



# Appropriateness of the EQ-HWB for Use in Residential Aged Care: A Proxy Perspective

Lidia Engel<sup>1,2</sup> · Cate Bailey<sup>3</sup> · Ekaterina Bogatyreva<sup>4</sup> · Frances Batchelor<sup>2,3,5</sup> · Nancy Devlin<sup>3</sup> · Briony Dow<sup>2,5,6</sup> · Andrew S. Gilbert<sup>2,7</sup> · Brendan Mulhern<sup>8</sup> · Rosalie Viney<sup>8</sup> · Tessa Peasgood<sup>3,9</sup>

Accepted: 12 August 2024  
© The Author(s) 2024

## Abstract

**Background and Objective** The EQ Health and Wellbeing (EQ-HWB) is a new generic quality-of-life measure for use in evaluating interventions in health, public health and social care. This study aimed to explore proxies' views regarding the appropriateness of the EQ-HWB for measuring residents' quality of life living in residential aged care facilities.

**Methods** Qualitative think-aloud and semi-structured interviews were conducted with family members and aged care staff across three facilities in Melbourne, Australia. Proxies completed the 25-item EQ-HWB proxy version 2 (i.e. proxy-person perspective) whilst talking through the reasons for choosing their response. All interviews were audio-recorded and transcribed verbatim. A thematic analysis was used for data analysis.

**Results** The sample included 29 proxies; nine family members and 20 aged care staff. The first theme summarised proxies' ability to proxy report residents' health and well-being using the EQ-HWB, which highlighted challenges with adherence to the proxy perspective, proxies' limited knowledge about residents, disagreement with residents' self-evaluation and use of heuristics. The second theme reflected feedback on the suitability of the EQ-HWB for use in residential aged care. Although proxies perceived that the EQ-HWB covered important domains, there were concerns about ambiguity, inappropriate examples, double-barrelled items and perceived repetition. Suggestions were made to improve the response options, comprehensiveness, recall period, layout and instructions of the questionnaire.

**Conclusions** While the EQ-HWB captures domains relevant to residential aged care, modifications to item wording and examples are necessary to improve its appropriateness. Use of the proxy-person perspective revealed some challenges that require further consideration.

---

✉ Lidia Engel  
Lidia.engel@monash.edu

<sup>1</sup> Monash University Health Economics Group, School of Public Health and Preventive Medicine, Monash University, 553 St Kilda Road, Melbourne, VIC 3004, Australia

<sup>2</sup> National Ageing Research Institute, Parkville, VIC, Australia

<sup>3</sup> Melbourne Health Economics, University of Melbourne, Parkville, VIC, Australia

<sup>4</sup> School of Health and Social Development, Deakin University, Burwood, VIC, Australia

<sup>5</sup> Medicine, Dentistry and Health Sciences, University of Melbourne, Parkville, Australia

<sup>6</sup> School of Nursing and Midwifery, Deakin University, Burwood, VIC, Australia

<sup>7</sup> Department of Social Inquiry, La Trobe University, Bundoora, VIC, Australia

<sup>8</sup> The Centre for Health Economics Research and Evaluation, University of Technology Sydney, Sydney, NSW, Australia

<sup>9</sup> School of Medicine and Population Health, University of Sheffield, Sheffield, UK

### Key Points for Decision Makers

The EQ Health and Wellbeing (EQ-HWB) is a new generic quality-of-life measure for use in evaluating interventions in health, public health and social care but its performance in residential aged care is unknown.

Think-aloud interviews, capturing the views of family members and aged care staff proxies, indicated that some modification to item wording and examples may be required to improve appropriateness and applicability of the EQ-HWB to the aged care setting.

While self-report should be the default position in obtaining quality-of-life data in residential aged care facilities, further considerations are also required when proxy report is sought, related to the adherence of the proxy perspective, choice of proxy type and central tendency bias.

## 1 Introduction

The EQ-HWB (EQ Health and Wellbeing) is a new generic measure that captures a broad range of health and well-being outcomes for economic evaluations of interventions in health, public health and social care [1]. It was developed to measure health, social care and carer-related quality of life (QoL), capturing both the health and well-being impacts of disability, health states and treatments/services. The content of the EQ-HWB was informed by a literature review of qualitative studies from which items were initially generated [2]. These items were supplemented by input from stakeholder groups, and then refined [3]. Candidate items were then examined qualitatively and quantitatively for face validity and psychometric performance across six countries (Argentina, Australia, China, Germany, UK, USA) [3, 4]. There are currently two experimental versions of the EQ-HWB available; a longer profile measure comprising 25 items and a short version of the measure, the EQ-HWB-S, which has nine items [1]. A pilot value set has been developed for the EQ-HWB-S in the UK to facilitate the generation of quality-adjusted life-years for use in economic evaluations [5]. The broad dimensions captured by the EQ-HWB include: (1) feelings and emotions; (2) cognition; (3) self-identity; (4) autonomy; (5) relationships; (6) physical sensation; and (7) activity [2]. The recall period of the EQ-HWB refers to the ‘last 7 days’.

Given that the EQ-HWB is a relatively new measure, further evidence is needed with respect to its performance across different settings. Social care is one setting for which the EQ-HWB was specifically developed that requires further exploration. In this context, social care services refer to services that aim to support a person with long-term conditions, disabilities or other needs to achieve daily activities, such as personal care, meal assistance, keeping active or socialising [6]. Social care services are provided to people living in the community or residential care homes, such as aged care facilities. Although economic evaluations within residential aged care are rarely conducted [7], previous evidence indicated that the EQ-5D measure has been the most commonly used instrument to derive quality-adjusted life-years in this setting [8, 9]. The EQ-5D focuses on health-related aspects of QoL [10]. However, previous research has highlighted that older adults and those living with dementia value broader aspects of their QoL including safety, autonomy and relationships [11, 12]. Although these broader dimensions are captured by the EQ-HWB, whether the EQ-HWB is a suitable and appropriate measure for use in residential aged care needs to be further tested.

