Qualitative development of candidate items for a hearing bolt-on for the EQ-5D-5L

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Objectives: The EQ-5D lacks sensitivity to differences and changes in hearing. A hearing-specific 'bolt-on' has been proposed to bridge this gap, yet progress in defining appropriate descriptors has been limited. This study is designed to provide the qualitative insights needed to advance the development of health state descriptors for EuroQol instruments. We aimed to identify and test candidate descriptors for a hearing bolt-on for the EQ-5D-5L.

Methods: The qualitative research programme included i) qualitative synthesis, ii) online discussion groups, and iii) semi-structured interviews. This paper describes our primary qualitative data collection and analysis across two phases: first to identify candidate items and second to test them. In the first phase, we targeted the concepts that define the health-related quality of life impact of problems with hearing, and the terminology that people with these problems use to express them. UK people with various experiences of hearing loss, participated in a series of online bulletin board discussions. In Australia, semi-structured online interviews were conducted. Subsequently, we conducted video interviews with UK British Sign Language (BSL) users. Thematic analysis was used to identify relevant concepts and terminology for all discussion groups and interviews. In the second phase, candidate items were tested in semi-structured online interviews exploring the suitability of different items for capturing aspects of quality of life that are important to people with hearing loss that are not captured by the EQ-5D.

Results: We conducted three online discussion groups with 23 UK participants in total, three interviews with UK BSL users and eight interviews with Australian participants. Participants identified terminology as important, with specific meaning attached to the words 'deaf' and 'hearing', and opposition to terms including 'impairment'. Important aspects of health-related quality of life aligned with the findings from our qualitative synthesis, including sound localisation and speech. Communication was identified as a dominant feature, particularly in BSL users' characterisation of the impacts of deafness. Many other impacts were also characterised as closely associated with communication. These findings were used to specify candidate items, which were tested in nine interviews with UK participants. Candidate items related to hearing in general, specific hearing-related functioning, and communication. Participants raised conflicting preferences about alignment with medical terminology when determining individual quality of life. Interviews revealed the importance of ensuring that profoundly deaf individuals can respond to the questions without placing 'deaf' in the most severe response state option. A communication-related item was considered by participants to capture additional aspects of quality of life when specific to hearing.

Conclusion: Online discussion groups and video interviews proved successful. There are important sensitivities around the wording of a hearing bolt-on for the EQ-5D-5L, with challenges to the notion of ranking states of hearing, especially among the deaf community. Communication is an important aspect that affects quality of life that may not be adequately captured by the EQ-5D-5L and may warrant explicit inclusion as an item within a hearing bolt-on. The qualitative insights developed in this research are essential for shaping health state descriptors for a hearing-related bolt-on.

Introduction

1.5 million people globally are estimated to experience deafness or hearing loss (WHO, 2025). Being deaf, having hearing loss or other hearing-related conditions such as tinnitus can have an impact on health-related quality of life (HRQoL). However, the EQ-5D-5L, a generic descriptive system used to assess quality of life, has been identified as not capturing aspects of HRQoL that are important to deaf individuals (Payakachat, Ali and Tilford, 2015; Grutters et al., 2007; Lutomski et al., 2017; Summerfield, Barton, and UK Cochlear Implant Study Group, 2019). A hearing-specific 'bolt-on' has been proposed to bridge this gap, yet progress in defining appropriate health state descriptors has been limited.

Qualitative research should be used to inform the development of health state descriptors for preference-based outcome measures (Al-Janabi, N Flynn and Coast, 2012; Stevens, 2009). In our previous research, we conducted a systematic review to explore the impacts of being deaf/hearing loss on the quality of life identified through qualitative research (Henderson et al., 2024). We identified through a qualitative synthesis that the HRQoL impacts are related to physical, mental and social aspects of health.

