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Understanding the valuation of paediatric health-related quality of life: a qualitative study protocol

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ABSTRACT

Introduction There is evidence from previous studies that adults value paediatric health-related quality of life (HRQoL) and adult HRQoL differently. Less is known about how adolescents value paediatric HRQoL and whether their valuation and decision-making processes differ from those of adults. Discrete choice experiments (DCEs) are widely used to develop value sets for measures of HRQoL, but there is still much to understand about whether and how the methods choices in the implementation of DCE valuation tasks, such as format, presentation and perspective, affect the decision-making process of participants. This paper describes the protocol for a qualitative study that aims to explore the decision-making process of adults and adolescents when completing DCE valuation tasks. The study will also explore the impact of methodological choices in the design of DCE studies (including decisions about format and presentation) on participants' thinking process.

Methods and analysis An interview protocol has been developed using DCE valuation tasks. Interviews will be conducted online via Zoom with both an adolescent and adult sample. In the interview, the participant will be asked to go through some DCE valuation tasks while 'thinking aloud'. After completion of the survey, participants will then be asked some predetermined questions in relation to various aspects of the DCE tasks. Interviews will be recorded and transcribed and analysed using a thematic analysis approach.

Ethics and dissemination Ethics approval for this study has been received for the adult sample (UTS ETH20-9632) as well as the youth sample (UTS ETH22-6970) from the University of Technology Sydney Human Research Ethics Committee. Results from this study will inform the methods to be used in development of value sets for use in the health technology assessment of paediatric interventions and treatments. Findings from this study will also be disseminated through national/international conferences and peer-reviewed journals.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Up to 100 Australian adolescents and adults will be interviewed, making it (to the best of our knowledge) one of the largest qualitative studies testing valuation methods.
⇒ This is one of the first qualitative studies to show adolescents choice tasks with duration.
⇒ 'Think aloud' cognitive interviews will be used to explore the impact of various methodological decisions made in valuation studies on participants' thinking process.
⇒ These interviews will be conducted online through Zoom, limiting recruitment to those that have a good internet connection.
⇒ 10–20 interviews will be conducted at a time which has the advantage of allowing interim analysis to determine whether interview content needs to be adjusted and the introduction of any new content.

INTRODUCTION

Quality-adjusted life-years (QALYs) are a measure of health outcomes for use in economic evaluation and are comprised two characteristics, the quality and quantity of life.[1 2] The quality of life is measured on an index scale (often called health utilities) anchored at the values 0 and 1 which correspond to dead and perfect health, respectively. Negative values corresponding to states worse than death are also possible.[3] QALYs are calculated by weighting the time in a health state by the corresponding health utility for that state. Health states are typically described using a health-related quality of life (HRQoL) instrument. These instruments usually consist of a set of questions pertaining to different aspects or dimensions of HRQoL, where the instrument also has a scoring algorithm that has been derived using a preference elicitation method. This provides a value set defining the relative importance of dimensions relative to each other, and to length of life they can be used to calculate QALYs. These instruments are often called preference-based/preference-accompanied measures or PBMs.

There are several PBMs for measuring adult HRQoL such as the EQ-5D-5L,[4 5] SF-6D[6–8] and the AQoL.[9] As well as instruments specifically designed to measure HRQoL in paediatric populations.[10 11] There also exists preference-based instruments such as the CHU-9D,[12] EQ-5D-Y[13] and the HUI2/HUI3.[14 15] There are also non-preference based instruments such as the PedsQL.[16] There is ongoing work to develop preferences for the PedsQL.[17]

HRQoL is most commonly valued through the use of stated preference techniques such as time-trade-off (TTO), standard gamble and discrete choice experiments (DCEs). Many valuation studies have used TTO and variations of the TTO have been developed specifically for valuing PBMs such as the EQ-5D-5L.[18 19] The use of DCEs in valuation studies have been growing in popularity.[20] In a typical valuation study using DCEs, adult respondents see a series of choice tasks. In each choice task, two or more health states are presented and respondents are asked to choose the one they prefer. Each health state is described by several attributes, often taken from an HRQoL instrument. These are referred to as latent scale DCE choice tasks. In some instances, the health states also include an extra attribute specifying the number of years the health state would be experienced before dying, these are referred to as DCE choice tasks with duration in this study. This attribute has been included to allow for explicit consideration of where 'death' lies on the QALY scale.[21] There is debate about the extent to which methods for valuing adult HRQoL can be applied to paediatric HRQoL. In particular, valuation tasks used in the valuation of adult HRQoL may not be appropriate for the elicitation of preferences for child HRQoL due to ethical and/or cognitive constraints. For instance, can respondents understand and complete DCE choice tasks with duration when valuing paediatric HRQoL.

