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ORIGINAL RESEARCH ARTICLE

Feasibility of Routine Quality-of-Life Measurement in Residential Aged Care: Results from a Pilot Study in Australia

Lidia Engel[1,2] · Nancy Devlin[3] · Briony Dow[2,3,4] · Andrew Gilbert[2,5] · Brendan Mulhern[6] · Tessa Peasgood[3,7] · Rosalie Viney[6] · Frances Batchelor[2,3]

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Abstract

Objective This study presents findings from a pilot study that aimed to examine the feasibility of routine measurement of quality of life in residential aged care, including the examination of barriers to and facilitators of collecting and using that data to improve quality of care.

Methods This study was conducted at two not-for-profit residential aged care facilities in Melbourne, VIC, Australia. All residents were eligible to participate if consent was provided. Self-reported quality-of-life data were collected from residents, alongside proxy-reported data from aged care staff and relatives, primarily using the EQ-5D-5L in addition to a randomly assigned second measure (i.e. The Adult Social Care Outcomes Toolkit [ASCOT], Quality of Life-Aged Care Consumers [QOL-ACC], EQ Health and Wellbeing Instrument [EQ-HWB]). Feasibility was assessed in terms of missing data, residents' level of engagement and understanding, and difficulty experienced by staff and relatives in providing proxy reports. Perceived facilitators and barriers were identified via qualitative interviewers with staff who collected the data.

Results From 103 consenting participants, we gathered quality-of-life data through self-report ($n=90$), staff proxy-report ($n=101$) and family proxy-report ($n=49$). Most residents (94%) were able to respond to the EQ-5D-5L questions and residents' level of engagement was rated by staff as good. Only a few missing values (0–10%) were recorded for the EQ-5D-5L. Qualitative findings indicate that while quality-of-life data collection has benefits, barriers include time pressures, residents being too unwell to self-report, staff uncertainty about responding on their behalf and issues with the measure itself.

Conclusions While it is feasible to routinely collect quality-of-life data in residential aged care, addressing the barriers identified will optimise the efficiency of the process and maximise the use of data to guide quality improvement strategies.

1 Introduction

The global ageing population is rising, with one in six people expected to be aged 60 years or older by 2030, and those aged 80+ years projected to triple between 2020 and 2050 [1]. As people age, there will be an increase in demand for aged care services, including home support services and residential care. In Australia, 16% of the population is aged 65+ years, expected to reach 23% by 2066 [2]. The number of people aged 85 years and over has increased by 117.1% over the past two decades, and those aged 85 years and over comprise the largest cohort of permanent residential aged care users [3]. In 2021, it was estimated that 165,000 people used permanent residential aged care that provides accommodation and care at a facility on a permanent or respite (temporary) basis; an increase of 11% from 2011 [4]. Most residents experience cognitive decline, frailty and chronic conditions, with over half having dementia [5].

There is a growing emphasis on routine measurement of quality of life (QoL) in residential aged care to provide older people with transparent information about the quality of aged care services and the extent to which services support their overall well-being as experienced by residents themselves. In Australia, the Australian Government has recently expanded the National Aged Care Mandatory Quality Indicator (QI) Program, which requires residential aged care providers to regularly collect and report data on key aspects of care quality, as a response to the Royal Commission into Aged Care Quality and Safety that revealed many

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Extended author information available on the last page of the article

Key Points

There is limited research on the feasibility of routine quality-of-life measurement in residential aged care, particularly regarding barriers, facilitators, and practical implementation challenges.

This pilot study demonstrates that routine quality-of-life data collection is feasible, with high resident engagement and minimal missing data. It also identifies key challenges and strategies for improving the data collection process.

Addressing identified barriers can enhance the efficiency of quality-of-life measurement, ensuring its effective use in guiding person-centred care and quality improvement strategies in aged care facilities.

failings in the aged care system. From the previous five clinical indicators (i.e. pressure injuries, use of physical restraint, unplanned weight loss, falls and major injury, and medication management), six indicators have been added to the QI Program, which now also include consumer experience and QoL [6]. From April 2023 onwards, all providers of residential care services are required to provide quarterly reports on the percentage of care recipients who report ‘good’ or ‘excellent’ QoL.

The introduction of routine QoL measurement in aged care facilities in Australia marks a significant milestone. While there has been a push towards capturing the patient’s voice in the healthcare sector via the use of patient-reported outcome measures (PROMs) [7], and a growing number of studies reporting the implementation of PROMs in clinical practice [8, 9], the routine collection of PROM data in residential aged care has largely remained an untapped area internationally. Moreover, while successful implementation of PROMs in healthcare is still hampered by barriers reported at the patient level (e.g. perceived irrelevance of PROMs), at the healthcare professional level (e.g. insufficient time and knowledge to interpret PROM data) and at the service level (e.g. absence of infrastructure and resources for PROM integration) [8, 10], a limited number of studies have previously explored the feasibility of routine QoL measurement in the residential aged care setting. Hoben et al. found that it was feasible for care staff to assess the QoL of residents with dementia in Canada, although the assessment was based on proxy reporting rather than residents’ self-reporting, limited to people living with dementia and included support from researchers who collected staff responses via video calls [11]. The DACHA (Developing resources And minimum dataset for Care Homes’ Adoption) study, which aimed to develop and test a minimum dataset for care homes in England, tested four QoL measures, showing that the QoL instrument was feasibly for care home staff to complete [12]. However, the feasibility of residents self-reporting QoL measures remains limited.

There is an urgent need to explore the feasibility of collecting routine QoL data from residents in aged care facilities, especially in Australia, where QoL measurement has been rolled out nationally across all residential aged care facilities. Additionally, the selection of QoL measure(s) for such a routine collection has received little attention, including assessment of instrument-specific implementation barriers [13]. While the Quality of Life-Aged Care Consumers (QOL-ACC) measure, a relatively new older person-specific measure developed in Australia [14], is used for routine measurement of QoL in residential aged care in Australia, a previous report recommended other measurement tools applicable to the Australian aged care landscape that measure a range of constructs [15], including the ASCOT (The Adult Social Care Outcomes Toolkit) [16], ICECAP-O (ICEpop CAPability measure for Older people) [17], QOL-AD (Quality of Life-Alzheimer’s Disease) [18] and the EQ-5D [19]. Despite little evidence about the performance of these measures for routine assessment in residential aged care, the EQ-5D has been most commonly used in older adults receiving aged care services [20]. However, different instruments capture distinct constructs, and previous research suggests they may be complementary in residential care home settings [21].

