Article:

Bailey, C. orcid.org/0000-0001-5030-430X and Peasgood, T. orcid.org/0000-0001-8024-7801 (2025) Content validity of the EQ-HWB in caregivers of children with health conditions. The Patient - Patient-Centered Outcomes Research. ISSN 1178-1653

https://doi.org/10.1007/s40271-025-00749-3

The Patient - Patient-Centered Outcomes Research
https://doi.org/10.1007/s40271-025-00749-3

ORIGINAL RESEARCH ARTICLE

Content Validity of the EQ-HWB in Caregivers of Children with Health Conditions

Cate Bailey[1] · **Tessa Peasgood**[2]

Accepted: 29 May 2025

Abstract

Introduction The EQ Health and Wellbeing instrument (EQ-HWB) is a new generic instrument designed for evaluation across health, social care, community, and caregiver populations. It has 25-item (EQ-HWB) and 9-item (EQ-HWB-S) versions. Validation across target populations is needed. As the instrument remains in an 'experimental' phase, modifications are being considered, including to item wording, item order, and positive versus negative framing of three items. We aimed to investigate the content validity of the EQ-HWB for caregivers of children with chronic health conditions and explore the potential modifications.

Methods In total, 21 caregivers from an Australian children's hospital sample completed semi-structured interviews, answering the 25 EQ-HWB items while 'thinking aloud', followed by interviewer probing. Interviews and coding focused on the COSMIN components of relevance, comprehension (understanding), and comprehensiveness.

Results Most EQ-HWB items were relevant and well understood by participants, especially the psychosocial items (e.g., loneliness, anxiety). Some participants were confused by the wording in the seeing and hearing items, which were also less relevant in this population. The item 'feeling unsafe' was only relevant for a few participants, but most considered it important. Responses to potential modifications to items were mixed. Many participants were keen to keep the three positively worded items. Some participants suggested that finishing with positive items may mitigate negative feelings on completion.

Conclusions EQ-HWB items have high relevance and are generally well understood by caregivers of children with health conditions. We recommend endorsing the modifications we tested for the EQ-HWB-S.

1 Introduction

The EQ Health and Wellbeing (EQ-HWB) is a new instrument that has been designed and developed by the EuroQol group with international collaboration for evaluations of interventions across health, social care, community, and caregiver populations [1]. The EQ-HWB was designed as a broad generic measure to capture health, social care, and carer-related quality of life. The full instrument contains 25 items (EQ-HWB), and a nine-item shorter version

Key Points for Decision Makers

The EQ Health and Wellbeing instrument (EQ-HWB) is a new instrument with two versions, a long form of 25 items and a short form of nine items, with accompanying UK pilot preference weights suitable for economic evaluation.

This study found that most EQ-HWB items were relevant and well understood by parents of children with health conditions and that the items included were comprehensive for this population.

As the instruments are prepared for future release, some minor modifications to item order, wording, and framing may be considered.

✉ Cate Bailey
cate.bailey@unimelb.edu.au

[1] Melbourne Health Economics, Melbourne School of Population and Global Health, The University of Melbourne, 207 Bouverie St, Carlton, VIC 3035, Australia

[2] School of Medicine and Population Health, Sheffield Centre for Health and Related Research, University of Sheffield, Sheffield, UK

(EQ-HWB-S) is also available [2]. Both instruments are currently ‘experimental’ and only available for the purposes of validation before wider release [3]. This experimental phase offers an opportunity for adjustments to the instrument at the item level in response to evidence on its performance in different groups and countries.

Validation studies on the EQ-HWB instruments have been conducted in a range of samples, with most on the EQ-HWB-S, including families experiencing adversity [4], informal caregivers in the USA [5], the general population in Australia [6], caregivers of children with health conditions [7], an Italian general population [8], and Chinese patients, caregivers, and general public [9]. These studies support the use of the EQ-HWB for measuring health and wellbeing in these populations. Quantitative studies suggest that the instruments performed well in regard to item response distribution [4–9], floor/ceiling effects [5, 9], convergent validity analysis [4–6, 8, 9], structural validity [6, 9], and known-group validity analysis [4–9]. Research on responsiveness to change has also produced promising results [4, 10].

Initial qualitative work was conducted to inform item selection across six countries [1, 11]. Recent qualitative work has evaluated the instrument in a range of caregiver, health condition, and general public settings. In an Australian study of caregivers of young children where families had experienced adversity, interview results suggested that the EQ-HWB-S was well accepted by participants, appropriately measuring the quality of life of parents experiencing adversity and parents of children with additional needs [4]. A comparative study of the content validity in the UK and USA for preference-based instruments for patients with cancer that was conducted using semi-structured interviews [12] found that the EQ-HWB-S was the favoured generic instrument over the EQ-5D-5L and Château-Santé Base [13]. A study investigating the content validity of the Italian translation of the instruments reported that participants found them easy understand and answer and relevant for patients, informal carers, and the general public [14]. A Chinese study of face validity found cultural issues, but results were overall ‘reassuring’ for the international application of the EQ-HWB [15]. In a sample of family members of, and aged care staff for, people living with dementia, the domains captured by the EQ-HWB were relevant for residential aged care, but modifications may be needed when using a proxy [16].

