lead investigator for an NHMRC partnership project incorporating the QOL-ACC tool.

This review whilst comprehensive was undertaken and reported upon in a concentrated amount of time. Whilst every effort has been made to identify all relevant quality of life, consumer experience and consumer satisfaction tools, it is possible that not all relevant tools

have been identified. This includes tools in development for which information is not yet accessible.