In this research, we build upon our qualitative synthesis to provide the additional qualitative insights needed to advance the development of hearing-related health state descriptors for the EQ-5D-5l, from here on referred to as bolt-on items. We aimed to conduct primary qualitative data collection in the UK and Australia to identify and test candidate bolt-on items.

Methods

The primary qualitative data collection consisted of two phases. In the first phase, we identified candidate bolt-on items. We targeted the identification of concepts that define the health-related quality of life impact of hearing and the terminology that people who are deaf/have hearing loss use to express them.

Participants in the UK were recruited via the Office of Health Economics' (OHE) social media (LinkedIn and X), engagement with deaf, hearing loss and BSL Facebook groups and through advertisement to RNID's (a national hearing loss charity) research panel. Ethics approval for all UK discussions groups and interviews was provided by the Economics Research Ethics Committee at City St George's, University of London.

In Australia, the interview participants were recruited by CRNRSTONE, a research panel. Ethics approval was provided by University of Technology Sydney (UTS).

Phase 1: Identifying Candidate Bolt-On Items

UK individuals with various experiences of hearing loss participated in a series of online bulletin board discussions, run on Discourse. The bulletin board was open for 24 hours, with participants able to engage in the discussion anytime within the 24 hours but were expected to participate for 1 hour. Participants were encouraged to engage with the six questions posted on the discussion board, both through responding the question directly and engaging in discussion with other participants. Each of the discussion boards was moderated (by CS, NH and/or SH), with the moderator prompting responses to questions and engagement between participants.

Questions were posted at two intervals throughout the day. The first three questions posted at 8 am were:

1. What are the most important ways in which your hearing influences your quality of life?
2. What words or phrases would you use to describe the impact of your hearing on your life?
3. When describing the impact of your hearing on your quality of life, are there any particular activities that you would refer to?

The second three questions posted at 12pm were:

1. Thinking about the effect on your quality of life, how would you describe your overall level of hearing today?
2. When you describe your overall level of hearing, do you take into account the role of aids and adjustments, such as hearing aids, cochlear implants etc.?
3. Are there words or phrases used to describe your hearing that you dislike or find problematic?

In Australia, semi-structured video interviews were conducted (by KP). The interviews were conducted via Zoom and lasted between 30 and 45 minutes.

The UK team has engaged with key stakeholders in the research and charity sectors during the previously conducted qualitative synthesis. Through this engagement, it became clear that some changes to the project would be necessary to ensure that the bolt-on(s) developed would be acceptable, relevant, and valid for the deaf community. Sign languages are the first language for many deaf people. Therefore, to encourage the participation of these individuals in our research, study materials, including participant information and the enrolment form, were translated into British Sign Language (BSL). Subsequently, CS conducted video interviews with UK BSL users using Zoom which lasted for approximately an hour.

The Australian and UK BSL interviews explored the same questions as the online discussion groups with an additional final question: Of all the things we've talked about today, what is the most important thing for you?

Thematic analysis was used to identify relevant concepts and terminology for all discussion groups and interviews.

Phase 2: Qualitative Testing of Candidate Bolt-On Items

In the second phase, candidate items were tested in semi-structured online interviews exploring the suitability of different items for capturing aspects of HRQoL that are important to people with hearing loss that are not captured by the EQ-5D-5L. Participants were first asked about their personal experience with hearing. Following this they were asked to complete the EQ-5D-5L questionnaire. Finally, participants were presented with a series of potential bolt-on items. They were asked to indicate how they would respond if presented as part of the questionnaire. Cognitive debriefing was then conducted, involving ‘think-aloud’ consideration of the items which included assessment of comprehension and response processing.

The potential bolt-on items explored various dimensions including hearing in general and communication.

Hearing in general was tested both alone and alongside additional descriptors. that related to various surroundings (e.g., in a public space with background noise), hearing function (e.g., sound clarity, localisation and effort) and the use of aids and implants. Communication was also tested alone and alongside additional descriptors that aimed to clarify the type of communication being asked about (e.g., understanding speech and being understood, social situations, face-to-face or on the telephone, due to hearing).