It is estimated that over half of people living in residential aged care have dementia [13]. While there is evidence that people with mild-to-moderate dementia can reliably rate their own QoL [14], as the disease progresses, there is typically a decline in memory, attention, judgment, insight and communication [15], which emphasises the need for proxy ratings. Proxies can be family members or friends who know the person as well as aged care staff or health professionals who provide care. A recent study examined the face validity of four QoL measures in residential aged care, including the EQ-HWB, from the perspective of 24 residents [16]. The study found that the EQ-HWB resulted in fewer response issues (related to comprehension, retrieval, judgement and response mapping) compared with the EQ-5D-5L, suggesting better face validity. However, it remains unknown whether proxies hold similar views as residents towards the EQ-HWB and how feasible it is for proxies to rate residents’ QoL using the EQ-HWB. Therefore, the aim of this study was to fill this critical evidence gap by exploring proxies’ views towards the appropriateness of the EQ-HWB proxy 2 version in measuring residents’ QoL, which is intended to be used for patients/residents who are unable to self-report.

## 2 Methods

### 2.1 Sample and Recruitment

Proxies (family members or aged care staff) were recruited using convenience sampling from three not-for-profit

residential aged care facilities in Melbourne, VIC, Australia. The recruitment took place between August and November 2022 and included posting of flyers in the aged care facilities, sending invitation e-mails to family members and staff (e-mails sent by facility managers), and holding information sessions during family and staff meetings at the respective facility. The recruitment of proxies did not involve residents directly; any aged care staff or family proxies who were interested in the study, above the age of 18 years, and could read and speak English could contact the research team to discuss the study further and to arrange the interview. Family proxies could be either the residents' relatives or non-relative acquaintances and the residents may or may not have had the capacity to self report. Aged care staff could participate in the interview regardless of their position and length of employment. All participants provided written consent prior to the interviews and received a gift voucher upon the completion of the interview. This study was approved by the Monash University Human Research Ethics Committee (Project ID: 32170).

## 2.2 Procedure

Interviews were completed either face-to-face in the aged care facilities or another place preferred by participants, with one interview taking place via Zoom. All interviews were conducted by one of the two interviewers (LE or EK). After participants provided written consent and completed a brief demographic questionnaire, participants were presented with the 25-item EQ-HWB English version for Australia, which has identical wording to the original version developed for the UK. The proxy version 2 was used, which is intended for the proxy to rate *how the proxy thinks the person would describe their own health and well-being if they could tell us*. This proxy-person perspective was chosen over the proxy-proxy perspective, which refers to *how the proxy would describe the person's health and well-being based on their own impression*, based on previous evidence showing a greater agreement with self-reported QoL when using the proxy-person perspective rather than the proxy-proxy perspective [17–19]. Aged care staff were instructed to think about a specific resident of their choice when completing the EQ-HWB and keep that person in mind throughout the entire interview.

Cognitive think-aloud interviews were conducted, whereby participants were instructed to speak out loud to articulate their thoughts about the EQ-HWB questionnaire while completing it [20]. Prompts were used to encourage participants to continue thinking aloud when they became silent. The interview then included semi-structured questions, following the topic guide developed for this study (see Electronic Supplementary Material [ESM]). The topic guide examined participants' understanding of the

EQ-HWB questionnaire, including clarity of certain words, response options and instruction, such as reference to the recall period. Participants were also asked to comment on the appropriateness of the EQ-HWB for use in residential aged care, whether they would be able to proxy complete the EQ-HWB on the resident's behalf, and their self-perceived adherence to the proxy-person perspective. The interview ended with some questions about participants' views towards the routine collection of QoL data in residential aged care facilities (this information was not used for the current analysis and will be discussed in a separate paper). All sessions were audiotaped and transcribed verbatim. Interviews lasted between 8 and 60 minutes (average: 26 minutes). One interview was conducted with two family members present at the same time. A previous review indicated that data saturation (i.e. the point at which gathering new data reveals no new themes) in qualitative interviews is reached after 9–17 interviews with homogenous study populations [21]. Therefore, we estimated a sample of around 30 participants to capture the views of both carers and aged care staff. Data saturation was determined through discussions between the two interviewers after each interview, evaluating the extent of repetition and new information gathered.

## 2.3 Analysis

Transcripts were imported into NVivo and analysed using a thematic analysis based on a combination of a deductive approach, guided by the structured interview questions, and an inductive approach that allowed the identification of new themes. First, transcripts were coded line by line, then codes were grouped into themes and sub-themes. The ESM provides the list of codes that informed the themes. Themes were refined by combining similar themes or separating distinctive themes, followed by deriving definitions and descriptions of each theme and sub-theme [22]. The first two transcripts were analysed by three people (LE, CB and TP) to develop an initial analysis framework of the themes and sub-themes. The coding framework was then applied to the remaining transcripts by two people (LE and CB). The coding framework was discussed regularly and refined where necessary; disagreements were resolved via discussions with a third person (TP).

## 3 Results

The sample included 29 proxies; nine family members (five daughters/sons, two sisters, two partners) and 20 aged care staff (nine personal care workers, five lifestyle coordinators, four nurses, one manager, one customer service

officer). Further characteristics of study participants are provided in Table 1. Qualitative data were summarised into two overarching themes and 14 sub-themes, which are outlined in Table 2 and discussed below. Quotes from family proxies are indicated by the letter F; the letter S is used when a reference is made to staff proxies.