This study presents findings from a pilot study that aimed to examine the feasibility of routinely measuring QoL in residents living in a not-for-profit aged care facility in Melbourne, Australia. It was initiated prior to the introduction of the QI Program and aimed to collect self-reported QoL data from residents, alongside proxy-reported data from aged care staff and relatives, primarily using the EQ-5D-5L measure in addition to a randomly assigned second measure (i.e. ASCOT, QOL-ACC, EQ Health and Wellbeing Instrument [EQ-HWB]), where possible. The EQ-5D-5L was selected as the primary measure owing to its widespread use in assessing QoL among older adults receiving aged care services [20], as well as its frequent application in economic evaluations [22, 23]. However, given the EQ-5D-5L’s focus on health-related QoL, the EQ-HWB was included for its broader evaluative scope, capturing aspects of health and well-being. The QoL-ACC was chosen for its alignment with the Australian QI Program and the fact that it was tailored specifically for older people. The ASCOT assesses social care-related QoL and was selected for its relevance to evaluating community aged care programmes in Australia [24]. Guided by the International Society for Quality of Life Research User Guide for Implementing Patient-Reported

Outcomes Assessment in Clinical Practice [25], this study comprised five steps: (i) interviews with residents to explore the face validity of four QoL measures and residents' views towards QoL data collection; (ii) interviews with aged care staff and relatives to examine the feasibility of proxy reporting residents' QoL and their perceptions towards QoL data collection; (iii) workshops with aged care staff and relatives to design the process for routine QoL data collection; (iv) piloting the QoL data collection process; and (v) interviews with aged care staff to reflect and evaluate the data collection process. This paper reports partial findings from step (iv) and full findings from step (v), focusing on the feasibility of the data collection and exploration of barriers to and facilitators of QoL assessments in residential aged care.

2 Materials and Methods

2.1 Sampling and Recruitment

We partnered with a not-for-profit provider that had 14 residential aged care facilities in Melbourne, VIC, Australia. Two of the residential aged care facilities were nominated by the provider based on sufficient bed capacity and prior discussions with facility managers who expressed interest in this study. Recruitment of residents was based on their capacity to consent, which was determined by the facility using cognitive assessment results. All residents were eligible to participate in this study if consent was provided. The aged care staff introduced the resident to a research staff member who then provided further information about the study, including a plain language statement. Prior to seeking written consent from the resident, the research staff asked the resident to summarise the study in their own words, ensuring that the resident fully understood what the study involved. If a resident had no capacity to consent but had a power of attorney (PoA), an e-mail was sent to their PoA with a plain language statement and a link to provide an e-consent. Residents and their PoA could provide consent for one or all three components of the study: (i) for the resident to self-report their QoL (if a PoA consented to this component, additional verbal consent was sought from the resident); (ii) for the aged care staff to proxy assess the resident's QoL; and (iii) for a relative to proxy assess the resident's QoL (residents could nominate a relative; a PoA could nominate themselves or another relative proxy). If a resident had no capacity to consent and no PoA, no further action was taken. Each resident and relative received a $30 gift card for participating in the study. Additionally, each facility received $50 per completed proxy staff assessment. This study was approved by the Monash University Human Research Ethics Committee (Project ID: 32170).

2.2 Procedure

The QoL data collection process was informed by workshops that were held separately at each facility to design the process, considering the resources available at each respective facility. Aged care staff and relatives were invited to these workshops, which discussed: (i) the purpose/benefits of QoL collection; (ii) selection of residents for QoL assessment; (iii) nomination of staff for data collection; (iv) determining the timing for data collection; and (v) other data collection considerations. Subsequently, Facility A opted for an online data collection process, while Facility B preferred a paper-based collection. The research team prepared online surveys, using REDCap, and shared a QR code and link with Facility A, which collected the data using facility-owned tablets. Facility B was provided with printed surveys. A password-protected cloud-based Excel spreadsheet was shared with each facility, where facilities could look up which residents (or their PoAs) consented to which components of the study and which QoL measures were assigned to the resident. Prior to data collection, training was provided by the research team to all aged care staff that were involved in the data collection process.

On the day of the assessment, the aged care staff initially checked the resident's availability and general well-being, ensuring that the assessment could be completed without any foreseen disruptions. The aged care staff member completed the proxy assessment prior to interviewing the resident to avoid biased responses. This was usually done with the resident being present in the room. Afterwards, the aged care staff obtained the resident's self-reported QoL, using interviewer-administered versions of the measures. The aged care staff member was instructed to time the administration of each measure during the interview with the resident only. After the resident assessment, the aged care staff member completed a brief evaluation form and submitted the date on which the assessment was conducted into the Excel spreadsheet. This then prompted the research staff to call the nominated relative (if applicable) and obtain a proxy assessment from relatives over the phone. During the pilot data collection process, the research staff regularly undertook visits to the facilities to discuss the progress with the aged care staff/facility managers to increase engagement with the data collection process. Data collection took place between February and July 2023 at Facility B and between May and August 2023 at Facility A. Although this timeframe overlapped with the roll-out of the QI Program, both facilities only implemented the QI Program after this study was finished. Therefore, while the rollout was scheduled for 1 April, 2023, implementation varied across facilities in both timing and extent (e.g. because of factors such as staff training or resource allocation).

2.3 QoL Measures

All residents and proxies were asked to complete the EQ-5D-5L, consisting of five dimensions (mobility, self-care, usual activities, anxiety/depression, pain/discomfort) with five response options each (no problems, slight problems, moderate problems, severe problems, extreme problems/unable) [19]. The EQ-5D-5L also includes a visual analogue scale, which is a vertical scale that ranges from zero (denoting 'the worst health you can imagine') to 100 (representing 'the best health you can imagine'). The recall period of the EQ-5D-5L refers to 'TODAY'. The Australian English-language version of the EQ-5D-5L for interviewer administration was used to obtain residents' self-reported QoL; proxies (aged care staff and relatives) completed the proxy version 2 of the EQ-5D-5L, which asks the proxy to rate how they (the proxy) thinks the resident would rate their own health if they could communicate it (proxy-person perspective). This version differs from the proxy-proxy perspective, which asks the proxy to rate the resident's health based on their own opinion or observation, rather than how they believe the resident would self-assess it.