We explored the severity of the response options through ascertaining preferences for the term mild over slight in this context and responses that may be suited to deaf individuals such the use of the profound, unable to hear and deaf.

Additionally, alternative terminology for the word ‘problems’ was explored, namely through replacement with the word difficulties and the phrase ‘hearing loss’ was also explored. A full list of candidate bolt-on items posed to respondents can be found in the Appendix.

In each phase of the research, we recruited participants who were aged 18 or over and be in the country where the qualitative research was being conducted (the UK or

Australia). Individuals with a broad range of types, severity and causes of hearing loss were eligible to participate. In the UK BSL interviews, a necessary additional requirement was that they used BSL and that they stated a preference for communicating via BSL.

Results

Table 1 summarises the participants included in each phase of the qualitative research.

Table 1

Phase	Location	Platform	Method	Number of participants
1	UK	Discourse (online discussion forum)	Focus group	23
	Australia	Zoom	Interviews	8
	UK	Zoom	Interviews with BSL interpreter	3
2	UK	Microsoft Teams	Interviews	9

Phase 1: Identifying Candidate Bolt-On Items

Three discussion groups were conducted with 23 participants (6, 7 and 10 respectively) and three BSL interviews were conducted with participants in the UK. Eight interviews were conducted with participants in Australia.

Key topics identified from this qualitative data included Relationships, Stigma, Communication, Emotional Impact, Effort, Aids & Technology, Impact on Employment, Safety Concerns, Activities, Terminology. These topics broadly align with the findings from our qualitative synthesis (Henderson et al., 2024). We observed some nuances in each topic by the level of hearing loss or identification as Deaf. There is also a degree of interconnectedness and spillover effects between topics.

Terminology

Participants identified terminology as important, with specific meaning attached to the words ‘deaf’ and ‘hearing’. The self-described terminology used by participants varied considerably, the most commonly used terms were deaf, Deaf, having mild/moderate/severe/profound hearing loss or hard of hearing. Some participants used the term ‘hearing impaired’ whilst others found this term problematic, particularly BSL users. BSL users also flagged the terms ‘deaf and dumb’ and hard of hearing as problematic.

Relationships

Relationships were commonly mentioned by participants as being impacted by their hearing loss, mainly pertaining to interacting or maintaining relationships with family and friends. This manifested in having to ask loved ones to repeat themselves, speaker clearer and slower or relying on others to translate. Impacts on intimacy were mentioned by some participants.

Stigma

Some participants reported experiencing stigma due to their hearing loss or deafness which can have an impact on self-confidence and self-identity. Individuals expressed fears of not being recognised as intelligent; one example of this related to asking colleagues to repeat themselves which may be construed as a lack of understanding rather than being hearing-related. Misconceptions around hearing loss and deafness mentioned included assumptions that hearing aids return hearing to perfect or assuming deaf people can’t drive. Another aspect captured in the data collection was the impact of stigma when considering visible or hidden hearing aids; some participants preferred hidden hearing aids to avoid the stigma whereas others wanted others to be aware of their hearing condition.

Communication

Communication was identified as a dominant feature, particularly in BSL users’ characterisation of the impacts of deafness. Difficulties with communication were experienced in various settings such as social, professional, consumer and healthcare, and could be exacerbated in loud places like restaurants, bars or supermarkets. Some participants had avoided social events or resorted to smiling and nodding politely if they did attend. Similarly, some had put off making phone calls or needed support from someone else; these created difficulties accessing services from the NHS, social services or utility providers. Many other impacts were also characterised as closely associated with communication such as relationships, aids & technologies and activities. BSL users expressed that they did not experience communication issues if they were born into a Deaf family and were integrated into the Deaf community.