These qualitative studies build on the international literature outlining the face and content validity of the EQ-HWB and EQ-HWB-S [12, 14–17], but detailed work is still required for a range of caregiver populations on the relevance and comprehensibility of the items, especially for those in the longer form. Clarification of item wording and response options is particularly important as these modifications are being considered before the instrument is released for wider use. Examining any potential changes is an essential next step in the development of the EQ-HWB.

Previously, we investigated the psychometric properties of the EQ-HWB-S in a large sample of caregivers of children with a range of health conditions [7]. The psychometric results from this paper were highly promising; however, data were limited to one time point, and the number of variables suitable for known-group validity analysis was limited. To address these shortcomings, we undertook a more in-depth study using this sample frame to provide detail for known-groups analysis specific to caregivers, to include test–retest reliability analysis, and to include the full 25-item version. Results from the baseline and follow-up survey [18] suggested that both forms of the EQ-HWB had good reliability and validity in the psychometric tests applied and were specifically good at distinguishing group differences for caring duration and intensity. This article presents results from the think-aloud/semi-structured interviews we conducted in a subset of survey participants.

1.1 Aims

We aimed to investigate EQ-HWB items in relation to the COSMIN (COnsensus-based Standards for the selection of health Measurement INstruments) components of relevance, comprehension, and comprehensiveness [19], followed by an examination of some potential modifications to the EQ-HWB item wording. We conducted a content analysis for each of the 25 EQ-HWB items to investigate the relevance and comprehensibility (aim 1). Here, the term ‘understanding’ instead of ‘comprehensibility’ has been used for ease of reading. We investigated the comprehensiveness of the EQ-HWB and the EQ-HWB-S (aim 2). Finally, we aimed to investigate participants’ views on the potential modifications of EQ-HWB items being considered by the EuroQol EQ-HWB working group (aim 3).

2 Method

2.1 Sample

Participants were drawn from the QUOKKA P-MIC hospital sample for caregivers of children attending intensive care or emergency departments, and including children born premature and children with rare genetic conditions from specialist clinics [7]. From this sample, 1005 participants indicated that they would be interested in further research and could therefore be approached for the current study. In total, 202 participants completed the survey [18], of whom 21 completed an interview (current study). In the interview sample, we aimed to include a range of health conditions to cover a broad spread of child health problems, including children with autism spectrum disorder (ASD), prematurity, and rare genetic conditions (with a range of possible comorbidities such as attention-deficit/hyperactivity disorder and eating disorders). To select the participants, we used the sample frame for these condition groups until we met the target sample size.

2.2 Procedure

We developed a semi-structured interview protocol adapted from previous work [4] (Table S1 in the electronic supplementary material [ESM]). The interviewer explained how to participate in a think-aloud study and demonstrated an example. For aim 1, participants were asked to describe their thoughts as they answered each of the Australian English 'experimental' version of the 25 items, and the interviewer asked probing questions as required. To assess comprehensiveness (aim 2), participants were asked whether they thought there were missing constructs or potentially redundant items in the instrument in the short version (we did not ask this for the long version to avoid participant burden). To assess the comprehensiveness specifically of the 9-item short form, participants were asked whether these were the most suitable items and whether they would like to replace any of the nine items with those from the long form. The developers had been interested in whether a finance question should be included. A recent study on financial toxicity for patients with cancer in Indonesia found that female patients with breast cancer had high subjective and objective financial toxicity, which was associated with lower quality of life as measured using the EQ-HWB-S [20]. To further investigate comprehensiveness, we queried participants on the finance question from the CarerQol instrument and two other CarerQol items that did not overlap with EQ-HWB items [21]. The CarerQol items were as follows:

- Item a: I have no/some/a lot of fulfilment from carrying out my care tasks.
- Item b: I have no/some/a lot of relational problems with the care receiver (*e.g. he/she is very demanding of he/she behaves differently; we have communication problems*)
- Item e: I have no/some/a lot of financial problems because of my care tasks.

Researcher error meant that the CarerQol questions were omitted from the first seven interviews. For aim 3, final questions were asked of all participants about potential changes to the EQ-HWB items that were being considered by the EuroQol EQ-HWB working group. Participants were invited to add any further comments at the end of the interview.

Interviews were conducted one on one and took 30–40 min to complete. Participants received an honorarium of $AU45 for participating. As this was a long questionnaire, all participants answered all 25 items, but not all follow-up questions were asked in every interview. In deciding how many questions to ask and how much probing to undertake, we considered participants' time and energy and noted participant strain. We completed the items in the order in which they appear in the EQ-HWB. To ensure evidence was gathered on later items while also considering participant burden, where someone confidently answered 'no problems' on a question, we did not necessarily ask for an explanation if we felt that this would contribute to high participant burden. We noted that many participants had high levels of caregiver stress, and we needed to take this into account in how we conducted the interviews. We had safety measures in place in case there was any concern for participants but did not need to use them.

Participants were interviewed online by the first author and recorded using Zoom. Transcriptions were derived through the Word transcription function, checked by the lead author for accuracy, and anonymised. Interviews were conducted until we felt there was adequate coverage of a range of child health conditions and different intensities of caregiving (data adequacy), following Vasileiou et al. [22].