In addition to the debate about the appropriate tasks to use in valuation studies of child HRQoL, there has also been debate about whose values should be measured in such valuation studies. Adults' preferences have been argued to be the most appropriate, for example, because from a public policy perspective, only preferences from those eligible to vote, that is, adults are taken into account and their views should be prioritised in the determination of public health resource allocation.[22 23] Opposing arguments are that children and adolescents are the beneficiaries of paediatric care and ensuring that the development of such care reflects the preferences of this population will improve the benefits to such a population.[24] An assumption underlying this debate about whose preferences are appropriate is that there are differences in how adults and adolescents value paediatric health states and when completing valuation tasks.

Previous literature suggests that there are differences in how adults and adolescents value HRQoL.[25] There is also evidence that there are differences in the decision-making process of adult participants when valuing paediatric HRQoL as compared with adult HRQoL. It has been reported that adults give children's health states higher values compared with adults' health states in both TTO and DCE studies.[26 27] One of the explanations is that adults prefer a longer life for children and are therefore reluctant to trade off life years.[28] There is also evidence that adults who are also parents place higher values on child health states than do adults without children.[29]

There is also evidence from the literature that adults think that adults and children have different coping abilities. For example, children and adolescents are thought to be more flexible and can adapt more easily to health challenges than can adults, in part because they will be able to get support from their parents/caregivers and society.[29–32]

This raises questions about the decision-making process participants go through when valuing paediatric HRQoL compared with adult HRQoL. This study will qualitatively explore how participants make decisions when completing valuation tasks. This study will also test how participants understand and respond to different valuation task formats. Most importantly, this study will explore how adults and adolescents value paediatric HRQoL and identify similarities and differences in how they approach valuation tasks.

Aims of study

The aims of this study are formally defined below. This study aims to investigate:

1. How participants complete DCE valuation tasks using a range of paediatric HRQoL instruments/PBMs, specifically, the EQ-5D-Y-5L, CHU-9D, the HUI2/3 and the PedsQL.
2. The impact of various methodological decisions on respondents. Specifically:
    1. Whether the choice of paediatric HRQoL instrument/PBM has an impact on the participant valuation process.
    2. The impact of adding duration as an extra attribute in DCE choice tasks on respondent decision-making.
    3. The impact of asking respondents to imagine themselves versus a child on respondent decision-making.
3. Whether there are any differences in perceptions and understanding of these DCE valuation tasks between adults and adolescents.

An iterative approach will be taken, whereby interviews will be conducted in rounds. A round will include 10–20 interviews. After each round, the results from the interviews will be assessed and used to inform the questions and valuation tasks shown in the next round.[33 34] The iterative nature of the interviews will also mean that various aspects of valuation studies for example, using different HRQoL instruments, different formats and presentation of valuation tasks, can be tested and varied as the interview rounds progress. This allows the researchers to refine the valuation tasks and introduce new questions or more focused questions arising from the response received in each round of interviews. Results from this study will also be used to inform the development of value sets for the EQ-5D-Y instruments.

METHODS AND ANALYSIS

Overview of approach and methods

A qualitative method, namely, 'think aloud' cognitive interviews[35–37] will be used to investigate the aims of this study. These interviews will consist of two main sections. The first section will be a 'think aloud'.[38 39] Participants will be asked to complete a survey while verbalising their thought process. In the second section, participants will be asked a series of preplanned questions relating to specific aspects of the survey.