Effort

People with hearing loss or deafness mention increased effort as a part of their daily lives, this can take many forms but mainly relates to listening effort, lip-reading effort and planning. Listening effort is a well-known concept in audiology but has no agreed-upon definition; an example of a working definition is “the mental exertion required to attend to, and understand, an auditory message” and is commonly associated with fatigue (McGarrigle et al. 2014). Research participants mentioned feeling tired from concentrating on conversation for so long and BSL users emphasised the extra effort required to plan activities or travel as mentioned below.

Activities

Participants mentioned the impact that hearing loss or deafness has on their activities, such as limiting their willingness to attend or no longer attending altogether. Activities mentioned included going to the cinema, theatre, church, quizzes and gym classes. Another aspect of this relates to travelling to and from activities, especially if they are alone; for example, not being able to hear announcements in train stations.

Emotional Effects

There are often emotional effects as a result of the aforementioned impacts which can also affect mental health. Difficulties with communication can lead to feelings of frustration, embarrassment and worry, affecting individuals’ confidence and independence. Missing information in important settings like medical appointments or while travelling can be stressful. Avoiding social activities can lead to isolation. Some participants reported anxiety or depression, which disproportionately affects people with hearing loss.

Aids & Technology

Many participants rely on aids & technology to assist them in their daily activities. UK-based individuals mentioned differences in the quality and accessibility of NHS hearing aids compared to those available privately, which can have financial implications. Other established aids and technologies mentioned were inductive loop systems and hearing dogs. A wide range of captioning technologies were also utilised such as subtitles on televisions and videos, smartphones for captioning phone calls, and video calls with captioning. BSL users highlighted a reliance on their mobile phones for communication, particularly video calls which use more battery than regular calls.

Employment

Some participants reported an impact on employment. This may be associated with communication or stigma, as mentioned above; one participant had experienced being omitted from meetings. Others mentioned barriers to employment and progression due to the presence of discrimination or a lack of reasonable adjustments by employers.

Safety Concerns

Participants also expressed safety concerns associated with their hearing loss or deafness. These included being unable to hear approaching traffic or people, especially from behind, and no longer being able to drive or cycle due to balance problems. Others worried about living alone at night as well as emergency situations where not being able to hear could have a detrimental impact.

Phase 2: Qualitative Testing of Candidate Bolt-On Items

The themes and topics identified in Phase 1 were considered and discussed by the research team to inform the descriptors taken forward to the Phase 2 interviews. The key aspects relevant to the next bolt-on development phase can be categorised into three areas: dimensions, framing and terminology. The potential dimensions identified for testing from Phase 1 were hearing in general (with and without descriptors), communication, social activities and fatigue. For conceptual and practical reasons, the research team decided that social activities and fatigue were beyond the scope of a hearing bolt-on. In terms of framing, the team wanted to consider the impact of using clinical terms to describe severity e.g., mild and profound instead of slight and extreme. Another aspect was the explicit consideration of aids/technologies or context (e.g. in social situations). Finally, the use of appropriate terminology was deemed necessary to be explored e.g., hearing problems vs. difficulties and the role of ‘deaf’ labels.

9 interviews were conducted with UK individuals. The findings relate to the dimensions (hearing function and communication), framing (surroundings and aids/implants), and terminology (alignment with existing scales and difficulties vs problems).

Dimensions

Hearing Function

Some participants did not know what was meant by sound clarity, localisation and effort, with localisation being the most understood. When understood, some participants did think that these aspects of hearing function are helpful for understanding what the questionnaire means by hearing. Some participants thought these assisted them in thinking about important aspects of their quality of life but many participants did not think not think that these terms were the most important aspects of HRQoL.

Participants struggled with the term "localisation" and suggested alternative wording such as "direction of sound" or "identifying the source of sound" for better clarity. As the concept of "sound localization" was not well understood, we tested replacing ‘localisation’ with ‘location of sound.’ This was better understood but overall was still not reflective of the participants HRQoL.

Communication

The communication questions were asked after the hearing questions in the interviews. During the hearing section of the interview, communication was discussed as being the most important aspect of quality of life for many participants.