2.3 Analysis

Demographic information was sourced by matching the interview participants to the survey dataset. The 'study child' was the child with a medical condition or disability that the parent was most concerned about. We used a content analysis approach [23] focusing on the COSMIN concepts of relevance, understanding, and comprehensiveness [19]. Data were imported into NVivo and coded to the COSMIN concepts. Both authors independently coded seven of the transcripts, and the remaining 14 were coded by the first author only. The authors compared selected quotes that aimed to demonstrate the concepts, and any differences were resolved by consensus. Information with complete responses was collated with relevant quotations. We defined complete responses as those where the question being analysed was asked (not all participants received all follow-up questions), and participants replied with more than a yes/no answer, and the interviewer had not probed further. We used deductive (based on the COSMIN framework) and inducted approaches to the analysis.

3 Results

Baseline characteristics of the caregivers are shown in Table 1. The mean age of participants was 44.9 years (range 31–61). We were only able to interview one male, although the survey sample frame was 37% male. Most participants were either full-time caregivers (29%) or in casual employment (29%). There was an even distribution of study-child sex, and a full range of child ages from 1 to 18 years (mean 9.7), plus a relatively high number of Indigenous children (14%). Five children had a rare genetic disorder, six children had ASD, six children were premature, three children had ASD plus a rare genetic disorder, and one child had all three conditions. Most (79%) participants considered that they undertook 81–100% of the child's care.

3.1 Relevance and Understanding of the EQ-HWB Items (Aim 1)

The number of participants selecting the lowest option (no problems) on each item is presented in Fig. 1 (Table S2 in the ESM) for the baseline survey, 2-day follow-up, and qualitative interview as numbers and percentages. Interviews were conducted approximately 3 months after the survey data were collected. Using the number of participants with 'no problems' as a possible indicator of lack of relevance, items with the lowest relevance appeared to be the physical items (seeing, hearing, mobility, activities, personal care), feeling unsafe, nothing to look forward to, and difficulty coping.

Table S3 in the ESM shows the results of the analysis by relevance and understanding across the 25 items, using the think aloud and probing information. Many of the items were highly relevant and were well understood by most participants; the table includes examples of this and illustrations of ways in which items were sometimes less relevant and where there were issues with understanding.

A central question was how relevant and important the seeing and hearing items were for parent caregivers, given that they may be more relevant for an older caregiver population. For 12 of the 17 participants, these items did not support their concept of their health and wellbeing: "They're strange, I would never think of those two questions in terms of my wellbeing." (P4), "They seem too specific." (P5) and "Why do you ask that question in relation to carers?" (P11).

Two participants noted that these items seemed different to previous surveys they had completed: "I've done other carer surveys, and I haven't seen these before. I don't think they really reflect my quality of life at all." (P6). One participant felt that these items may be offensive: "I don't mind answering them, but some people might get a bit offended under 50." (P3).

Table 1 Baseline caregiver and child characteristics

Variable	*N* (%)
Caregiver	
Sex	
Female	20 (95.2)
Male	1 (4.8)
Number of children	
1	4 (19.0)
2	13 (61.9)
3	2 (9.5)
4	2 (9.5)
Number of adults in house	
1	7 (33.3)
2	10 (47.6)
3	1 (4.8)
4	1 (4.8)
Missing	2 (9.5)
Number of children in house	
1	5 (23.8)
2	12 (57.1)
3	1 (4.8)
4	1 (4.8)
Missing	2 (9.5)
Healthcare card	8 (42%)
Education	
Bachelor's degree or above	8 (38.1)
Certificate III/IV, diploma, etc.	6 (28.6)
Certificate I/II	1 (4.8)
Year 12	2 (9.5)
Year 9–11	1 (4.8)
Year 8 or below	1 (4.8)
Missing	2 (9.5)
Employment	
Full time	2 (9.5)
Part time	4 (4.8)
Casual	6 (28.6)
Seeking work	1 (4.8)
Student	2 (9.5)
Full-time caring	6 (28.6)
Child variable	
Sex	
Female	11 (52.4)
Male	10 (47.6)
Indigenous	3 (14.3)
Language other than English	3 (14.3)

Five participants supported the inclusion of these items, but perhaps not for the reasons that they were originally included: "Because some people might not be able to see the questionnaire correctly, or some people might also … need to hear it … ." (P18). "It seemed odd, but it didn't bother