In addition to the EQ-5D-5L, a second measure was randomly assigned to the resident (and proxies were assigned the same measure) that either included the QOL-ACC, the ASCOT or the EQ-HWB. The QOL-ACC is an older person-specific QoL measure, which has been recommended for the QI Program in Australia. It includes five dimensions (independence, mobility, pain management, emotional well-being, social connection and activities) with five response levels each, which range from the best level 'all of the time' to the worst level 'none of the time' [14]. The interviewer-administered version was used for interviews with residents and the proxy version for a proxy report, which adopts a proxy perspective. The ASCOT is a social care-related QoL measure that includes eight domains (personal comfort and cleanliness, personal safety, food and drink, occupation, control over daily life, social participation, home cleanliness and comfort, and dignity) with four levels (ideal state, no needs, some needs and high needs) [16]. The SCT-4 version was used for the residents' self-report; the proxy version was used for the proxy assessment, which uniquely asks proxies to rate the resident's QoL from both perspectives, the proxy-proxy and proxy-person perspective [26]. The EQ-HWB is a measure of health and well-being, which was also developed by the EuroQol group that developed the EQ-5D-5L, but extends the evaluative scope beyond health, capturing broader aspects of well-being. The experimental 25-item long measure [27] was used in this study. In the absence of an interviewer-administered version, the self-report version was used for interviews with residents, whereas the proxy version 2 (i.e. proxy-person perspective) was used for the proxy assessment.

2.4 Qualitative Interviews with Data Collectors

Once the pilot data collection phase was completed, aged care staff involved in the data collection process were invited to participate in a semi-structured interview. The aim of the interviews was to reflect on the process, including the identification of barriers and facilitators to routine QoL data collection. All interviews followed a topic guide (see Electronic Supplementary Material) and were audio recorded. Interviews were held face-to-face at the respective facility or via Zoom. Participants received a $50 gift card for their time and contribution.

2.5 Analysis

Survey data from Facility A were exported from REDCap into STATA; survey data from Facility B were entered electronically and then merged with Facility's A data in STATA. Descriptive statistics were used to analyse the quantitative data, using percentages for categorical data and means (standard deviation) for continuous data. Feasibility of the QoL data collection was assessed in terms of missing data of the QoL measures, residents' level of engagement and understanding of the QoL questions (based on aged care staff's evaluation report), difficulty experienced by staff and relatives in providing proxy reports, and perceived facilitators and barriers (based on qualitative data). Qualitative data were transcribed, imported into Nvivo and analysed thematically [28]. The person who conducted the interviews also analysed the data by reading the transcripts, organising and coding the data to uncover recurring themes that provided insights into the barriers and facilitators to QoL data collection. To enhance the credibility of the findings, the researcher engaged in regular discussions with members of the research team to review emerging themes and interpretations. Themes were developed through an iterative process of coding, comparison and refinement until a consensus was reached on their final form.

3 Results

Figure 1 depicts the consent and data collection process in a flowchart. Out of the 103 consenting participants (either by residents or their PoAs), we gathered QoL data through a self-report ($n = 90$), a staff proxy report ($n = 101$) and a family proxy report ($n = 49$). However, because of an administration error, multiple assessments were conducted for some residents (i.e. seven self-reports and seven staff proxy reports) for certain QoL measures. Most consents were provided by the residents themselves rather than their PoAs. Reasons for declining participation were often related to the resident not being interested in the study; PoAs often declined for no reason with four PoAs declining participation because of residents' insufficient English proficiency. Despite consent being provided, some assessments were not completed because the resident had passed away ($n = 2$), left the facility ($n = 4$), withdrew ($n = 1$) or was unable to complete the QoL measures ($n = 4$). Most family members were unavailable or hard to reach by phone ($n = 30$) or declined participation ($n = 4$).

The characteristics of staff and relatives are provided in Table 1. Aged care staff who were involved in the QoL assessment were mostly female (83%), aged 40 years on average and the majority had worked in the facility for more than 1 year; 33% reported working at the facility between 1 and 6 months. For Facility A, the three aged care staff involved in the study were after-hours nurses who completed the assessments in the afternoon or evening. For Facility B, three lifestyle coordinators/assistants were involved in the QoL assessment, with data collection taking place throughout the day. Relatives were mostly female (60%), aged 65 years on average, retired (52%) and most were people completing the QoL measure on behalf of their mother/father (69%) who lived in the aged care facility.

Table 2 shows the proxy responses prior to completing the QoL measure on behalf of the resident. While the majority of staff spoke to the resident (96%) on the day of the assessment, and usually would speak to the resident on most days of the week (48%), only 20% reported knowing the resident very well. Additionally, only 6%, 14% and 29% of relatives reported that they would visit their relative in the aged care facility daily, most days of the week or at least once a week, respectively, with 20% visiting only once a month or never. Some relatives (33%) reported that they did not usually speak to the resident over the phone.

Table 3 shows feedback from the proxy respondents after the QoL proxy completion. While 59% of relatives did not find it difficult to complete the QoL measure on behalf of the resident, the majority of the staff (41%) found it somewhat difficult to proxy report on residents' behalf. This is also reflected in proxies' responses towards the question whether they thought that the resident would have rated their QoL differently, with the majority of staff (73%) perceiving that the resident would rate their own QoL better than the staff, whereas only 23% of relatives reported that residents would rate their own QoL better, with 54% of relatives reporting that their rating would align with the residents' own rating. The majority of both staff and relatives, however, did not think that someone else should have acted as a proxy.

Evaluation results following the interview with the resident are shown in Table 4, highlighting that most residents (94%) were able to respond to the EQ-5D-5L, and only 6% of the residents appeared to have difficulty comprehending the questions or were unwell. Staff generally perceived that residents were very engaged (34%) or somewhat engaged (41%) with the QoL data collection process and that it was easy to follow the study protocol.