The survey that the participants complete during the 'think aloud' will consist of DCE choice or valuation tasks. In each choice task, participants will be presented with two hypothetical health states described using existing PBMs and asked which health state they would prefer to experience. The health states described will be taken from several widely used and validated generic paediatric HRQoL instruments: the CHU-9D, EQ-5D-Y and HUI2/3. The PedsQL instrument has also been proposed to be part of the study, but its inclusion will depend on the timing of work being undertaken to develop a PBM from the PedsQL.[17]

The preplanned questions after the 'think aloud' will be related to the aims of the study. There will also be questions relating to general feedback on the survey.

Aspects to be explored in interviews

An iterative approach will be taken for deciding the content of interviews in each round. That is, the specific DCE choice tasks to be included in the 'think aloud' and the questions afterwards will depend on the specific round of interviews. The data will be analysed periodically (interim analysis) while interviews are being conducted and used to inform changes in choice tasks and preplanned questions during the rounds of interviews. Figure 1 provides an overview of this process. All data will be formally analysed at the end after data collection is complete.

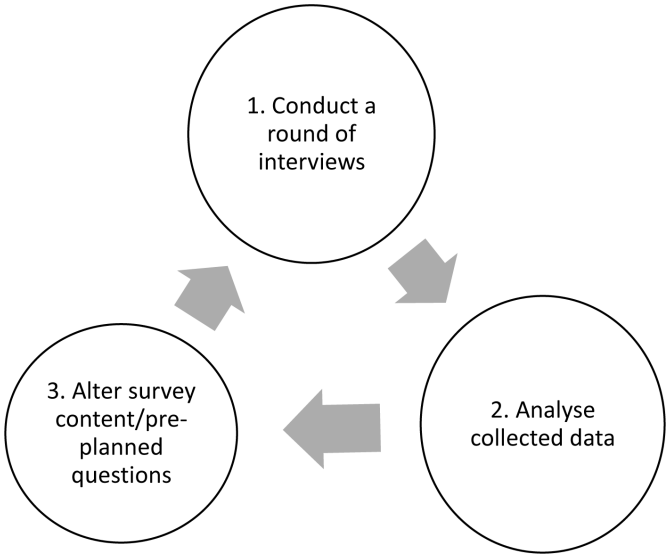

Figure 1 Diagram of interview rounds process.

Table 1 Aspects explored in choice tasks

Type of variation	Description and examples
Perspective when completing choice tasks	1. Imagine self 2. Imagine a child, for example, 10 years old
Choice task format	1. Latent scale (LS) DCE choice tasks include only the attribute and levels from a PBM 2. DCE TTO choice tasks include the attribute and levels from a PBM and also an extra attribute for duration phrased as 'live for [insert number] number of years before you die'
PBM shown to participants	1. Participants may see a block of choice tasks based on only one PBM 2. Participants may see a block of choice tasks based on two or more PBMs, for example, four choice tasks based on EQ-5D-Y-5L and four choice tasks from the CHU-9D

DCE, discrete choice experiment; PBMs, preference-accompanied measures; TTO, time-trade-off.

Although the choice tasks seen in the survey and preplanned questions asked afterwards may vary between rounds. This variation will always centre around the aims of the study, namely, in relation to interpretation and understanding different PBMs, how respondents complete tasks when imagining different perspectives and the impact of including duration as an attribute on decision-making. Table 1 summarises the different aspects that could be varied in choice tasks within a round of interviews or across different rounds of interviews.

It could also be the case that only one or two aspects are explored per round. For instance, in the pilot round, perspective and choice task format is varied but the PBM used in choice tasks is constant for each participant. In subsequent rounds of interviews, it could be the case that choice task format and PBM seen by participants varies, while perspective remains constant. Alternatively, it could be the case that all aspects are varied in one round. This process allows the researchers to explore the impact of various methodological decisions from different angles while also allowing for the flexibility of focusing on a particular aspect or a number of aspects in any given round.

Paediatric HRQoL instruments included in DCE choice tasks

The EQ-5D-Y-5L, CHU-9D and the HUI2/3 will be included in DCE choice tasks. The PedsQL is also planned to be included, although this is subject to whether a PBM for the PedsQL is developed in time.