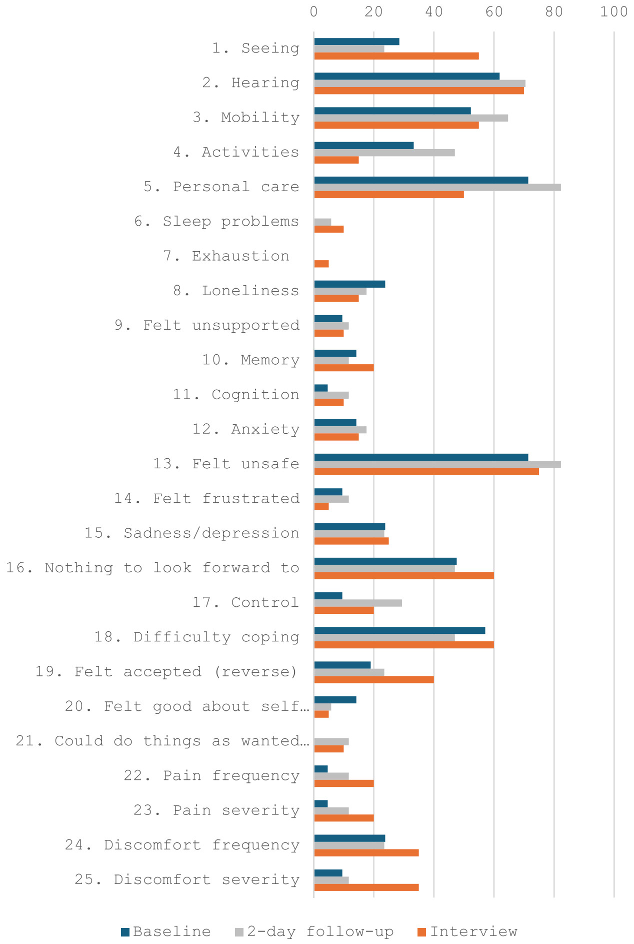

Fig. 1 Percentage of participants who selected 'no problem' by item at baseline, at 2-day follow-up, and during the qualitative interview. No problem was defined as follows: items 1–5 'no difficulty', items 6–22 and 24 'none of the time', item 23 'no physical pain', item 25 'no physical discomfort'. Items 19–21 were positive items and were reverse scored for sum-scoring, so a response of 'most or all of the time' is interpreted as 'no problem'

me." (P21). One participant felt that seeing and hearing were implicitly included in the activities item and could be included in those examples: "I assume [that] getting around inside and outside the house involves seeing and hearing as well. You could even use an example there of seeing, hearing, walking, using a wheelchair." (P3). One participant suggested that these items were less important, "Seeing and hearing to me seem like sub items." (P16), and noted some concern about completing the whole instrument when faced with these items: "I was actually thinking, 'Oh God, is it going to be like this all the way through?'" (P4).

Few participants had concerns with their own mobility, but some noted the difference between having good mobility themselves compared with when they were caring for their child: "I do have difficulties because my daughter uses a wheelchair and it … it is difficult to get out of the house, but not myself." (P13). Most participants had no personal care problems; some participants associated this with emotional or mental health issues, suggesting differences in understanding: "It is related to motivation. It's not that I'm having any physical difficulty." (P4). Sleep and exhaustion items were highly relevant and well understood by participants: "I'd say maybe 30% [of exhaustion is] from the sleep, 30% from my daily chores. And maybe 40% from the caring of the kids." (P3).

The items asking about loneliness, support, memory, cognition, anxiety, frustration, sadness/depression, looking forward, sense of control, and coping were highly relevant and well understood by participants: "I'm doing things that I need to but … it's a continual battle." (P19) and "I know I do have some good support there. It's just not always practical to be able to take it up." (P12). 'Felt unsafe' was highly pertinent for one participant who had experienced family violence, and other parents mentioned concerns about caring for children with socio-emotional issues: "If one of my sons is having one of his meltdowns … he can be violent and … he … he can hurt me, and I can then struggle to function." (P7). For most participants, this item was not as relevant.

Relevance was mixed for the three positive items (felt accepted, felt good about self, could do things as wanted), with some finding these items highly pertinent and others finding them less important, particularly in reference to changes over time: "With age comes that sort of not caring about other peoples' opinions." (P6) and "As I'm getting older, I'm tolerating a lot less in terms of judgement from others." (P8).

Participants were able to clearly understand the pain and discomfort items across both frequency and severity types, as evidenced by descriptions of health issues: "I've developed COPD [chronic obstructive pulmonary disease] since my caring duties as well, so breathlessness is part of everyday [discomfort]." (P8). Participants were mostly able to distinguish between severe and very severe response options for pain/discomfort, although some found it harder: "very fine line between them" (P14). Very severe pain was often voiced in terms of hospitalisation, whereas severe pain was incapacitating but the person remained at home. People found the difference harder to distinguish for discomfort: "Physical discomfort … mild or severe, I wouldn't be able to say." (P17).

3.2 Comprehensiveness (Aim 2)

We explored the comprehensiveness of the items included in the short-form from the EQ-HWB and in relation to items that appear in the CarerQol but not the long form. Participants were asked whether they had any further comments or questions at the end of the interview; no participant spontaneously reported any concepts as missing.

3.2.1 Comprehensiveness of the EQ-HWB-S

We asked participants whether they felt that the right items from the full 25-item instrument were included in the short form; there were 10 complete responses. For some participants, we also asked which item they might take out if they wanted to include a different item in the short form. Overall, participants were positive about the items selected for the EQ-HWB-S: "I think it's quite good [as] an overall snapshot." (P6), "I think they're the right ones to pick." (P5) and "That's condensed it down really well." (P15). Most participants did not want to replace any items: "They all seem quite specific, so I don't know what you could take out to replace it." (P8). When asked which item they would take out if they wanted to include another item, two participants suggested that anxiety and depression items could be combined, and one suggested that the mobility and activities items could be combined. No participants suggested replacing the sleep item with the exhaustion item, despite the sleep item being seen as highly relevant by participants.

3.2.2 Comprehensiveness of the EQ-HWB Regarding Items Included in the CarerQol

We asked participants about three items that appear in the CarerQol but not the EQ-HWB to investigate how important these concepts were for participants. For the caregiver fulfilment item, views were mixed, with 7 of the 12 complete responses from participants suggesting that this was an important issue: "I can be down, but I still get a lot of fulfilment out of helping my children." (P15) and "If we're looking at the quality of life of the carer, I think fulfilment that they're experiencing is an enormous part of that." (P5). Five participants either felt this was not as relevant or that the item was ambiguous: "It's tricky, I'm not sure how to answer that question." (P20) and "I'm wondering what kind of data you're getting from that question." (P16).