Measurement-specific evaluation results are presented in Table 5. There were only a few missing values for proxy-reported data by staff and relatives; missing values for residents ranged from 2% for the EQ-5D-5L to 25% for certain items that were not completed using EQ-HWB. It is evident that for all measures, staff had to repeat or explain questions more than once, with varying levels of support needed across measures. However, staff generally judged residents' level of understanding of the instructions, questions and response options as good.

3.1 Qualitative Interview Findings

Qualitative data, exploring barriers to and facilitators of QoL assessments in residential aged care with the six aged care staff members who collected the data, were summarised into seven themes: (i) perceived benefits; (ii) conflicting priorities; (iii) resident-related challenges; (iv) measurement-driven issues; (v) choice of proxy; (vi) strategies for data collection, and (vii) biases.

3.1.1 Perceived Benefits

The consensus among all six aged care staff interviewed was that the most significant advantage was the chance to deepen their understanding of the residents. Staff members revealed that they normally did not think to ask residents certain questions and that the administration of standardised QoL questions provided them with a deeper understanding of residents' QoL, uncovering previously unnoticed aspects of their lives.

> "You might not have thought to ask these questions […] and you wouldn't really notice until they answered the question." [S2]

Staff also described not usually having enough time to sit and talk to residents and welcomed the opportunity of designated time specifically allocated for interacting with residents.

> "No one really just sits down and asks, "How's your pain level?" So, actually sitting there with them and asking the questions makes you realise they are actually in a lot more pain." [S3]

The residents' responses to QoL questions also prompted staff members to modify their approach in delivering care and addressing specific issues that surfaced during the QoL assessment.

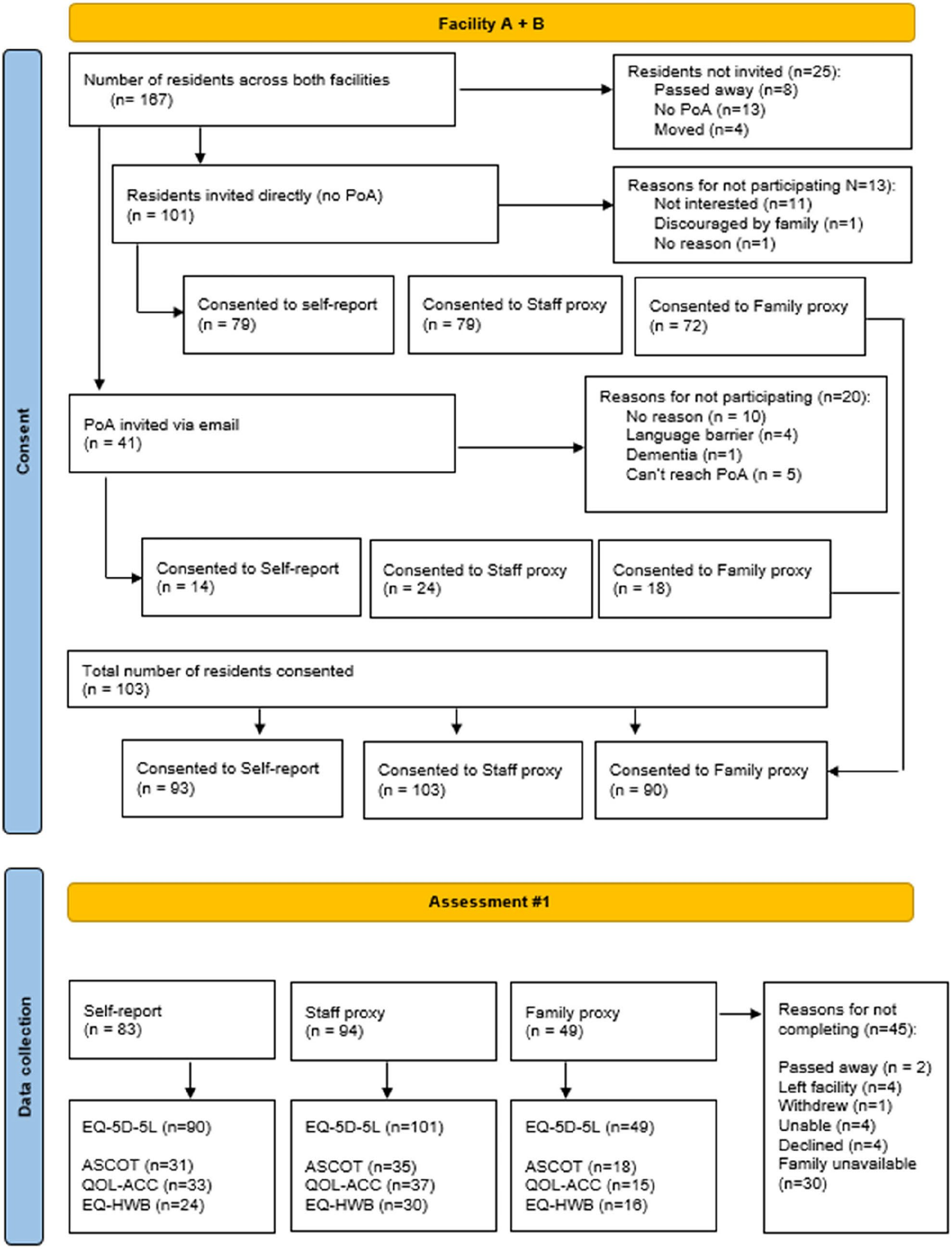

Fig. 1 Flow chart depicting the consent and data collection process. *ASCOT* The Adult Social Care Outcomes Toolkit, *EQ-HWB* EQ Health and Wellbeing Instrument, *PoA* power of attorney, *QOL-ACC* Quality of Life-Aged Care Consumers