When ‘communication’ alone was used as the descriptor, several participants raised that there are many types of communication, including many not related to hearing. In addition, participants raised communication challenges may arise not only from hearing loss but also from other factors such as social anxiety, dyslexia or autism. Therefore, some participants in the first interviews felt that communication-related questions should specify whether they refer to difficulties due to hearing loss to avoid capturing unrelated issues. This question was added to later interviews.

‘Understanding and being understood’ was generally preferred to ‘communication’ alone for reasons including that it helps to clarify what is meant by communication and emphasises that communication is two-way, so the person with hearing loss is not the problem when communication is difficult. Other participants raised that someone may be able to do one and not the other and so may not know where to place themselves and that this still does not provide the type of communication. "Understanding and being understood due to hearing" was suggested as a clearer phrasing that would help to relate this descriptor to hearing.

Providing ‘face-to-face and telephone’ as example forms of communication are considered confusing Participants felt that they would give different answers based on each of these types of communication, with some noting that in face-to-face communication you receive additional support visual cues.

Adding ‘due to hearing’ to the communication descriptor is helpful for visualising when they have struggled with communication due to their hearing, with the term ‘hearing loss’ being suggested as an alternative to ‘hearing’ alone. Two participants who were asked this question did not like it. One felt that it placed all the problems with the communication on them whilst the other felt like it could be “for a normal hearing person” who can have problems communicating in certain situations (such as where there is loud music and they are unable to lip read) that are not related to hearing loss.

Framing

Surroundings

Participants found that asking about ‘current surroundings’ helped them to focus on today, but that the surroundings in which they may complete the questionnaire may not reflect the other surroundings they will experience today. This is important as the impact of hearing on quality of life is dependent on the surroundings.

‘Social situations’ effectively captures a broad range of real-world experiences, enabling participants to think about the social situations they encounter. However, some participants considered this too broad and found it challenging to respond as their problems/difficulties vary significantly depending on specific factors. Participants in our first two interviews suggested that questions should explicitly define the characteristics of the surroundings.

Based on these comments additional surroundings were tested in future interviews including:

- whether the conversation was with a familiar or unfamiliar person,
- whether the setting was one-on-one or in a group,
- the level of background noise present.

The inclusion of details of a specific scenario were considered beneficial in eliciting more accurate reflections of real-life hearing challenges. The most challenging scenarios involved group conversations in noisy environments, while one-on-one conversations in quiet settings were considered an optimal listening environment.

Some participants found these additional details more confusing and raised more questions such as the specific number of people or their role in the conversation. One participant also raised that the more detailed scenarios are too specific for a quality of life issue and they do not think there is sufficient justification for giving preference to one situation over another as they all impact HRQoL.

A participant also raised that as in the EQ-5D-5L, the response options should include the information in the descriptor (e.g., I have no difficulties hearing in a quiet room with someone you know).

Hearing Aids & Cochlear Impants

Generally across many questions there was uncertainty about whether participants should respond to questions based on their hearing with or without hearing aids or cochlear implants. A participant noted that as the question is about today, they would respond according to whether they were using aids or implants today. However, for others, even when they were wearing hearing aids today there was a mixed response with some responding with their aids/implants but others responding without their aids/implants, often aligning with their audiologist's assessment.

When 'with aids or implants if you use them' was included in the descriptor some participants felt that this added clarity as to how they were expected to respond. However, the term 'aids' was felt to not be clear enough, with it not being clear if this included bone-anchored hearing aids (BAHAs) and other assistive devices. In addition, some participants felt the addition was unnecessary. It could confuse people without aids or implants, including some deaf individuals, as to how to respond. Also, the mobility question in the EQ-5D-5L does not ask about mobility aids so asking here would be an unnecessary bias. One participant stated that the inclusion of this descriptor gave them an "anxiety response."