A series of steps were undertaken to identify the appropriate candidate HRQoL instruments. This included a literature search[11] and internal consultation within the research team. There was also a formal consultation

session with the Decision Maker's Panel (DMP). This included a half-day workshop. In this workshop, the research team presented some descriptive comparisons of instruments as well as psychometric performance and comparisons of instruments to generate discussion. The DMP represents a range of health policy decision-making bodies in Australia including the Pharmaceutical Benefits Advisory Committee (PBAC), Medical Services Advisory Committee (MSAC), Australian Technical Advisory Group on Immunisation, Australian Life Sciences Industry as well as clinicians and a consumer representative.

A brief overview of these instruments is provided in the following sections.

CHU9D

The CHU9D[12 40] consists of nine questions. The CHU-9D was originally developed with children aged between 7 and 11. However, it can be completed via proxy for children aged between 4 and 7 and has been used in adolescents aged 12–18 years of age.

EQ-5D-Y-5L

The EQ-5D is a widely used generic measure of health. The EQ-5D-Y[13] is the child version of the EQ-5D and consists of three levels across five dimensions. The dimensions include mobility, looking after myself, doing usual activities, having pain or discomfort and feeling worried, sad or unhappy. The EQ-5D-Y-5L is an experimental version of the EQ-5D-Y which has five levels instead of three levels. It can be used in children aged between 8 and 15 years. The EQ-5D-Y-5L will be used in this study.

HUI2/3

The HUI2/HUI3[14 15] consists of 15 questions. The HUI3 has been designed for adolescents above the age of 12/13. There is another version, called the HUI2, which is suitable for children above the age of 5.

PedsQL Short Form

The PedsQL[16 41] has 23 questions in total. There are currently 12 different versions of the PedsQL instrument, with differences in wording to suit different age groups. The version used in this study is an experimental short form version. This is currently still under development, and it is hoped that the PedsQL Short Form will be added as an instrument for valuation in one of the later rounds of interviews.

Formulation of DCE choice tasks in 'think aloud' section

As the objective of this study was qualitative exploration, the ability to quantitively analyse choice tasks was not a priority. Instead, the focus was on showing participants sufficient variety in order to promote discussion from participants and to better understand their thinking process. Therefore, a combinatorial design approach was not used and instead the choice tasks are hand crafted. This approach of using hand crafted choice tasks to understand the decision-making process of participants has been used in previous studies.[31 42]

Each participant will see eight choice tasks. Each choice task will require participants to choose which of two hypothetical health states they prefer. Task formats included are the latent scale DCE choice tasks and DCE choice tasks with duration. In latent scale DCE tasks, health states consist only of the different attributes of HRQoL for consideration. In DCE choice tasks with duration, health states also include an extra attribute for the length of time they would experience the health state for before dying. In some of the choice tasks, level overlap is used that is, some of the attribute levels will be the same across health states, while in other choice tasks, respondents see all attribute levels are different between health states seen in each choice task. This is done with the goal of showing respondents a variety of choice task presentation formats.

For the pilot round of interviews, three HRQoL instruments will form the basis of valuation tasks: the EQ-5D-Y-5L, CHU-9D and the HUI2/3. An example of a latent scale DCE task and a DCE choice task with duration is presented in figures 2 and 3, using the EQ-5D-Y-5L. An example choice task based on each of the three different instruments to be used in the pilot round has been included in online supplemental appendix A.

Respondents in the pilot round of interviews will only see valuation tasks based on one HRQoL instrument. However, as one of the goals of this study is to compare the impact of using different HRQoL instruments on decision-making, respondents will see valuation tasks based on more than one HRQoL instrument in a future round/s of interviews.

Preplanned questions after completion of the 'think aloud' section

After completion of the DCE survey, participants will be asked several preplanned questions relating to the aims of the study. The complete set of questions for the pilot round of interviews can be found in the interview protocol (online supplemental appendices B and C).

Participants will be asked several questions to explore:

1. The strategy or thought process when choosing between the two health states in each question.
2. The impact of adding duration to the health states on decision-making.
3. The impact of thinking of health states in the context of themselves versus a 10-year-old child.