There was some ambivalence from participants about the carer–care receiver relationship domain. Of the 10 complete responses, six participants felt that the item was important and/or relevant: "I think that it would be a very good question to help understand the impact of a caring role, in terms of … fulfilment, even though you don't get along with that person that you're caring for?" (P19). Four participants found the item confusing or problematic: "I would [query] some of the wording of that question. Really problematic. Demanding is quite a loaded word." (P8), "I feel like that's a difficult question. I don't know how many parents are going to come out and say, 'my child is too demanding', so I don't know how honest the answers would be." (P12), and "Then what are your choices anyway? Why would you think about your relationship with them if you still need to care for them?" (P13).

Of the 12 respondents, nine thought the financial strain item was important and relevant: "Financial issues are really important in terms of carers and the domains of carer wellness." (P8). One participant felt that the question was less appropriate: "That might be maybe a little bit too personal for some people to respond." (P11), and some participants were receiving government funding that made this item less relevant: "NDIS [National Disability Insurance Scheme] covers the costs of therapy." (P21). Eight of the 12 responses mentioned difficulties caregivers had in working while caregiving: "I can only get a crappy part-time or casual job because I've got a kid to look after and no-one wants to employ me properly because they just assume I'm not going to be available as much, and that's less money around, less resources. It's got a massive impact." (P12) and "I was unable to work for many years." (P16).

3.3 Potential Modifications to the Instruments (Aim 3)

We investigated potential changes to the EQ-HWB being considered by the EQ-HWB working group, including changing the response option from "only occasionally" to "a little of the time", changing the wording of the control item, potential wording changes from positive to negative for items 19–21, and the order of the first two items in the short version.

3.3.1 Response Option Change from 'Only Occasionally' to 'A Little of the Time'

One modification being considered is changing the second (mildest) level of the frequency response options from 'only occasionally' to 'a little of the time'. In the interviews, participants often replied 'occasionally' rather than 'only occasionally' when stating their response. When asked whether they would prefer 'a little of the time' instead, one participant thought that this was not usual language: "I just don't really feel like people use that language." (P19). Interestingly, when the interviewer stated the responses in order with the revised wording, that is (1) None of the time, (2) A little of the time, (3) Sometimes, (4) Often, (5) Most or all of the time, participants were more likely to endorse the change as they heard the 'time' element in all except the fourth response option. "I think it just makes sense, because then they're all time based." (P20). No participants had strong feelings about the change, and many did not have a preference: "It makes sense to me either way." (P14). Of the seven responses, three preferred the change, two preferred the original, and two had no preference. Other than this change, we did not specifically ask participants about the response options, and there were no spontaneous comments on them.

3.3.2 Control Item, Change from no Control to Lack Control

The working group is considering changing this item from "feel like you had no control over your day-to-day life?" to "feel you lacked control over your day-to-day life?". .l’ Of ten responses, six were in favour of the word change from 'no control' to 'lacked control', one was against, and the rest were neutral. Those in favour suggested: “I think [lacked control is better] because I can’t say I’ve got no choice. However, my choices are limited.” (P7) and “‘No control’ is probably a bit harsher, whereas ‘lack’, it’s not as strong of a word.” (P6). The participant who was against the change stated “I prefer the ‘no control’ question because it’s more straightforward.” (P9).

3.3.3 Changing Positive Items to Negative, Items 19–21

We asked about changing the three positively framed items to be negatively framed and asked about the specific potential wording change for each of the three items.

3.3.3.1 EQ-HWB 19 – Feeling Accepted The working group is considering changing item 19 from “Did you feel accepted by others? (e.g. felt like you were able to be yourself and that you belonged) to “Did you feel excluded by others? (e.g. felt like you did not belong or you were not able to be yourself).

Of nine participants, five did not like the change to the negatively worded item, and a further four felt that it was not the same question in the negative form. Those not liking the change noted, “It is the same thing, but it feels different.” (P12) and “It feels emotionally very different.” (P16). Participants objected to the use of the word ‘excluded’: “I know that the opposite of accepted would be excluded. It just doesn’t feel right.” (P12). One participant wondered whether people’s responses might be more honest to the negative framing: “I have a feeling that people would respond more honestly though, if it was negative.” (P16).

Some participants felt that their scores would change if the question was reframed from positive to negative, suggesting that they were not the same concepts: “Even though I’ve said I’ve often felt accepted by others, I would probably nearly also score as high if it was ‘excluded’. Sometimes it’s not even a person not making you feel accepted, but the physical environment is huge for us. There are places that we just can’t get in the door.” (P20) and “I think that they will be testing different things. I would probably have said that I never feel excluded by others, but that doesn’t mean that I feel accepted.” (P21).

3.3.3.2 EQ-HWB 20 – Feel Good About Self The working group is considering changing item 20 from “Did you feel good about yourself?” to “Did you feel negative about yourself?”

Of the 13 responses, seven did not want the item to change, and six felt that the change did not matter, as the item was essentially the same. Those who did not want the change did not feel as strongly about it as they did for the change to item 19: “Same thing but different as well, so I would rather keep it feel good about yourself.” (P9). These participants felt that the positive items were helpful in keeping a positive attitude: “If you put a positive [item], I come up with a positive response; with a negative, [I] most likely will come with a negative response.” (P13). Those who did not mind the change felt that the items were similar enough: “That sounds like it’s asking the same thing.” (P12).