Table 1 Characteristics of proxies

	Staff *N* (%)	Relatives *N* (%)
Sex		
Female	5 (83%)	29 (60%)
Male	1 (16%)	19 (40%)
Mean age, SD	40 (11.09)	65.25 (9.60)
Country of birth, Australia	2 (33%)	40 (83%)
English your first language, yes	3 (50%)	46 (96%)
Employment status		
Retired	0	25 (52%)
Employed, full-time	2 (33%)	11 (23%)
Employed, part-time	3 (50%)	5 (10%)
Self-employed	0	4 (8%)
Casual/seasonal	1 (17%)	2 (4%)
Volunteer	0	1 (2%)
Home duties	0	1 (2%)
Education		
Year 10 or less	0	5 (10%)
Year 11/12	0	12 (25%)
Certificate III/IV	3 (50%)	8 (17%)
Diploma	0	11 (23%)
University degree	3 (50%)	12 (25%)
Job description	0	
Nurse	3 (50%)	–
Lifestyle coordinator	3 (50%)	–
How long have you been in your position?		
Less than 1 month	0	–
Between 1 and 6 months	2 (33%)	–
Between 6 and 12 months	0	–
1–3 years	1 (17%)	–
3–5 years	1 (17%)	–
More than 5 years	2 (33%)	–
Relationship to resident; he/she is my:		
Partner	–	7 (15%)
Mother/father	–	33 (69%)
Another family member	–	6 (13%)
Friend	–	1 (2%)
Other	–	1 (2%)

SD standard deviation

> "You're like, I think some of these need to be addressed. Or maybe I need to spend more time with my resident because they are feeling a little down or more happy or would like to do more things like, especially the activity questions or mobility questions. It kind of changed my thinking a little bit as well on what to ask my residents." [S2]

There was generally a perception that using QoL measures in their daily work would help staff to provide a higher level of person-centre care.

> "So, by talking to them closely and interviewing them, I come to understand them very well. And it helps me also to understand how am I going to care for them." [S5]

3.1.2 Conflicting Priorities

The most commonly mentioned barrier to collecting QoL data included time constraints and conflicting priorities. Despite the perceived benefits, aged care staff would often struggle to fit the QoL assessment into their already stretched daily routine tasks.

> "You're trying to fit it in [but then] you're getting something else thrown at you. And like I said about conflicting priorities, if I know I'm meant to start something or I've got to be with a relative in half an hour, and this has taken longer than I wanted it to, that is really an issue for us." [S1]

Staff also described the frequent interruptions during the QoL assessment, which increased the duration of the assessment and decreased the resident's level of engagement.

> "One is time management and the interruption between the interview. Even though it is taking very short time, like five minutes, sometimes between that five minutes we have to prioritise [other tasks] as well. Then we are interrupted in between, which makes it difficult for the residents and they get a bit annoyed that you're going and coming back." [S4]

However, aged care staff also suggested potential solutions to this issue by designating a specific staff member to conduct the assessments and establishing dedicated time slots.

> "I believe that it would be better to make a separate time, allocate the staff, set a time to do this interview so that they can just go." [S4]

3.1.3 Resident-Related Challenges

The QoL assessment was perceived as more challenging with some residents than with others. When prompted to describe the characteristics of residents for whom the assessments were more difficult, staff identified residents with comorbidities who were unwell, residents with dementia or cognitive impairment, residents with hearing

Table 2 Proxy responses to pre-proxy assessment questions

	Staff *N* (%)	Relatives *N* (%)
Did you speak to the resident today?		
Yes	94 (96%)	–
No	4 (4%)	–
Over the last week, how often did you speak to the resident?		
Daily	13 (13%)	–
At least once a week	25 (26%)	–
Most days of the week	47 (48%)	–
Fortnightly	0	–
A handful times	9 (9%)	–
Once	2 (2%)	–
Never	2 (2%)	–
Based on your personal judgement, how well do you know the resident?		
Very well	20 (20%)	
Somewhat	76 (77%)	
Very little	3 (3%)	
Not at all	0	
Over the last month, on average, how often did you visit your relative in the aged care home?		
Daily	–	3 (6%)
At least once a week	–	14 (29%)
Most days of the week	–	7 (14%)
Fortnightly	–	9 (18%)
A handful times	–	6 (18%)
Once	–	5 (10%)
Never	–	5 (10%)
Over the last month, on average, how often did you speak to your relative on the phone?		
Daily	–	13 (27%)
At least once a week	–	11 (23%)
Most days of the week	–	3 (6%)
Fortnightly	–	0
A handful times	–	5 (10%)
Once	–	1 (2%)
Never	–	16 (33%)
Unsure	–	0

difficulties and communication problems, and residents with English as a second language.

> "The ones that I found a little bit harder to do is some people that had dementia because they kind of got a little off track and you just had to reengage them to bring them back. As I said before, people that had trouble hearing." [S2]

One staff member highlighted additional challenges associated with residents who tend to wander.

> "Wanderers were the hardest because they did not want to sit still for longer than about three minutes at a time. You can only really engage them for about three minutes before they're wanting to get up and move around or go walking or even just change subject." [S3]

Staff also reported that some residents were unavailable or difficult to reach, resulting in the need for multiple attempts to complete the QoL assessment.

> "… you're going in and they're on the phone or you come back. It's a lot of toing and froing and going around then coming back to it and they're asleep or they're watching a movie, "No, it's not convenient now" it's that sort of thing."

Table 3 Proxy responses to post-proxy assessment questions

	Staff *N* (%)	Relatives *N* (%)
How difficult was it to complete the quality of life survey on behalf of the resident?		
Not at all	22 (26%)	29 (59%)
A little bit	24 (29%)	11 (23%)
Somewhat	34 (41%)	4 (8%)
Quite a bit	2 (2%)	5 (10%)
Very much	2 (2%)	0
Do you think the resident would have rated his/her quality of life differently?		
No	18 (21%)	26 (54%)
Yes, better than my rating	61 (73%)	11 (23%)
Yes, worse than my rating	5 (6%)	11 (23%)
Do you think someone else should have acted as proxy other than yourself?		
No	70 (84%)	43 (90%)
Yes[a]	13 (16%)	5 (10%)
How often do you think should the quality of life of the resident be assessed by a proxy?		
Weekly	0	1 (2%)
Fortnightly	0	1 (1%)
Monthly	21 (26%)	9 (21%)
Quarterly	47 (58%)	7 (17%)
Every 6 months	1 (1%)	11 (26%)
Other[b]	13 (16%)	13 (31%)
Do you think that the quality of life assessment today fitted within your working schedule?		
Yes	75 (88%)	n.a.
No[c]	10 (12%)	n.a.

n.a. Not applicable

[a] Staff: personal care worker ($n=7$), family ($n=1$), regular staff ($n=1$); relatives: other relatives ($n=3$), staff ($n=2$)