Participants will also have the opportunity to provide any additional general feedback or comments.

Development of interview materials and survey content

A draft of the interview protocol and survey contents for the pilot round of interviews was developed based on input from the research team. Feedback was also sought from the two interviewers employed by the market research company to ensure the interview protocol was using language that is suitable for an adolescent sample. A copy of the pilot interview protocol sheet for the adolescent and adult sample is available in online supplemental appendices B and C, respectively. The protocol was kept

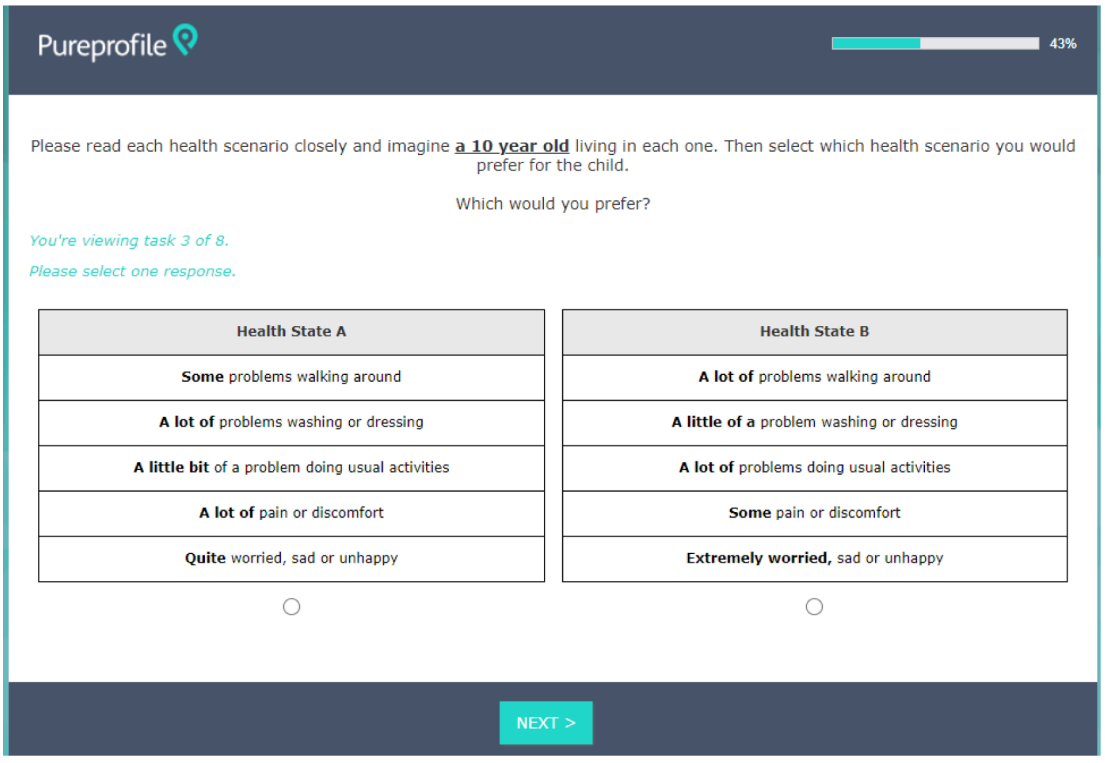

Figure 2 Example of latent scale discrete choice experiments choice task using the EQ-5D-Y-5L.

as similar as possible between the two samples to ensure as much consistency as possible.

The introduction to the interview protocol will remain relatively unchanged across rounds, as it outlines essential information to be provided to the participant. The interview protocol includes the preplanned questions to be asked in interviews. As mentioned in previous sections, the preplanned questions may be different for each