Terminology

Alignment with Existing (Medical) Scales

Participants recognised that the scale used is similar to that used to describe different levels of hearing loss by medical professions. The difference being that medical professionals use mild instead of slight and profound instead of severe.

Some participants preferred the use of mild to slight as it aligned with medical terminology and provided a clearer scale. Some participants were indifferent, and one participant felt that slight was sometimes seen as allowing for greater personal interpretation, including from those who have not had a formal hearing assessment.

Participants raised that in general it should be clear how someone who was born deaf would respond to the question. This was particularly important for the question that referred to hearing loss as these individuals did not have hearing to lose.

Some participants were very happy to see response options where the term deaf was included. However, participants advised not to use the response option ‘I am deaf’ without the use of the word ‘profoundly’ as many individuals with mild, moderate and severe hearing loss identify as deaf. Therefore, this would make it confusing as to how they should respond.

Specifying profoundly deaf in a response option was liked by some participants as they thought it was clear and profound difficulties was thought by one participant to be “not as bad”. The term "profound difficulties" was seen by one participant as potentially misleading, as it could imply a temporary condition, while "profoundly deaf" was preferred for clarity. Participants emphasized the need to phrase questions in a way that does not inherently categorize profoundly deaf individuals as having an "extreme problem" by not placing ‘profoundly deaf’ as the last response option as a replacement for extreme problems.

In contrast, for other participants, profound difficulties was favoured over profoundly deaf in a quality-of-life context, as it conveyed challenges faced.

In noisy situations, one participant preferred ‘unable to hear’ as a replacement for profoundly deaf, as it encompassed both profoundly deaf individuals and those experiencing temporary hearing difficulties in challenging listening environments. Other preferred unable to hear in general as it was less clinical.

"Difficulties" vs. "Problems"

8 out of 9 participants interviewed expressed a strong preference for using the term "difficulties" over "problems", with the other participant not having a preference over the terms. Problems was perceived as more negative and there was concern that using the term could potentially lead to underreporting of the HRQoL impact due to the reluctance to acknowledge a "problem” as a result of stigma associated with hearing loss.

Two participants also felt that problems implies permanency, so difficulties better reflected how quality of life can vary overtime due to their permanent problem.

When exploring this preference further, some participants indicated that they had a general preference for the term differences in the context of quality of life and would have preferred the EQ-5D-5L to also use the word problems. However, some participant felt that problems made sense in the EQ-5D-5L but due to hearing being a hidden disability that difficulties was more appropriate than problems in this context both for the hearing and communication questions.

Medical vs. Personal Perception of Hearing

When asked about hearing loss in general, responses typically aligned with their audiologist's assessment. However, when presented with context-based questions, responses reflected their subjective experience at that moment, often incorporating situational variables such as background noise or number of people they are communicating with.

While medical terminology was seen by some participants as a useful anchor for responding to the question, participants emphasized that their personal experience is more important for capturing their HRQoL.

One participant raised that the term moderate-severe is a category now used by medical professionals. Therefore, participants labelled with moderate-severe hearing loss as a result of an audiologist's assessment may have to make a choice between moderate and severe and so it would not be possible to directly align their response with their medical assessment.

Discussion

The findings from the online discussion groups and video interviews provide insights into the lived experiences of individuals with hearing loss/are deaf and are a vital step in the construction of a hearing-related bolt-on item.

In Phase 1, the identified key themes—relationships, stigma, communication, emotional impact, effort, aids and technology, impact on employment, safety concerns, activities, and terminology—reflect the multifaceted nature of hearing loss and its effects on HRQoL. Additionally, the qualitative data reflect the interconnectedness of these themes and the nuanced experiences across different levels of hearing loss and settings.

Including participants who use BSL enhanced the inclusivity of our research, improving the likelihood that the bolt-on(s) will apply to this population. However, it is important to note that it is possible that due to the use of an interpreter, there may be nuances and details provided by the interviewee that may not be accurately reflected in our findings.