### 3.1 Theme 1: Providing Accurate Proxy Report Using the EQ-HWB

#### 3.1.1 Adhering to the Proxy Perspective

While most proxies adhered to the proxy-person perspective, some proxies deviated from that perspective (consciously or unconsciously) or were not sure which perspective to adopt: “Well, I’m thinking for the first three [questions] from her perspective. Or maybe I am thinking from my perspective, let me think about that” [F1]. It was evident that proxies perceived a conflict between adhering to the perspective and ensuring that their answers represented the actual state of the resident, especially if the resident had severe cognitive impairment or dementia. When a family member was asked which perspective is more accurate, the response was: “I think from mine because the dementia is so advanced” [F6]. Prompts from the interviewer were helpful in reminding proxies of the perspective, with one proxy admitting: “If you weren’t there, then I’d probably revert to answering from my perspective” [S1].

#### 3.1.2 Acknowledging Disagreement with a Resident’s Own Assessment

Despite adhering to the proxy-person perspective, proxies often acknowledged disagreement with resident’s own assessment: “I think she’d say she has slight difficulty there, but that would be another one where I would say unable” [F1]. Different reasons were identified for the disagreement. Often a dementia diagnosis or the inability to communicate were mentioned by proxies: “Getting around inside and out, well not by himself ... He’s unable to do it by himself .... He gets wheeled around. But because of the nature of his Alzheimer’s, he might even say, “I can walk” [F7]. A family proxy also struggled to answer the pain-related questions, as there was a conflict between what the proxy witnessed in terms of the resident’s pain and the resident’s verbalisation or perception of pain: “He’s had an ulcer and a pressure sore on his heel, which they’re dealing with. But when I ask him, he says it’s not hurting” [F7]. Some proxies also stated that the resident would not be truthful, either because they do not want to complain (“That generation would have said no difficulty all the time [...] because they’re too polite and don’t complain.” [F2]) or because they do not want to cause work for staff: “You can physically see on her face she is in pain. But if you were to go up and ask her, she will probably say, “No, no. It’s only mild” [...] Just because she doesn’t want to cause anybody any extra work or any extra frustrations” [S3]. Responding more negatively to the EQ-HWB was also described as a way to initiate a change

**Table 1** Characteristics of study participants, *N* (%)

Family member ( <i>N</i> = 9)		Aged care staff ( <i>N</i> = 20)	
Gender		Gender	
Female	6 (67%)	Female	17 (85%)
Male	3 (33%)	Male	3 (15%)
Mean age (SD)	63 (17)	Mean age (SD)	44 (12)
English first language	9 (100%)	English first language	10 (50%)
Relationship to resident		Job description	
Daughter/son	5 (56%)	Personal care worker	8 (40%)
Partner	2 (22%)	Lifestyle coordinator	6 (30%)
Sister	2 (22%)	Nurse	4 (20%)
Frequency of visits		Manager	1 (5%)
At least once a week	5 (56%)	Other	1 (5%)
Daily	2 (22%)	Nature of position	
Most days of the week	1 (11%)	Part-time	12 (60%)
A handful times	1 (11%)	Permanent/full-time	7 (35%)
Frequency of phone calls		Casual	1 (5%)
Never	4 (44%)	Employment duration	
Daily	2 (22%)	2 years and above	12 (60%)
Most days of the week	2 (22%)	1–2 years	5 (25%)
At least once or twice a week	1 (11%)	Between 1 and 6 months	3 (15%)

*SD* standard deviation

**Table 2** Overview of themes and sub-themes

Theme	Sub-theme
Providing accurate proxy report using the EQ-HWB	Adherence to the proxy perspective Acknowledging disagreement with a resident's own assessment Feasibility/ability to proxy report Choice of proxy type (family vs staff) Response process and strategies (finding evidence)
Appropriateness of the EQ-HWB for use in residential aged care	Item wording and comprehension (ambiguity) Double-barrelled items Appropriateness of examples Repetition and (ir)relevance of items Item dependency on care provision Comprehensiveness/missing items Appropriateness of response options Recall period Layout and instructions

*EQ-HWB* EQ Health and Wellbeing

in care: “*But if you get her on a bad day, she would just tick all the unable, all the most of the times, all of the ... Just so she could see change. Initiate that change*” [F4&5]. Being in denial was another reason for disagreement, where a proxy stated that: “... *they're probably not going to say 'most of the time' because they don't want to feel completely helpless*” [S6]. Table 3 lists the items for which a disagreement was noted along with items that were more difficult to answer for proxies (discussed below).

### 3.1.3 Feasibility/Ability to Proxy Report

Some questions were easier for proxies to answer than others. The most challenging question for family proxies was question 6 (problems with sleep), given that they would normally visit the resident during the day and do not witness the resident sleeping at night: “*No idea. I'm not here when he's trying to sleep. He sleeps through the daytime sometimes when I am here*” [F7]. Another family member struggled with question 9 (i.e. felt that people did not support them): “*I really don't know the answer to that one*” [F7]. The coping question (question 18) was difficult to answer for one family member: “*I don't know how aware he is that he can't do it anymore. I can't judge that*” [F7]. While staff proxies said that they could refer to the medication records to answer questions related to pain, family proxies struggled with pain-related questions: “*But if she's reporting no pain, maybe it's a low threshold or it's been covered by her existing pain management or there's pain and then she forgets the pain. So, it could be one of many things*” [F1]. Generally, proxies perceived that questions related to physical health and observable domains were easier to answer than questions related to mental health: “*For physically, I can see easy.*

*Psychologically, it is really hard to tell what is going on their head*” [S9]. One proxy raised that assessing a person's emotional state was especially difficult for male residents: “*Feeling lonely and that sort of stuff. You would have to judge it ... Because that's an emotion that you don't see that often, especially the males don't show that side*” [S2].