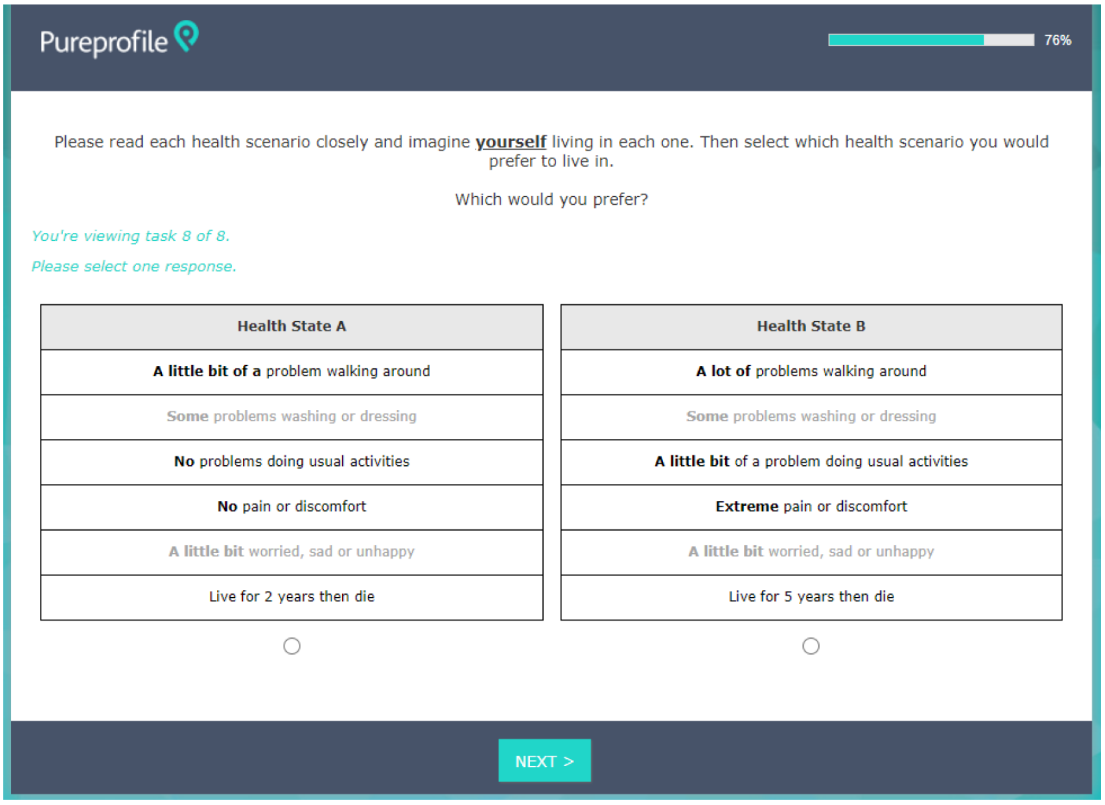

Figure 3 Example of discrete choice experiments choice tasks with duration using the EQ-5D-Y-5L.

round of interviews, depending on the aspects for exploration during that particular round.

Approach to sampling and interviews

An important aim of this study is to understand whether there are differences in the cognitive processes and in the valuations between adolescents and adults, and therefore the study will include both an adolescent and adult sample. The adolescent sample will consist of young people aged between 11 and 17 years of age. The adult sample will consist of people aged 18 and above, stratified to obtain a mix of those with and without children.

The interviews will be conducted by three interviewers. Interviews will be conducted by experienced interviewers. Two of whom are employed by a market research company with experience conducting qualitative interviews with adolescents. The third interviewer will be someone from the research team who has experience conducting qualitative interviews with adults. The third interviewer will only conduct interviews with the adult sample. While, the other two interviewers will be responsible for conducting interviews with the adolescent as well as adult sample, as they have the necessary experience working with adolescents in a qualitative context. A half-day training session will be provided to ensure consistency of the protocol application among the three interviewers. The three interviewers will also be in regular contact via email and virtual meetings as necessary to discuss interview materials and updates between rounds. The first round of interviews will be a pilot of approximately 10 interviews.

The sample will include up to 50 adolescents aged between 11 and 17, and up to 50 adults. The study has enough funding for up to a maximum of 100 interviews. The final sample size will depend on the findings from each round of interviews and whether the aims of the study have been sufficiently addressed, that is, no new additional information being added from interviews on the aims/topics.[43]

Data analysis and outcomes measured

The interviews will be conducted via Zoom. This has its advantages and disadvantages. This will mean only respondents with a good internet connection will be able to participate. However, this will also allow recruitment across Australia with relative convenience and low cost. Participants were recruited through a market research company and will be offered $A50 as compensation for their time. The interviews will be audio and visually recorded using Zoom. Interviews will also be transcribed for the purposes of analysis.