Insights from Phase 1 shaped the development of descriptors for Phase 2 interviews, focusing on dimensions, framing, and terminology. Hearing and communication were both considered dimensions within scope. Framing considerations involved the impact of clinical severity terms (e.g., mild vs. profound) and the inclusion of aids or situational context. Terminology discussions focused on distinctions like "problems" vs. "difficulties" and the appropriate use of 'deaf' labels.

Examples of hearing function were overall not perceived as key factors in assessing HRQoL in the context of hearing. In contrast, communication is an important factor, but communication alone is too broad and an appropriate descriptor would need to be used that ensured the communication was relevant to hearing, whilst ensuring that individuals with hearing loss/who are deaf do not feel like they are a problem.

The impact on HRQoL as a result of being deaf/hearing loss is context-dependent. While including 'social situations' in the descriptor was seen as useful to some for bringing to mind scenarios where they face difficulties, it was sometimes too broad. More specific details, such as background noise and the familiarity of conversation partners, improved clarity but also raised concerns about excessive specificity. It was also raised that no single scenario should be prioritized over another in assessing HRQoL.

Participants varied in whether they responded based on their hearing with or without aids. Adding 'with aids or implants if you use them' would increase consistency in responses across participants. However, some participants found the addition unnecessary. Some felt this inclusion could bias responses compared to the EQ-5D-5L dimensions, which do not reference assistive devices.

Most participants favoured ‘difficulties’ over ‘problems,’ as the latter was seen as more negative and potentially stigmatizing. ‘Difficulties’ also better captured the varying nature of the hearing-related challenges that depend on context. Some participants generally preferred difficulties, even as a replacement for problems in the EQ-5D-5L, raising the question as to whether the bolt-on should use problems to align with the EQ-5D-5L or if there is sufficient justification that in the context of hearing difficulties is more appropriate.

Some participants preferred medical terms (e.g., ‘mild’ instead of ‘slight’) for consistency with professional assessments, while others valued more flexible language.

In general, across all potential bolt-on items, there must be a place for profoundly deaf individuals to be able to respond. With regards to explicitly including the term profound in response options, preferences vary between "profoundly deaf" and "profound difficulties" depending on whether the participant felt the response should align with their medical assessment or allow for more flexibility to enable a better reflection of HRQoL. The placement of ‘profoundly deaf’ in response options requires careful consideration to avoid implying an extreme problem.

Participants generally aligned with their audiologist’s assessment when responding to general hearing questions. However, context-based questions elicited more subjective responses based on situational factors. While some found medical terminology useful, HRQoL was seen as best captured through personal experience rather than clinical classifications.

Participants agreed that descriptors should not include multiple examples where the response to each example could be contradictory, making the question more difficult to respond to.

These insights are essential for ensuring that the descriptors accurately capture the impact of hearing on HRQoL and align with the experiences and perceptions of individuals with hearing difficulties. Additional Phase 2 interviews will be conducted in Australia to further explore the findings already identified from this qualitative research. Following this, in Phase 3 we will conduct quantitative analysis of descriptors. This will entail an online survey administered to a cross-sectional sample of people with hearing loss/who are deaf and the general public in the UK and Australia. The survey will explore themes such as whether there is a role of a communication item in a hearing bolt-on, whether concerns about specifying context affect results and whether it's important to be explicit about the use of aids/implants.

Conclusion

This study highlights the complexity of assessing HRQoL in the context of hearing and the importance of carefully designed descriptors. Findings emphasize that communication is a key aspect affecting HRQoL that may not be adequately captured by the EQ-5D-5L. Therefore, it may warrant explicit inclusion as an item within a hearing bolt-on.

The challenges faced are dependent on the surroundings and whether individuals are using aids/implants. A balance needs to be sought between providing additional information in the descriptor that provides clarity and/or additional context that aids the respondent in answering the question and causing confusion and/or a lack of inclusivity.