### 3.1.4 Choice of Proxy Type (Family vs Staff)

Proxies highlighted that the accuracy of proxy assessment would also depend on who the proxy is. Family proxies felt that they would rely on discussions with staff to be able to complete the EQ-HWB questionnaire: “*The staff would know that better than me in some ways, especially the night staff with the sleep*” [F2]. One family proxy highlighted the risk of bias associated with family proxy reports: “*I definitely don't think it should be relatives [due to] risk of bias. So, the relative imposing their own views or wording the question improperly, you get too much variability*” [F1]. Disagreement even amongst family members was also acknowledged: “*Even my husband and I have differing opinions because he thinks she's happy so she's got good quality-of-life. Whereas I look at it as no, it's not good quality-of-life*” [F6]. In line with the views of family proxies, staff proxies also felt that they should act as proxies rather than relatives who do not visit the resident frequently enough: “*If the family comes every day, they will answer the same. But if they come once in a week or once in a fortnight, I think they would not know ... They will ask me, 'How is mum's behaviour?'*” [S4]. In addition to daily visits, it was also acknowledged that residents should be observed at different times throughout the day: “*[Family members] know only the basic outline, unless that family member is coming every day and they*



**Table 3** Items for which a disagreement was acknowledged with a resident's own assessment and items that were difficult for proxies to answer

Sub-theme	Relevant items
Items for which a disagreement was acknowledged with a resident's own assessment	Q3 (getting around); Q4 (activities); Q5 (personal care); Q8 (lonely); Q9 (support); Q10 (remembering); Q11 (concentrating); Q14 (frustrated); Q16 (nothing to look forward to); Q18 (cope); Q22/23 (pain)
Items that were more difficult for proxies to answer	Q6 (sleep); Q7 (exhausted); Q8 (lonely); Q9 (support); Q15 (sad and depressed); Q16 (nothing to look forward to); Q17 (control); Q18 (cope); Q19 (accepted by others); Q20 (felt good about themselves); Q21 (could do the things they wanted); Q22/23 (pain); Q24/25 (discomfort)

have come at different times" [S17]. However, even staff proxies recognised that not all staff members would know the residents well: "... some staff they do not work every day and some they're here for a couple of days and they don't know exactly what's going on with the residents" [S14]. The gender of the staff member also seemed to play a role, where one male staff proxy stated that: "... if he's talking to me, he might say mild pain. [If] he's talking to a female, he'll say moderate pain.... That's a male thing, I reckon" [S2].

### 3.1.5 Response Process (Finding Evidence)

Proxies provided a number of comments, outlining their response process when selecting an appropriate response option. Often, they tried to recall what the resident had told the proxy ("So mum has expressed loneliness to me in the past" [F1]) or referred to certain events that would provide evidence for their selected response option: "The loneliness is an issue. There are some days where my mother, she might ring three or four times a day and just wants to hear my voice" [F13]. Proxies stated that although some residents would not verbalise their health and well-being, proxies are able to read the resident's body language based on long-lasting relationships. This applied to both family proxies ("... if you're anxious, you can see it in their face or their body language" [F2]) and staff proxies ("... but also I could physically see the expression on his face" [S13]). When proxies struggled to find an appropriate response option, a common approach observed was to select the second or third response option: "I'm just going to go moderate, because I'm really not sure" [S12].

## 3.2 Theme 2: Appropriateness of the EQ-HWB for Use in Residential Aged Care

Theme 2 summarises participant commentary on the appropriateness of the EQ-HWB for use in residential aged care. Positive and negative quotes by participants for theme 2 are provided in the ESM and discussed in the following.

### 3.2.1 Item Wording and Comprehension (Ambiguity)

Providing an accurate proxy report strongly depends on respondents' understanding of the item, including understanding the meaning of specific words. However, some participants noted ambiguity or interpreted the items differently than intended by the instrument's developers. For example, question 5 (washing, using the toilet) was linked to doing laundry rather than personal care and Q11 (concentrating) was narrowly interpreted, related to communicating and being understood: "So, communicating to others and being understood by others. For me that comes into concentrating or thinking clearly." [F1]. There was also uncertainty whether Q2 (difficulty hearing) would include a lack of understanding because of language barriers and to what extent Q7 (felt exhausted) was different to feeling tired. With regard to sleep (Q6), proxies were reflecting not only about the quality of sleep at night but also about the length of time residents spend in their beds and taking naps during the day: "My mother is somewhat frustrated about the length of time that she is in bed, but not necessarily sleeping." [F3] Different interpretations were noted for Q3 (getting around inside and outside), where some equated outside with outside the facility, or outside the resident's room: "I consider outside being outside the room. So, if she wants access to the activity lounge or she wants to access the other floor." [S17]. Similarly, some proxies were unclear about whom to consider when a reference was made to 'people' in Q9 (people did not support) and 'others' in Q19 (accepted by others): "People can be the clinical staff, can be management, can be her family members too. Even people can be her co-residents too." [S17]. While questions 1–3 (seeing, hearing, getting around) refer to health aids (e.g. glasses, hearing aids, mobility aids), which are highly relevant to older adults, some proxies struggled with answering the question if no aids were used: "What I'm saying is he doesn't wear glasses, he doesn't wear hearing aids, so it's not applicable." [S13]. As for Q22 (physical pain) and Q24 (physical discomfort), some proxies were unclear whether migraines would fall

under discomfort or pain, how to include emotional pain, and one queried whether ‘feeling sick’ was referring to ‘feeling nauseous’: *“To me, felt sick is a culturally specific term if English is more your first language. If English is not your first language, felt sick doesn’t mean nausea.”* [S16]