3.3.3.3 EQ-HWB 21 – Could do Things as Wanted The working group is considering changing item 19 from “Could you do the things you wanted to do?” to “How much difficulty did you have doing enjoyable activities (e.g. leisure, hobbies)?”

Overall, the 10 participants who responded were more positive about this change but also felt that the two items were asking different things, with the negative item specifically referring to enjoyable activities. “You’re cementing the fact that it’s about leisure and hobbies, and it’s about you. Although I know that the first one does mean that, I’m not sure if everyone would think about those things straight away.” (P16). Those who still favoured the positive item suggested including examples: “I feel like [the positive question] is easier to understand. But I would just give an example [such as] hobbies, etc.” (P19).

3.3.3.4 Positive Items Generally When considering the positive items overall, many participants felt that these items were more personal: “I like those three questions more than the rest. They’re more about me, whereas other questions are more about the family than me.” (P1), “It primes you to think of something positive.” (P4), and “It’s reminded me of the good things I have done, all the things that I’ve gotten right or the times that I’ve gotten stuff done … for me.” (P7). Participants felt that the positive items balanced out the negative: “I think it is good that they are in there because it is a hard survey, and it really does hit some raw nerves.” (P7) and “I think it makes you reflect on how you feel about yourself. Oh well, it’s not all bad. I’m not that bad.” (P13). One participant suggested that moving items into the negative could worsen how the user might feel: “Having them all in a negative light could maybe cause a person that is having a bit of a struggle to fall deeper into that struggle.” (P18).

Two participants suggested that moving the positively worded items to the end of the instrument would help the participant leave on a positive note: “It can be quite depressing when you do questionnaires. With the three positive ones at the end, it stops you to think, oh, I’m okay.” (P14) and “My suggestion would be to have the positive at the very end. So, it lets you off on a bit of a lighter note you can reflect back on." (P18).

3.3.4 Item Order

We asked about the opening items for both the EQ-HWB and the EQ-HWB-S.

3.3.4.1 Starting the EQ-HWB with the Seeing and Hearing Items A modification to the order of the items in the EQ-HWB is being considered; in particular, whether items on seeing and hearing should stay at the start of the questionnaire. When asked about this, some participants felt that they were simple items to ease the participant in: "and then you ask some more serious ones." (P14) and "It doesn't necessarily make me feel like you're hitting the point. It feels like an ice-breaker question." (P19). Two participants suggested placing these items closer to the end: "Probably not [put them] at the beginning. I would go with pain first, and then [seeing and hearing] probably just towards the end (P13)."

3.3.4.2 Changing the Item Order of First Two Items in the EQ-HWB-S – Activities and Mobility In the experimental version, the mobility item was placed before the activities item. In our previous research [4], we found that participants were basing their responses on the activities item in regard to the prior mobility item. In the modified version of the EQ-HWB-S, these two items have been swapped so that the activities item comes first, and we asked participants for their thoughts about this potential change. There were seven responses, with four participants keen on the change: "I would put activities first, because it's a more open and general question." (P4) and "I think that would make more sense just because you're asking, 'do they have trouble doing things day to day'? And then you're breaking it down a little bit further asking what difficulty they have?" (P18). Two participants were neutral: "To me, it's much of a muchness." (P5).

4 Discussion

We aimed to investigate the EQ-HWB items in relation to the COSMIN concepts of relevance, comprehensibility, and comprehensiveness to aid in building the evidence for the EQ-HWB instruments across a range of countries and specific populations. We first looked at the relevance and comprehensibility of each of the 25 EQ-HWB items. The items resonated well with participants, with most participants able to speak freely about the relevance of each of the items for themselves and/or in their caregiver role. Items with the highest relevance appeared to be sleep (often because of children with high needs waking caregivers at night), exhaustion (often to do with either interrupted or poor sleep, or because of caregiving responsibilities), lack of support – or difficulty in asking for it, issues with memory or cognition, high levels of anxiety, frustration, depression, feeling like there was nothing to look forward to, and low sense of control, often because of caregiver responsibilities. Seeing and hearing were less relevant in this population, most participants did not feel unsafe (those who did were in significantly difficult situations), and pain and discomfort were present but not a high contributor to quality of life.

Most participants displayed clear evidence of a good understanding of the items, apart from the seeing and hearing items, where there was some confusion about the examples (e.g., aids for seeing and hearing). This issue also arose regarding the mobility item, where one person gauged their response as 'no problems' on the basis that they did not use a mobility aid. We suggest that these items may need further investigation before the instruments are finalised and worded such that respondents who do and do not use aids easily understand the question. Participants had a good understanding of items such as loneliness and anxiety, which were seen as important issues that related to participants' caregiving roles. Participants blamed issues with poor memory and cognition on the stress of caring for children with significant health needs, indicating that these questions were considered important in light of their caregiving activities.

Participants strongly endorsed the choice of the nine EQ-HWB-S items. Participants would only drop an item if forced to, and only one participant wanted to include an extra item (support). Regarding the questions we asked about the CarerQol domains, a slight majority of participants felt that the 'fulfilment from caregiving' item from the CarerQol was important, though some felt that it was ambiguous and wondered how useful this information would be. Some participants felt that the caregiver–recipient relationship item was problematic for parents of children with health conditions, given their sense of responsibility for their children.