[b] Staff: occasionally ($n=12$), annually ($n=1$); relatives: occasionally ($n=10$), annually ($n=3$)

3.1.4 Measurement-Driven Issues

Barriers were also identified that were related to the specific QoL measures administered. Each aged care staff member held individual perspectives on the efficacy of different QoL measures. The majority of staff found that the EQ-5D-5L was acceptable in "*length, but also, the questions are straight to the point"* [S2], although one staff member raised issues around the negatively phrased and problem-oriented wording:

> "I'm not anxious or depressed, I'm slightly anxious, depressed? You're saying the same thing: anxious and depressed, anxious and depressed, anxious and depressed. And so when you get there, they're going, "I don't think I am. Should I be?" It's not a positive thing. So, I'm looking at just the word pain, anxiety, depression, things like that." [S1]

The opposite was noted for the QOL-ACC, which was positively worded.

> "I have good social relationships with my family and friends. That's a positive statement. I have leisure and activities I enjoy, is a positive statement. So out of the whole lot, this is a good one." [S1]

Generally, the staff perceived the ASCOT and EQ-HWB to be more challenging because of their length and complex wording. Furthermore, some residents found the ASCOT questions pertaining to cleanliness and appearance to be sensitive, leading them to inquire about the rationale behind these questions. One staff member perceived difficulties with EQ-HWB's recall period of 7 days, which would disregard pain experienced beyond that period. There were no comments about EQ-5D-5L's recall period of 'today'.

Staff also found that questions around feelings or mental health, which are included in all measures, were challenging to ask and sometimes resulted in untruthful responses.

> "I found the mobility ones and things like that, that I knew about easier. Not so much like the emotional, because I know some residents can be very guarded

Table 4 Evaluation results of interviews with residents

	N (%)
Did the resident complete the EQ-5D-5L?	
Yes	82 (94%)
No	5 (6%)
Reasons for not completing the EQ-5D-5L	
Appeared to have difficulty comprehending the question(s)	4 (5%)
Unwell	1 (1%)
Were you able to administer the survey in private?	
Yes	73 (97%)
No (common area, other staff interrupting)	2 (4%)
Resident's level of engagement	
Very engaged	25 (34%)
Somewhat engaged	30 (41%)
Neither engaged nor unengaged	7 (9%)
Somewhat unengaged	6 (8%)
Very unengaged	6 (8%)
Level of difficulty following the protocol	
Very difficult	5 (7%)
Somewhat difficult	17 (23%)
Neither difficult nor easy	11 (15%)
Somewhat easy	22 (29%)
Very easy	20 (27%)

> and change their answers to think what you want to hear." [S2]

Aged care staff also spoke about difficulties answering questions related to feelings when doing their staff proxy assessment, acknowledging the subjective nature of QoL.

3.1.5 Choice of Proxy

Generally, aged care staff considered that their proxy report provided an accurate assessment of residents' QoL. However, challenges arose when they felt that they did not know the resident well.

> "I'm on four days a week, so I would know more than someone who's only here once a week." [S2]

Different views were proposed in terms of who should serve as proxy and complete the QoL measures on behalf of residents, such as personal care workers, lifestyle staff, registered nurses, families or even the research staff.

> "I would recommend, for the PCAs to do it and preferably someone that's on quite frequently that knows their residents." [S2]
>
> "It needed someone who knew all your residents. So, Lifestyle did need to be a part of it, I think, because we do know each resident." [S3]
>
> "Truthfully, it would be better for families to do these, I reckon, truthfully, because they know their parents or family better and I reckon they'll be more honest with their family." [S2]

One staff member suggested that for the most accurate proxy assessment, you would need more than one person completing the QoL measure:

> "[I would suggest to] involve the lifestyle, to involve with the carer, the registered nurses, even the management, family, it might give a good picture and a good report. [S5]

3.1.6 Strategies for QoL Data Collection

Aged care staff developed a number of different strategies for the interviews over the course of the study. To ensure efficient use of their time, staff usually prepared the QoL assessment for more than one resident, anticipating scenarios where a resident might be unavailable or unwell. Depending on their workload and daily responsibilities, staff would prioritise residents with better cognitive capacity, reserving interviews with those experiencing cognitive impairment or dementia for days when more time was available.

> "I pretty much had to go straight for the cognitive people that would be able to answer the questions really fast, like without a long period of time […] and it'd be a 20 minute, 30 minute thing. And then on the days where I did have a bit more time, I would go and spend it for those who do have a bit more dementia and Alzheimer's, and I knew it would take a bit more time." [S3]

If a resident was not in the mood to talk, staff often had to approach the resident multiple times to complete the assessment.

> "I don't engage when they are tired or when they're agitated, I leave and maybe after ten minutes or 15 minutes when I come back also they become a different person and they are happy to talk. Or maybe I'll go and just bring them a cup of coffee or a cup of juice and stuff like that and we start our conversation again. So, I use some kind of strategy to create that comfort zone." [S5]

Apart from choosing a quiet location for the interview, typically the resident's room, the timing of the assessment proved crucial, with staff noting that mornings were generally perceived as more conducive than afternoons.