### 3.2.2 Double-Barrelled Items

A few double-barrelled items were noted, where proxies suggested splitting the question because different parts of the question would require different responses. These included Q3 (getting around inside and outside), Q15 (felt sad or depressed) or Q5 (washing, using the toilet, getting dressed, eating or caring for their appearance): *“Using toilet, he can go by himself but dressing up, eating .... he does dress up but few of the things we still have to help him.”* [S15]. It was also noted that for Q9 (people did not support them) residents may perceive a different level of support by different people. A similar comment was made for Q19 (felt accepted by others): *“I might split that into three again. So, I’m thinking in my mind of residents, so other residents and then the staff she interacts with and then family members really ... There’s different connections and different senses of belonging with different groups.”* [F1]

### 3.2.3 Appropriateness of Examples

Five of the EQ-HWB items are supported by examples, which are displayed in brackets. While such examples were perceived as helpful by the majority of proxies, as they provided more context around the intended meaning of the item, some proxies discussed their inappropriateness for residential aged care. Examples listed in Q4 (doing day-to-day activities? [e.g. working, shopping, housework]) were perceived as particularly inappropriate, as they did not reflect the day-to-day activities commonly observed in aged care facilities: *“This is a nursing home and working, shopping and housework doesn’t apply for a nursing home.”* [F2] A family proxy suggested to replace those with activities offered in the facility, such as knitting or artwork, whereas a staff proxy equated day-to-day activities with personal care, such as showering. While examples provided for Q13 (felt unsafe? [e.g. fear of falling, physical harm, abuse]) and Q19 (felt accepted by others? [e.g. felt like they were able to be themselves and that they belonged]) were perceived as relevant and important for residential aged care, a proxy suggested to add an element around ‘having preferences understood and respected’ for Q17 (control).

### 3.2.4 Repetition and (Ir)relevance of Items

Some proxies perceived some repetition in the EQ-HWB questionnaire, such as Q12 (anxious) and Q13 (unsafe):

*“Those two are together, to be honest, 12 and 13, felt anxious and unsafe.”* [F9] Mixed views were expressed towards having separate frequency and severity items for Q22/23 (physical pain) and Q24/25 (physical discomfort), as some participants felt they were duplicative, whereas others highlighted the importance of both: *“I think keep them both because they might have the pain often and it might be severe pain.”* [S12]. Q4 (day-to-day activities) was perceived as irrelevant, as some proxies associated day-to-day activities with personal care, which was already captured by another item: *“Day-to-day activities, if that includes going to the toilet, does it? ... Oh, here it is, sorry. It’s the next question, using the toilet. So that’s my fault. Day-to-day activities needs to maybe even disappear.”* [F2]. One proxy also commented that Q7 (exhausted) is not applicable to residents in aged care facilities who would feel often tired but not exhausted: *“Exhausted. None of them feel exhausted. It would be more that they feel a bit tired. They wouldn’t feel exhausted.”* [S8]. Q14 (frustrated) and Q16 (had nothing to look forward to) were stressed as relevant for residents: *“So that looking forward is important and we are, as a family, seeking ways in which we might provide that stimulus.”* [F3].

### 3.2.5 Item Dependency on Care Provision

When assessing resident’s health and well-being, a few proxies noted that their response would not necessarily reflect residents’ functioning and ability to do things but rather the quality of the care received in the facility. For example, difficulty with day-to-day activities would be dependent on the activities offered in the facility: *“Because she needs to have her activities brought to her.”* [F2]. Similarly, a family proxy noted that residents who are reliant on staff may be discouraged from some activities: *“Could do the things they wanted to do. Sometimes she wants to get up, and she tried to get up and they’re basically discouraged from that.”* [F2]. Similarly, those dependent on glasses require staff help to put them on: *“Well, the first question, they should put her glasses on more often. Otherwise, she might be able to see better.”* [F2]. Proxies also noted that whether residents felt safe or feel accepted by others was dependent on which staff member was on duty: *“Felt unsafe, fear of falling, physical abuse, occasionally. It depends if she has a consistent staff member.”* [S1].

### 3.2.6 Comprehensiveness/Missing Items

The EQ-HWB was generally perceived as a comprehensive measure, covering important domains and encapsulating residents’ day-to-day life in a residential aged care facility: *“The questions are good. You do have a selection. I would say it covers everything.”* [S13] However, when prompted whether certain dimensions are missing, a few proxies

provided some further suggestions, including: doing purposeful activities (contributing); interaction with others; passive versus active activities; food; feeling cold or hot; happiness/contentment; feeling stimulated by activities offered; degree of dependency on others; and questions around culturally and gender-appropriate care. One proxy also commented on the fact that many items are negatively worded and more positively phrased items could be added: “*So, there’s a lot of the negative and the stressors ... But there’s only three good things in 19-21. So maybe that’s where some of the questions about social activities and other things could go.*” [F1]

### 3.2.7 Appropriateness of Response Options

Response scales of the EQ-HWB include difficulty scales, frequency scales and severity scales. While no comments were made with respect to the difficulty and severity scales, some proxies noted issues with the frequency scales, where the difference between options ‘only occasionally’ and ‘sometimes’ was not obvious: “*Only occasionally and sometimes, when you think about it, that could mean the same thing, couldn’t it?*” [F2] One proxy also expressed the need for an ‘always’ response option, which was perceived to be different to ‘most or all of the time’: “*Felt lonely, always. Where’s always?*” [F4/5].