Thematic analysis will be used to explore the interview data.[42 44 45] Analysis will be in two parts, interim analysis while interviews are being conducted and formal analysis of all interview data after all interviews have been completed. The interim analysis will be periodically conducted between rounds of interviews. This will allow the researchers to gain an overview of current results, to identify general trends. This will also assist in deciding whether to continue testing the same blocks of choice sets or change to test new blocks of choice sets that may focus on the same or different aspects. An interim analysis framework to be completed by interviewers for the pilot round is provided in online supplemental appendix D. This is based on the preplanned questions to be asked in the pilot round as well as the aspects explored. The interim analysis framework may be periodically updated with the rounds of interviews to reflect any changes in the aspects of focus in that particular round.

Patient and public involvement

This study is being conducted as part of a larger research programme, namely, the *Quality Of Life in Kids: Key evidence to strengthen decisions in Australia* (QUOKKA) research programme. The QUOKKA programme includes a Consumer Advisory Group (CAG), made up of relevant stakeholders including parents of children with complex needs. The CAG has provided input and feedback through several meetings where the aims, methods and planned interview materials of this study have been shared with them.

Ethics and dissemination

There are potentially sensitive ethical considerations in conducting a valuation study, particularly with adolescent participants. Prior to each interview, participants will be given a participant information sheet and a consent form. This consent form will have to be signed and returned by the participant or the participant's guardian (if under the age of 15) before the interview can take place. This is to ensure that participants are aware of the purpose and expected content of the interviews. A copy of the participant information sheet and consent form for the parent/guardian (if participant is younger than 15), youth sample (those aged 15 and above) and adult sample is available in online supplemental appendices E–G.

The participant information sheet explains that participants will see some descriptions of health states that are quite severe. Some of the health states will also require thinking about living for a certain number of years before dying. This is also explained again at the beginning of the interview and participants are reminded that this interview is voluntary and they can discontinue at any point. A distress protocol was also developed to assist the interviewer if the participant shows any sign of distress. A copy of the distress protocol is available in online supplemental appendix H.

The consent form also details that the interviews will be audio and visually recorded for the purpose of data analysis. The consent form will be sent electronically to participants once they have indicated interest in participating. Participants or their guardians will then have the option to add an electronic signature or to print out the form to sign, scan and then send back via email to the recruiter. The signed consent forms will then be passed on to the research team for safe keeping. All collected information including consent forms, interview recordings and

transcriptions will be kept on the university approved OneDrive folder. This folder can only be accessed by the relevant team members working on the data analysis. Ethics approval for this study has been received for the adult sample (UTS ETH20-9632) as well as the youth sample (UTS ETH22-6970).

The insights from this study will help to establish which instruments to use and how they should be framed in a large-scale multi-arm DCE, as part of the QUOKKA research programme (https://www.quokkaresearchprogram.org/). Findings from this study will also be disseminated in the form of papers and presentations at national and international conferences.

Insights gained from this study will potentially improve the Australian PBAC's and MSAC's use of child-specific and adolescent-specific PBMs in health technology assessment. This will, in turn, help policymakers to make more informed decisions around reimbursement and government subsidy of child health services. Healthcare providers and paediatric researchers will be able to better understand the effectiveness of paediatric interventions in improving those aspects of HRQoL that matter most to patients and their families.

Collaborators on behalf of the Quality Of Life in Kids: Key evidence to strengthen decisions in Australia (QUOKKA) project team.

Contributors ND, RN, RV, DS, BJM, AY, MB, YL contributed to the overall study concept and design through regular meetings. ND is the CIA of the QUOKKA research programme, BM and AY developed the detailed study protocol. YL provided input through her literature review and this formed the first draft of the introduction to the manuscript. AY drafted the overall manuscript. All authors revised provided comments, feedback and approved the final manuscript.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

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