Most participants felt that the finance item was important, and many gave examples in their lives where caregiving had affected their finances and their ability to work to support their families. In initial research on the domains of quality of life to be included in the EQ-HWB [11], researchers considered job security and the financial considerations associated with this but did not include such an item as this would not be pertinent to all instrument users if they were not in paid employment. In our recent qualitative study [4], participants discussed the impact of financial stress from caregiving as a factor affecting their wellbeing. In known-group validity analysis in our paper analysing the survey data related to the current project [18], both EQ-HWB instruments could distinguish between groups having and not having financial difficulties, or effects from caregiving on employment, with large effect sizes. This suggests that the instruments may be indirectly incorporating this concept.

For the EQ-HWB-S specifically, we found moderate to good support for the proposed modifications and endorse (1) changing the response option from ‘only occasionally’ to ‘a little of the time’, (2) changing words in the control items from ‘no control’ to ‘lack of control’, and (3) changing the order of the first two items (putting ‘activities’ before ‘mobility’). We hope that these results will be useful to the EQ-HWB working group in finalising the instrument for release. For the items pertaining only to the longer form, we found that the seeing and hearing items were not as relevant to participants in this population and that some participants saw placing them at the beginning of the questionnaire as a disincentive to complete the instrument. We suggest that removing these items will not affect the cohesion of the instrument and will make it more relevant to a wider range of populations.

Having positively framed items alongside the negatively framed items in the long form of the instrument poses difficulties for preference-based scoring and may lead to incorrect responses if people do not see the change in the response options [24]. We recently found this in the CarerQol in our study, where the items changed from negative to positive response options [25]. However, many participants liked the positive items in the survey; they reported that they helped them to think more positively about their lives and reminded them of good aspects of themselves. Two participants suggested moving these items to the end of the instrument to end it on a positive note, given that the earlier items have asked them about the many difficulties they may be having. If the positive items are separated from the previous response options, such as being asked after the four pain and discomfort problems, people may also be more likely to notice the change and respond correctly. We also note a duty of care to participants; leaving with positive items may help balance negative thoughts or emotions brought up by completing the questionnaire.

4.1 Strengths and Limitations

We recruited participants with children with a range of health conditions, included even numbers of boys and girls, and 14% of the sample of children were from an Indigenous background, demonstrating an appropriately diverse sample of children. We note that we were only able to recruit one father in this sample, as it was difficult to recruit men to attend interviews. We were limited in the depth of analysis we could achieve because of the length of the instrument. We included all items, but it was not possible to get in-depth information on comprehension and relevance for every person on every item. Where we asked about the items in the CarerQol, the interpretation of the responses needs to take into account that these items were presented in the interview as possibly missing, making this evidence weaker than if the respondent had raised the item as missing without prompting.

5 Conclusions

This is the first qualitative study on all EQ-HWB items using COSMIN attributes of relevance, understanding, and comprehensiveness. Most items had high relevance and were easily understood. Further research is warranted on the placement of the seeing and hearing items and their relevance for parents. EQ-HWB-S items were considered appropriate for a short form, with almost all participants endorsing the items chosen. Three domains from the CarerQol were considered; none appeared to be essential additions. Participants’ responses to potential changes to the instrument were assessed. Participants were keen on keeping the positive items; moving them to the end of the instrument may solve some of the response direction issues and leave participants on a positive note. This article contributes to growing evidence supporting the EQ-HWB instruments as suitable for a wide range of caregivers.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s40271-025-00749-3.

Acknowledgements The authors thank the members of the QUOKKA project Caregiver Consumer Advisory Group.

Funding Open Access funding enabled and organized by CAUL and its Member Institutions.

Declarations

Conflicts of Interest Dr Peasgood is a member of the EuroQol group and was involved with the development of the EQ-HWB. Dr Peasgood is a member of the EQ-HWB working group and Dr Bailey is a member of the EQ-HWB special interest group. Dr Bailey is a member of the *PharmacoEconomics* editorial board. The authors have no competing interests to declare that are relevant to the content of this article.

Funding Funded by the EuroQol Foundation (1559-RA). Views expressed by the authors in the publication do not necessarily reflect the views of the EuroQol Foundation.

Ethics Ethics approval was received from the University of Melbourne Human Ethics Committee (2023-27184-46174-5).

Consent Informed consent was obtained from all individual participants included in the study.

Data Availability It is not possible to share data because of the potential for individual privacy to be compromised.

Author Contributions Both authors contributed to the study conception and design. Cate Bailey and Tessa Peasgood prepared the material and collected and analysed the data. Cate Bailey wrote the first draft of the manuscript, and both authors commented on subsequent versions. Both authors read and approved the final manuscript.