Table 5 Missing values and staff evaluation of interviews with residents

	EQ-5D-5L	QOL-ACC	EQ-HWB	ASCOT
Eligible sample, staff	$N=101$	$N=37$	$N=30$	$N=35$
N of respondents (%) with 'all items missing'	1 (1%)	0	0	Proxy: 0, person: 2 (6%)
N of respondents (%) with 'certain items missing'	0	0	5 (17%)	Proxy: 3 (9%); person: 5 (14%)
Eligible sample, family	$N=49$	$N=15$	$N=16$	$N=18$
N of respondents (%) with 'all items missing'	0	0	0	Proxy: 0, person: 1 (6%)
N of respondents (%) with 'certain items missing'	7 (14%)	2 (13%)	3 (19%)	Proxy: 0, person: 2 (11%)
Eligible sample, resident	$N=90$	$N=33$	$N=24$	$N=31$
N of respondents (%) with 'all items missing'	7 (8%)	5 (15%)	1 (4%)	1 (3%)
N of respondents (%) with 'certain items missing'	2 (2%)	2 (6%)	6 (25%)	3 (10%)
Repeat or explain questions more than once				
No	28 (36%)	10 (36%)	6 (30%)	11 (39%)
Yes	50 (64%)	18 (64%)	14 (70%)	17 (61%)
Level of support needed				
Unable to understand/complete	1 (1%)	1 (4%)	0	0
A lot of support	12 (15%)	3 (11%)	4 (20%)	5 (18%)
Moderate amount of support	25 (32%)	6 (21%)	9 (45%)	10 (36%)
Little support	18 (23%)	10 (36%)	3 (15%)	4 (14%)
No support needed	22 (28%)	8 (29%)	4 (20%)	9 (32%)
Resident's understanding of instructions				
Poor	13 (17%)	5 (18%)	3 (15%)	5 (18%)
Fair	33 (42%)	9 (32%)	11 (55%)	12 (43%)
Good	32 (41%)	14 (50%)	6 (30%)	11 (39%)
Resident's understanding of the questions				
Poor	11 (15%)	3 (11%)	4 (22%)	4 (15%)
Fair	32 (43%)	10 (36%)	8 (44%)	13 (48%)
Good	32 (43%)	15 (54%)	6 (33%)	10 (37%)
Resident's understanding of the response options				
Poor	6 (8%)	2 (7%)	2 (11%)	2 (8%)
Fair	34 (47%)	10 (36%)	10 (56%)	13 (52%)
Good	33 (45%)	16 (57%)	6 (33%)	10 (40%)

ASCOT The Adult Social Care Outcomes Toolkit, *EQ-HWB* EQ Health and Wellbeing Instrument, *QOL-ACC* Quality of Life-Aged Care Consumers

> "I also preferred to do it in the morning because I found they were more engaged in the morning than in the afternoon. I found timing was everything when asking these questions." [S2]

When staff had to do the proxy assessment but felt that they did not know the resident well, they often looked at care plan notes to form a better impression of the resident's QoL.

> "For me, to be honest, I don't know much about the residents but I went through the care plan, I went through everything and then I did it." [S4]

Challenges related to the QoL measures, where some residents had difficulties understanding the questions, highlighted the importance of rephrasing the questions in a language that was more accessible to the residents.

> "Sometimes I have to re-modify the questions. Sometimes they don't like to be like a yes or no question answer so we have to make it up the way we can." [S6]

3.1.7 Biases

A few aged care staff members also spoke about potential biases involved in the QoL assessment, questioning the integrity and validity of the results. Staff spoke about interviewer bias and the possibility that residents did not answer truthfully because of the staff's role in conducting the interview.

> "Sometimes they would rate themselves better than me. But I think they were changing their answer because that's what they think you want to hear." [S2]

Aged care staff also perceived that especially for questions related to feelings and emotions, residents would be more open to speak about it with their relatives than the staff.

> "I think maybe for emotional, if it was maybe their families or close friends that they might be a bit more truthful because it's not so much a stranger, it's someone they're closer to and they're willing to admit more. I found sometimes, my residents will tell me, "I'm fine. I'm fine" and then they get on the phone to their families and go, "I'm not fine". [S2]

Two staff members also raised further considerations around the gender of the person interviewing the resident.

> "Some residents have a gender preference too, due to some of their personal or past histories, or some of them do prefer male or female participants only." [S6]

The interviews further revealed the potential for shortcuts when completing the QoL assessments, driven by time constraints and lacking capacity.

> "I did see a few staff members trying to cheat it and just fill it in themselves. They're busy. They have a full day worth of work and then to add something like a long survey in, it is hard to sit there and do it with 10 residents when you're the only one in there, you're showering everybody." [S3]

4 Discussion

This is the first study to explore the feasibility of routinely collecting QoL data from residents directly, alongside proxy-reported data from staff and relatives. Our study demonstrated that despite some barriers, it is feasible to collect routine QoL data in residential aged care, as evidenced by the high completion rates (either self-reported or proxy reported), low level of missing data, good level of residents' engagement and understanding of the QoL questions, and minimum difficulty experienced by staff and relatives in providing proxy reports. However, our qualitative findings have also shown that despite a number of perceived benefits associated with the QoL data collection process, there are some barriers that need to be addressed. Conflicting priorities and time constraints were mentioned most commonly, consistent with the quantitative data showing that 12% of staff reported the QoL assessment did not fit within their work schedule. Further challenges arose when residents were unable to communicate or were too unwell to self-report their QoL. This is reflected in the quantitative findings, where some residents reported problems with understanding the questions and instructions, requiring additional support. Qualitative data further indicated that staff found it more difficult to complete the QoL measure when they did not know the resident well enough, an issue particularly relevant given that most staff reported knowing the resident only "somewhat". Finally, several issues also arose related to the QoL measure, suggesting areas for future refinement.

Our qualitative findings align with a previous study that explored care home staff perceptions of implementing a QoL instrument into routine care practice [29]. Similar to our findings, there was a strong theme around the perceived gains of collecting QoL data, with a perception that it could provide positive outcomes for both care staff (i.e. improving staff's knowledge of the residents) and residents (i.e. improving residents' QoL). However, the interviews also revealed a number of factors that could enhance or impede its adoption, such as time constraints and fitting the QoL assessment into current practice, staff confidence, challenges related to residents who are unable to communicate and uncertainties about the process [29].

It is important to note that the process implemented in our study differs from the current QI Program guidelines in Australia in a number of ways. First, residents' QoL was collected by aged care staff via an interview. Although current guidelines recommend self-completion, a previous study by our team found that residents had comprehension issues with QoL measures [30], suggesting some assistance may be required. Proxy completion is currently only recommended by the QI Program for residents who are unable to answer on their own (because of moderate of severe cognitive impairment). Despite the challenges in collecting QoL data from residents with cognitive impairment or dementia, staff suggested strategies for success, indicating it may be possible with additional resources. The QI Program currently suggests that relatives or someone who knows the person well should complete the proxy assessment for residents if they are unable to self-report. Although aged care staff suggested that relatives could complete the QoL measure for residents, our study highlights the difficulty in reaching many relatives and their infrequent visits, which affects their ability to complete the measures confidently.