### 3.2.8 Recall Period

The 7-day recall period was often perceived as too short, especially by family proxies who do not visit residents that often. Proposed alternatives included 2 weeks, 4 weeks (1 month) and 6 months. Often, fluctuations in health and well-being were mentioned, which are better captured by longer time periods: “*The last seven days, if you had been here three weeks ago, it would have been most of the time. She went through hell. They finally fixed it.*” [F8]. However, one staff proxy reflected on other assessments commonly done in residential aged care (e.g. pain, sleep, behaviour), which generally tend to refer to the last 7 days, aligning with the EQ-HWB’s recall period. Another proxy staff also commented that when used for self-reporting, some residents with cognitive impairment may even perceive a 7-day recall period as too long: “*If the resident is answering it for themselves, they may probably can’t remember what they did yesterday. So, this would be a day-by-day.*” [S6]

### 3.2.9 Layout and Instructions

Only a few comments were made related to the layout or instructions of the EQ-HWB. These included layout modification to the last four questions (pain severity, pain frequency, discomfort severity, discomfort frequency), enabling

a clear visual distinction between items. One family proxy also suggested to amend the instructions of the proxy-person perspective and referring to ‘*select one response based on what you know of the person’s preferences and personality and the standard of care they get*’ rather than ‘*to select the one response that you think the person would choose to describe their own health*’ [F2], acknowledging that proxy report cannot substitute self-report. Finally, while most of the EQ-HWB items are negatively worded, items 19-21 are positively worded, yet the direction of the response scale does not change, which led a few proxies in selecting the worst response option rather than the best or vice versa.

## 4 Discussion

This study, for the first time, examined the appropriateness of the EQ-HWB for use in residential aged care from the perspective of proxies. All proxies, generally, endorsed the content of the EQ-HWB for use in the residential aged care setting, with only a few additional suggestions made regarding the expansion of the instrument’s QoL coverage. However, some modification to item wording and examples may be required to improve appropriateness and applicability of the EQ-HWB. This includes some modifications to the activity domain, where considerations should be given towards: (i) separating or adding explanation for Q3 (getting around inside and outside) and Q5 (washing, using the toilet, getting dressed, eating or caring for their appearance) and (ii) replacing or adding examples for Q4 (working, shopping, housework) with day-to-day activities that are more applicable to aged care. It should be noted that the use of examples and composite items is an area for broader consideration in the measurement of QoL (i.e. beyond just the EQ-HWB) [23, 24]. Additionally, to avoid ambiguity, terms such as ‘outside’, ‘inside’, ‘people’ and ‘others’ should be defined in Q3, Q9 and Q19, although we acknowledge the difficulty in developing definitions that are universally applicable. It is also advisable to alert respondents to the change of scale or flip the response options for the positively worded items (Q19–21), as our findings have shown that some proxies missed the reverse scaling given that all other EQ-HWB items are negatively worded.

While none of the proxies mentioned that anything substantial was missing from the EQ-HWB, a few further items were suggested for consideration. However, it needs to be noted that proxies were specifically asked whether they think something was missing, which may not have come up without explicit probing. Additionally, prior to dropping or adding items to the existing questionnaire, further research is recommended examining to what extent the suggested items are captured indirectly by existing items (e.g. hobbies could be captured indirectly in items day-to-day activities or could



do the things they wanted to do). Similarly, given the mixed comments provided regarding the 7-day recall period, it is recommended to undertake further research on what the best option would be. These findings largely confirm the results from interviews conducted with 24 residents as part of this larger project [16], where some perceived the 7-day recall period as too long whereas other residents suggested ‘the last month’ as a better recall period. It is noteworthy that some proxies suggested a longer recall period that aligned with their frequency of visits rather than the appropriateness of the recall period, which underscores the importance of carefully selecting an appropriate proxy.

While our study examined the long version of the EQ-HWB, our findings are also relevant for the short version, the EQ-HWB-S, which includes nine items: mobility, daily activities, exhaustion, loneliness, cognition, anxiety, sadness/depression, control and physical pain [5]. Although some issues raised are only applicable to the long version (e.g. seeing, personal care), suggesting that the EQ-HWB-S may be better suited for use in residential aged care, it still contains items that were perceived as problematic, especially related to mobility and day-to-day activities that may require modifications to improve appropriateness and applicability.

When proxy report is sought using the EQ-HWB, our study provides important evidence in terms of proxies’ abilities to provide an accurate assessment using the EQ-HWB. Some items were more challenging for proxies than others, which were often tapping into psycho-social domains of QoL (e.g. feelings and relationships). Further, adherence to the proxy-person perspective was sometimes compromised when proxies felt that the resident’s perspective would not provide a valid representation of the resident’s state. Disagreement with resident’s own assessment was particularly mentioned for items related to cognition, activity and physical sensation, such as pain. A third perspective was recommended based on proxy’s knowledge of the person’s preferences and personality as well as the standard of care the person gets. Previous research has demonstrated that different proxy perspectives result in different scores, with the proxy-person perspective more aligning with the self-reported scores than the proxy-proxy perspective [17–19]. Despite stating the perspective in the instructions, it is likely that some proxies may deviate from the perspective, which needs to be considered when interpreting proxy-reported scores. Some proxies also needed a reminder about which perspective should be adopted, as some deviated to the proxy-proxy perspective. Given the difficulty in adhering to the proxy perspective and the fact that each proxy perspective offers distinct insights [17], some QoL instruments, such as the Adult Social Care Outcome Toolkit (ASCOT) proxy version, ask proxies to complete questions from both perspectives, from their *own opinion* and *how they think the person would answer* [25]. Further research is needed to

investigate the comparability of different proxy perspectives for the EQ-HWB, similar to previous examinations conducted for the EQ-5D measures [18, 19]. Additionally, we observed a central-tendency bias, where proxies selected the midpoint of a scale rather than choosing extreme responses when they were unsure how to answer the question. This has implications for using missing response patterns for a feasibility analysis and compromises the validity of proxy reports.