References

1. Brazier J, Peasgood T, Mukuria C, et al. The EQ-HWB: overview of the development of a measure of health and wellbeing and key results. Value Health. 2022;25:482–91. https://doi.org/10.1016/j.jval.2022.01.009.
2. Peasgood T, Mukuria C, Carlton J, et al. What is the best approach to adopt for identifying the domains for a new measure of health, social care and carer-related quality of life to measure quality-adjusted life years? Application to the development of the EQ-HWB? Eur J Health Econ. 2021;22:1067–81. https://doi.org/10.1007/s10198-021-01306-z.
3. 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;25:525–33. https://doi.org/10.1016/j.jval.2021.11.1361.
4. Bailey C, Dalziel K, Constable L, et al. The performance of the EQ-HWB-S as a measure of quality-of-life of caregivers in families that have experienced adverse events. Eur J Health Econ. 2025;26:7–21. https://doi.org/10.1007/s10198-024-01688-w.
5. Kuharic M, Mulhern B, Sharp LK, et al. Comparison of EQ Health and Well-Being long and short with other preference-based measures among United States informal caregivers. Value Health. 2024;27(7):967–77. https://doi.org/10.1016/j.jval.2024.03.003.
6. Lee P, Engel L, Lubetkin E, et al. Exploring the comparability between EQ-5D and the EQ health and wellbeing in the general Australian population. Value Health. 2024;27(4):508–17. https://doi.org/10.1016/j.jval.2024.01.004.
7. Bailey C, Dalziel K, Jones R, et al. In collaboration with the Quality of Life in Kids: Key evidence to strengthen decisions in Australia (QUOKKA) Project team. The validity of the EuroQol Health and Wellbeing short version (EQ-HWB-S) instrument in parents of children with and without health conditions. Pharmacoeconomics. 2024;42:163–79. https://doi.org/10.1007/s40273-024-01351-5.
8. Kuharić M, Pickard AS, Mukuria C, et al. The measurement properties of the EQ-HWB and the EQ-HWB-S in Italian population: a comparative study with EQ-5D-5L. Value Health. 2024;27:955–66. https://doi.org/10.1016/j.jval.2024.03.002.
9. Long C, Mao Z, Yang Z. A head-to-head comparison of EQ-HWB and EQ-5D-5L in patients, carers, and general public in China. Value Health. 2024;27:848–56. https://doi.org/10.1016/j.jval.2024.02.012.
10. Pangestu S, Purba FD, Setyowibowo H, et al. The psychometric properties of the EQ-HWB and EQ-HWB-S in patients with breast cancer: a comparative analysis with EQ-5D-5L, FACT-8D, and SWEMWBS. Value Health. 2025;28:449–59. https://doi.org/10.1016/j.jval.2024.12.003.
11. 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;25:492–511. https://doi.org/10.1016/j.jval.2021.11.1371.
12. Gibson AEJ, Longworth L, Bennett B, et al. Assessing the content validity of preference-based measures in cancer. Value Health. 2024;27:70–8. https://doi.org/10.1016/j.jval.2023.10.006.
13. Zhang X, Vermeulen KM, Veeger NJGM, et al. Generating utilities for the Château-Santé Base: a novel, generic, and patient-centered health-outcome measure. Value Health. 2024;27:1426–35. https://doi.org/10.1016/j.jval.2024.06.013.
14. Masutti S, Falivena C, Purba FD, et al. Content validity of the EQ-HWB and EQ-HWB-S in a sample of Italian patients, informal caregivers and members of the general public. J Patient Rep Outcomes. 2024;8:36. https://doi.org/10.1186/s41687-024-00706-y.
15. Zhang G, Yang Z, Luo N, et al. Can items derived from international literature be used in national quality of life instruments? A qualitative study conceptualising the EQ-HWB in China. J Patient Rep Outcomes. 2024;8:83. https://doi.org/10.1186/s41687-024-00767-z.
16. Engel L, Bailey C, Bogatyreva E, et al. Appropriateness of the EQ-HWB for use in residential aged care: a proxy perspective. Patient. 2024;17:673–83. https://doi.org/10.1007/s40271-024-00715-5.
17. 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;16:655–66. https://doi.org/10.1007/s40271-023-00647-6.
18. Bailey C, Dalziel K, Constable L, et al. Validity and reliability of the EQ-HWB in parents of children with health conditions. Value Health. 2025. https://doi.org/10.1016/j.jval.2025.05.013.
19. Mokkink LB, Prinsen CA, Patrick DL, et al. COSMIN study design checklist for Patient-reported outcome measurement instruments. Amsterdam: COSMIN; 2019. https://www.cosmin.nl/wp-content/uploads/COSMIN-study-designing-checklist_final.pdf
20. Pangestu S, Purba FD, Setyowibowo H, et al. Associations between financial toxicity, health-related quality of life, and well-being in Indonesian patients with breast cancer. Qual Life Res. 2025;34:1709–22. https://doi.org/10.1007/s11136-025-03925-y.
21. Brouwer WBF, Van Exel NJA, Van Gorp B, et al. The CarerQol instrument: a new instrument to measure care-related quality of life of informal caregivers for use in economic evaluations. Qual Life Res. 2006;15:1005–21. https://doi.org/10.1007/s11136-005-5994-6.
22. Vasileiou K, Barnett J, Thorpe S, Young T. Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. BMC Med Res Methodol. 2018;18:148. https://doi.org/10.1186/s12874-018-0594-7.
23. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res. 2005;15:1277–88. https://doi.org/10.1177/1049732305276687.
24. Bulut HC, Bulut O. Item wording effects in self-report measures and reading achievement: Does removing careless respondents

help? Stud Educ Eval. 2022;72: 101126. https://doi.org/10.1016/j.stueduc.2022.101126.

25. Bailey C, Peasgood T, Michalowsky B, Engel L. The psychometric performance of the EQ-HWB in caregivers of persons living with dementia [online ahead of print]. Value Health. 2025. https://doi.org/10.1016/j.jval.2025.04.2168.