4.1 Implications

Our study found that collecting QoL data helped staff better understand residents and encouraged a shift toward person-centred care. Nevertheless, to achieve improvements in the quality of care at the organisation and system level, there is a need for future guidance in terms of how to utilise QoL data to drive improvements in care. While the QI Program in Australia focuses on the reporting of the data to the government, further developments are needed in this area. First, QoL data should be reported at the resident level to support ongoing monitoring and personalised care. Second, there is a need for well-defined action points in terms of how to effectively address and respond to residents' QoL data, thereby establishing a consistent approach. Third, as QoL is a subjective construct that should be, ideally, elicited via a self-report, further resources and training are necessary for aged care facilities to enable self-reporting where possible. Previous research has explored the cascading inclusive methodology, where tailored supports enable home care users with cognitive and physical impairments in the assessment of their care-related QoL [31]. Some measures, such as the ASCOT have an 'easy read' version available, which was adapted for use with older people with cognitive impairment [32], which can facilitate greater self-reporting of QoL. Fourth, further guidelines and processes need to be implemented to avoid biases associated with an interviewer-led QoL data collection as well as proxy completion via relatives or staff to ensure the rigour and quality of the data, which are aimed to improve quality of care and inform policy and regulation. Finally, the current QI Program lacks practical guidance on data collection, leading to inconsistent processes across facilities, which require evaluation and improvement. Future guidance could include clearer protocols on when and how QoL assessments should be conducted, along with dedicated staff training to ensure consistent understanding and administration. Establishing a designated staff role, such as a "QoL Champion", may help coordinate data collection, promote staff engagement and address time constraints identified in this study. For the QI Program, these insights suggest that successful implementation of QoL measures will require sufficient resourcing, clear accountability structures, and the integration of a QoL assessment into existing care and reporting workflows.

4.2 Limitations

One limitation of our study is the selection of aged care facilities based on convenience rather than purposive sampling. While both facilities were interested, implementation required ongoing staff and management engagement, likely similar in other facilities. Both belonged to the same not-for-profit organisation, making applicability to private or government facilities unclear. Our study also offered incentives, which may have influenced completion rates and the feasibility results. The need for participant consent limited real-world feasibility testing. However, data from the QI program in the fourth quarter of 2024 indicate that 67.4% of residents provided consent for their QoL assessment. Of these, 28% were able to self-report, 55% completed assessments with interviewer facilitation and 17% were assessed via proxy [33]. We could not assess QoL data collection among residents with lower interest or complex health needs, as facility staff determined participation eligibility based on a perceived capacity to consent. This approach may have inadvertently excluded residents with more severe cognitive impairment, a group that represents a substantial proportion of the aged care population, and could therefore limit the generalisability of our findings. While PoAs were approached for some residents with complex needs, language barriers prevented some PoAs from participating, which may have further constrained the representativeness of the sample. Limited funds restricted interpreter use. Another potential limitation is social desirability bias in residents' self-reports, as interviews were conducted by facility staff. This may have led some residents to provide more positive responses, consciously or unconsciously, owing to the presence of staff or perceptions of how their answers might be received. We were also unable to explore the feasibility of QoL data collection in terms of completion time. Despite the instructions provided to staff to time and record the administration of each measure, we noticed during the data analysis that some staff recorded the time it took to administer two measures (i.e. the EQ-5D-5L in addition to a second measure) or for the entire data collection process. We were unable to obtain QoL assessments at multiple timepoints because of resource constraints and project delays related to coronavirus disease 2019 restrictions that prevented entry into facilities, changes to the facility management and staff, and the longer than expected consent process, limiting our ability to examine barriers and facilitators of repeated data collection. Finally, although our data were collected through a dedicated study rather than existing administrative systems, the methods closely reflect how routine PROM collection could be implemented in residential aged care, providing insights into feasibility, acceptability and potential barriers.

5 Conclusions

This study provided important findings in terms of the feasibility of routinely measuring QoL in residential aged care, demonstrating that it is feasible to routinely collect QoL data in residential aged care. However, existing barriers, such as time constraints, challenges in obtaining self-reports from residents, biases associated with proxy reporting and concerns regarding the validity of the QoL measure itself, create significant limitations in accurately assessing residents' QoL and implementing consistent evaluation practices. Further research is needed to address some of the barriers identified, optimise the efficiency of the process and maximise the use of data to guide quality improvement strategies.

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Declarations

Conflict of Interest Lidia Engel, Nancy Devlin, Brendan Mulhern, Tessa Peasgood and Rosalie Viney are members of the EuroQol group that developed the EQ-5D-5L and EQ-HWB discussed in the study. Briony Dow, Andrew Gilbert and Frances Batchelor have no conflicts of interest that are directly relevant to the content of this article.

Ethical Approval This study was approved by the Monash University Human Research Ethics Committee (Project ID: 32170) and all participants provided a written consent prior to the interviews.

Consent to Participate Not applicable.

Consent for Publication Not applicable.

Availability of Data and Material The data generated in the current study are not publicly available but are available from the corresponding author on reasonable request.

Code Availability Not applicable.

Author Contributions All authors contributed to the study conception and design. Material preparation and data collection were performed by LE. Data analysis was performed by LE with interpretation provided by all authors. The first draft of the manuscript was written by LE and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Authors and Affiliations

Lidia Engel[1,2] · Nancy Devlin[3] · Briony Dow[2,3,4] · Andrew Gilbert[2,5] · Brendan Mulhern[6] · Tessa Peasgood[3,7] · Rosalie Viney[6] · Frances Batchelor[2,3]

✉ Lidia Engel
lidia.engel@monash.edu

[1] Health Economics Group, School of Public Health and Preventive Medicine, Monash University, 553 St Kilda Road, Melbourne, VIC 3004, Australia

[2] National Ageing Research Institute, Parkville, VIC, Australia

[3] Melbourne School of Population and Global Health, University of Melbourne, Parkville, VIC, Australia

[4] School of Nursing and Midwifery, Deakin University, Burwood, VIC, Australia

[5] Department of Social Inquiry, La Trobe University, Bundoora, VIC, Australia

[6] The Centre for Health Economics Research and Evaluation, University of Technology Sydney, Sydney, NSW, Australia

[7] School of Medicine and Population Health, University of Sheffield, Sheffield, UK