Our study has shown that the accuracy of proxy assessments also depends on who the proxy is. Previous literature has shown that proxies tend provide lower QoL scores compared with people living with dementia in care homes themselves [26, 27]. Family proxies are more likely than staff proxies to rate resident’s QoL as poor, possibly because family proxies tend to assess the resident’s QoL in relation to their past, while formal caregivers may draw comparisons with other individuals with dementia under their care [28]. Interestingly, our findings indicated that both staff and family proxies felt that the staff would provide a more accurate proxy assessment than family proxies who may not be able to visit residents as often and, as such, would rely on prior discussions with the aged care staff before filling out the EQ-HWB. Recent guidelines on proxy reporting developed by the ISOQOL task force alluded to the importance of specifying the criteria who can act as proxy and consider factors which may influence proxy raters, such as their degree of emotional involvement [29].

Considering the challenges proxies faced when reporting on residents’ health and well-being, it raises questions about the accuracy and appropriateness of relying on proxy reports. For these reasons, some agencies, such as the US Food and Drug Administration in the USA, discourage the use of proxy reports [29]. Within the context of residential aged care, the proxy report appears to be unavoidable among older adults with severe cognitive impairment or dementia who are unable to self-report their health and well-being. This becomes particularly important when determining the quality of care or evaluating interventions in this setting, where a large amount of missing data could lead to incorrect conclusions about the comparative performance of providers or interventions. However, because of the subjective nature of QoL, it is necessary to justify the use of proxy reports. A previous study estimated the cognition threshold beyond which self-reported QoL for older people with cognitive impairment and dementia is unreliable, suggesting that older residents with a Mini-Mental State Examination score  $\geq 24$  have sufficient cognitive capacity to self-complete the EQ-5D-5L [30]. Similar research is needed for the EQ-HWB.

In interpreting our study findings, a few limitations are worth noting. First, our study sample was based on a convenience sampling approach rather than purposive sampling. Although we had a broad representation from

different family and staff proxies, future research could undertake a more detailed analysis by proxy relationship, age and gender. Our study also focused on proxy report only and we were unable to contrast proxy responses to a resident's own assessments. In undertaking the interviews and doing the analysis, we aimed to uncover 'problems' with the use of the EQ-HWB measure in residential aged care, which may have provided biased views that do not balance sufficiently positively comments. As a final limitation, this study explored the EQ-HWB only, and further head-to-head comparisons are warranted between the EQ-HWB and other generic measures (e.g. EQ-5D-5L or SF-6D) as well as older adults specific measures (e.g. QOL-ACC [31], WOOP [32], ICECAP-O [33]) using both qualitative and quantitative approaches. Further, while evidence is growing of the psychometric performance of the EQ-5D proxy measures in residential aged care [34], future research is needed to examine other psychometric properties of the EQ-HWB in residential aged care, including the level of agreement between self-reported and proxy-reported scores.

## 5 Conclusions

Findings from this qualitative study involving family and staff proxies suggest that although the EQ-HWB captures domains relevant to residential aged care, there were concerns about ambiguous and double-barrelled items, use of inappropriate examples and perceived repetition. Therefore, modifications to item wording and examples are necessary to improve appropriateness and applicability of the EQ-HWB to the aged care setting. While self-report should be the default position in obtaining QoL data in residential aged care facilities, proxy report may be necessary for residents who are unwell or have cognitive impairment. Further considerations are also required when a proxy report is sought, related to the adherence of the proxy perspective, choice of proxy type and central tendency bias.

**Supplementary Information** The online version contains supplementary material available at <https://doi.org/10.1007/s40271-024-00715-5>.

## Declarations

**Funding** Open Access funding enabled and organized by CAUL and its Member Institutions. Funding for this study was obtained from the EuroQol Research Foundation (150-RA); views expressed are those of the authors and are not necessarily those of the EuroQol Research Foundation. Lidia Engel is currently supported by a National Health and Medical Research Council Investigator EL1 grant.

**Conflict of interest** Lidia Engel, Nancy Devlin, Brendan Mulhern, Tessa Peasgood and Rosalie Viney are members of the EuroQol group that developed the EQ-HWB discussed in the study. Cate Bailey,

Ekaterina Bogatyreva, Frances Batchelor, Briony Dow and Andrew S. Gilbert have no conflicts of interest that are directly relevant to the content of this article.

**Ethics approval** This study was approved by the Monash University Human Research Ethics Committee (Project ID: 32170).

**Consent to participate** Participants provided a written consent prior to the interviews.

**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 and EB. Data analysis was performed by LE and CB, with input from TP. 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.

**Open Access** This article is licensed under a Creative Commons Attribution-NonCommercial 4.0 International License, which permits any non-commercial use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by-nc/4.0/>.

## References

1. Brazier J, Peasgood T, Mukuria C, et al. The EQ Health and Wellbeing: overview of the development of a measure of health and wellbeing and key results. *Value Health*. 2022;25(4):482–91.
2. Mukuria C, Connell J, Carlton J, et al. Qualitative review on domains of quality of life important for patients, social care users, and informal carers to inform the development of the EQ-HWB. *Value Health*. 2022;25(4):492–511.
3. Carlton J, Peasgood T, Mukuria C, et al. Generation, selection, and face validation of items for a new generic measure of quality of life: the EQ-HWB. *Value Health*. 2022;25(4):512–24.
4. Peasgood T, Mukuria C, Brazier J, et al. Developing a new generic health and wellbeing measure: psychometric survey results for the EQ-HWB. *Value Health*. 2022;25(4):525–33.
5. Mukuria C, Peasgood T, McDool E, et al. Valuing the EQ Health and Wellbeing Short (EQ-HWB-S) using time trade-off and a discrete choice experiment: a feasibility study. *Value Health*. 2023;26(7):1073–84.
6. Forder J, Malley J, Rand S, et al. Identifying the impact of adult social care: interpreting outcome data for use in the adult social care outcomes framework. 2015. <https://www.pssru.ac.uk/pub/5158.pdf>. Accessed 30 Aug 2024.