Preferences for terminology varied, particularly regarding the usefulness of alignment with medical terminology and the use of "problems" versus "difficulties," with the latter generally preferred. Finally, there are important sensitivities around the wording of a hearing bolt-on for the EQ-5D-5L, with challenges to the notion of ranking states of hearing, especially among the profoundly deaf.

Further interviews in Australia and subsequent quantitative analysis will refine these descriptors to ensure they accurately reflect lived experiences and align with the EQ-5L-5L.

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Appendix

Yellow highlighted text indicates the differences from H1P1 that are being tested in each candidate item.

H1P1	**HEARING** I have no problems with hearing I have slight problems with hearing I have moderate problems with hearing I have severe problems with hearing I have extreme problems with hearing
H1D1E1	**HEARING** (in your current surroundings) I have no difficulties hearing I have slight difficulties hearing I have moderate difficulties hearing I have severe difficulties hearing I am unable to hear
H1P2E2	**HEARING** (e.g. sound clarity, localisation, and effort) I have no problems with hearing I have mild problems with hearing I have moderate problems with hearing I have severe problems with hearing I have profound problems with hearing
H1P3E3	**HEARING** (with aids or implants, if you use them) I have no problems with hearing I have slight problems with hearing I have moderate problems with hearing I have severe problems with hearing I am deaf
H1P4E4	**HEARING** (in social situations) I have no problems with hearing I have slight problems with hearing I have moderate problems with hearing I have severe problems with hearing I am deaf
H2P1	**COMMUNICATION** I have no problems with communication I have slight problems with communication I have moderate problems with communication I have severe problems with communication I have extreme problems with communication
H2P1E4	**COMMUNICATION** (e.g. understanding speech and being understood) I have no problems with communication I have slight problems with communication I have moderate problems with communication I have severe problems with communication I have extreme problems with communication
H3P1	**COMMUNICATION** (in social situations) I have no problems with communication I have slight problems with communication I have moderate problems with communication I have severe problems with communication I have extreme problems with communication
H1D2	**HEARING** I have no difficulties hearing I have slight difficulties hearing

	I have moderate difficulties hearing I have severe difficulties hearing I have extreme difficulties hearing
H1D3	**HEARING** I have no difficulties hearing I have slight difficulties hearing I have moderate difficulties hearing I have severe difficulties hearing I am profoundly deaf
H1D4E5	**HEARING** (in your current surroundings) I have no difficulties hearing I have slight difficulties hearing I have moderate difficulties hearing I have severe difficulties hearing I have profound difficulties hearing
H1D5E6	**HEARING** (in a quiet room with someone you know) I have no difficulties hearing I have mild difficulties hearing I have moderate difficulties hearing I have severe difficulties hearing I am profoundly deaf
H1D1E6	**HEARING** (in a public place with background noise) I have no difficulties hearing I have slight difficulties hearing I have moderate difficulties hearing I have severe difficulties hearing I am unable to hear
H1D6E7	**HEARING** (in social situations with some background noise and more than one other person) I have no difficulties hearing I have mild difficulties hearing I have moderate difficulties hearing I have severe difficulties hearing I am profoundly deaf
H2P1E5	**COMMUNICATION** (e.g., face-to-face or on the telephone) I have no problems with communication I have slight problems with communication I have moderate problems with communication I have severe problems with communication I have extreme problems with communication
H2P1E6	**COMMUNICATION** (due to hearing) I have no problems with communication I have slight problems with communication I have moderate problems with communication I have severe problems with communication I have extreme problems with communication
H3M1	**HEARING** I have no hearing loss I have mild hearing loss I have moderate hearing loss I have severe hearing loss

	I have profound hearing loss
H1P2E3	**HEARING** (e.g. sound clarity, identifying location of sound, and effort) I have no problems with hearing I have mild problems with hearing I have moderate problems with hearing I have severe problems with hearing I have profound problems with hearing