7. Easton T, Milte R, Crotty M, Ratcliffe J. Where's the evidence? A systematic review of economic analyses of residential aged care infrastructure. *BMC Health Serv Res.* 2017;17(1):226.
8. Bulamu NB, Kaambwa B, Ratcliffe J. A systematic review of instruments for measuring outcomes in economic evaluation within aged care. *Health Qual Life Outcomes.* 2015;13:179.
9. Cleland J, Hutchinson C, Khadka J, Milte R, Ratcliffe J. A review of the development and application of generic preference-based measures with the older population. *Appl Health Econ Health Policy.* 2019;17(6):781–801.
10. Devlin NJ, Brooks R. EQ-5D and the EuroQol Group: past, present and future. *Appl Health Econ Health Policy.* 2017;15(2):127–37.
11. Engel L, Bucholz J, Mihalopoulos C, et al. A qualitative exploration of the content and face validity of preference-based measures within the context of dementia. *Health Qual Life Outcomes.* 2020;18(1):178.
12. Milte CM, Walker R, Luszcz MA, et al. How important is health status in defining quality of life for older people? An exploratory study of the views of older South Australians. *Appl Health Econ Health Policy.* 2014;12(1):73–84.
13. Australian Institute of Health and Welfare. *Dementia in Australia.* 2023. <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/aged-care-and-support-services-used-by-people-with-residential-aged-care>. Accessed 20 Nov 2023.
14. Bosboom PR, Alfonso H, Eaton J, Almeida OP. Quality of life in Alzheimer's disease: different factors associated with complementary ratings by patients and family carers. *Int Psychogeriatr.* 2012;24(5):708–21.
15. Scholzel-Dorenbos CJ, Rikkert MG, Adang EM, Krabbe PF. The challenges of accurate measurement of health-related quality of life in frail elderly people and dementia. *J Am Geriatr Soc.* 2009;57(12):2356–7.
16. Engel L, Kosowicz L, Bogatyreva E, et al. Face validity of four preference-weighted quality-of-life measures in residential aged care: a think-aloud study. *Patient.* 2023;16(6):655–66.
17. Engel L, Sokolova V, Bogatyreva E, Leuenberger A. Understanding the influence of different proxy perspectives in explaining the difference between self-rated and proxy-rated quality of life in people living with dementia: a systematic literature review and meta-analysis. *Qual Life Res.* 2024;33:2055–66.
18. Hutchinson C, Whitehurst DGT, Crocker M, et al. Measuring quality of life in residential aged care using the EQ-5D-5L: a cross-sectional study on the impact of cognition level and proxy perspective on interrater agreement. *Health Soc Care Community.* 2023;2023:1–11.
19. Leontjevas R, Teerenstra S, Smalbrugge M, Koopmans RT, Gerritsen DL. Quality of life assessments in nursing homes revealed a tendency of proxies to moderate patients' self-reports. *J Clin Epidemiol.* 2016;80:123–33.
20. Willis GB, Artino AR Jr. What do our respondents think we're asking? Using cognitive interviewing to improve medical education surveys. *J Grad Med Educ.* 2013;5(3):353–6.
21. Hennink M, Kaiser BN. Sample sizes for saturation in qualitative research: a systematic review of empirical tests. *Soc Sci Med.* 2022;292: 114523.
22. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3(2):77–101.
23. Belay YB, Mihalopoulos C, Lee YY, Mulhern B, Engel L. Examining the psychometric properties of a split version of the EQ-5D-5L anxiety/depression dimension in patients with anxiety and/or depression. *Qual Life Res.* 2023;32(7):2025–36.
24. Engel L, Whitehurst DGT, Haagsma J, Janssen MF, Mulhern B. What is measured by the composite, single-item pain/discomfort dimension of the EQ-5D-5L? An exploratory analysis. *Qual Life Res.* 2022;32(4):1175–86.
25. Rand S, Caiels J, Collins G, Forder J. Developing a proxy version of the Adult Social Care Outcome Toolkit (ASCOT). *Health Qual Life Outcomes.* 2017;15(1):108.
26. Crespo M, de Quiros MB, Gomez MM, Hornillos C. Quality of life of nursing home residents with dementia: a comparison of perspectives of residents, family, and staff. *Gerontologist.* 2012;52(1):56–65.
27. Griffiths AW, Smith SJ, Martin A, et al. Exploring self-report and proxy-report quality-of-life measures for people living with dementia in care homes. *Qual Life Res.* 2020;29(2):463–72.
28. Robertson S, Cooper C, Hoe J, et al. Comparing proxy rated quality of life of people living with dementia in care homes. *Psychol Med.* 2020;50(1):86–95.
29. Lapin B, Cohen ML, Corsini N, et al. Development of consensus-based considerations for use of adult proxy reporting: an ISOQOL task force initiative. *J Patient Rep Outcomes.* 2023;7(1):52.
30. Ratcliffe J, Lay K, Crocker M, et al. Unravelling the self-report versus proxy-report conundrum for older aged care residents: findings from a mixed-methods study. *Patient.* 2024;17(1):53–64.
31. Ratcliffe J, Bourke S, Li J, et al. Valuing the Quality-of-Life Aged Care Consumers (QOL-ACC) instrument for quality assessment and economic evaluation. *Pharmacoeconomics.* 2022;40(11):1069–79.
32. Himmler S, Jonker M, van Krugten F, et al. Estimating an anchored utility tariff for the well-being of older people measure (WOOP) for the Netherlands. *Soc Sci Med.* 2022;301: 114901.
33. Coast J, Flynn TN, Natarajan L, et al. Valuing the ICECAP capability index for older people. *Soc Sci Med.* 2008;67(5):874–82.
34. Cheng LJ, Engel L, Chen LA, et al. Using EQ-5D for proxy assessment of health-related quality of life in residential care facilities: a systematic review of feasibility and psychometric properties. *J Am Med Dir Assoc.* 2024;25: 104870.