van Heusden *et al. Health and Quality of Life Outcomes* (2026) 24:6
https://doi.org/10.1186/s12955-025-02456-x

Health and Quality of Life Outcomes

RESEARCH **Open Access**

Exploring valuation of a modified EQ-5D-Y-3L adapted for 2–4 year olds: a think-aloud study

Alexander van Heusden[1*], Renee Jones[1], Alice Yu[2], Brendan Mulhern[2], Kim Dalziel[1] and Nancy Devlin[1]

Abstract

Aim This study aimed to establish the feasibility of using discrete choice experiments (DCE) to value health states described by the modified EQ-5D-Y-3L adapted for 2-4-year-olds, and to explore participants' views on relevant preferences, valuation perspective, age framing, and spillover effects, and how all of these are impacted by parental status.

Methods Online interviews were conducted with Australian adults, comprising six think-aloud DCE (imagining a hypothetical 3-year-old) and open-ended questions to explore the key aims. Interview transcripts were double-coded using an inductive and deductive approach and analysed using framework analysis.

Results A total of 17 participants took part (parents/caregivers, $n=9$; non-parents, $n=8$). Participants emphasised the inclusion of preferences from parents/caregivers or professionals who interact with children. Participants tended to instinctively think of their own child or a child they know. Both caregiver and future spillover effects were observed, and participants included information beyond the description of the task when providing valuations. Participants reported a high level of ease and understanding in completing the DCE tasks.

Conclusions DCE appears to be feasible for obtaining stated preferences regarding dimension importance for the modified EQ-5D-Y-3L adapted for 2-4-year-olds. Participants expressed views that preferences for these health states should be elicited from adults with experience of young children. It is important for future valuation studies to examine the types of spillover effects and other factors influencing participants' assessments of health states for young children.

Keywords Adapted EQ-5D-Y, Paediatric, Valuation, Think-aloud, DCE

Background

Measuring health-related quality of life (HRQoL) in very young children (< 5 years) is important, as many key interventions, including vaccines and genetic screening, occur within this critical age range. The EQ-5D-Y-3L was adapted for use in children aged 2–4 to address the gap in HRQoL instruments in this age range that can be used for valuation and quality-adjusted life years (QALY) estimation [1–3]. The modified EQ-5D-Y-3L differs from the original EQ-5D-Y-3L by being a proxy-completion only instrument for 2-4-years-olds, including age-appropriate examples in each dimension, and featuring more

*Correspondence:
Alexander van Heusden
alex.vanheusden@unimelb.edu.au
[1] Health Economics Unit, Melbourne School of Population and Global Health, The University of Melbourne, 4/207 Bouverie Street, Carlton, VIC 3053, Australia
[2] Centre for Health Economics Research and Evaluation, University of Technology Sydney, Sydney, Australia

appropriate wording [1]. For example, ‘looking after self’ was modified to ‘helping look after self’ to reflect the intermediate point of independence [1]. The modified EQ-5D-Y-3L adapted for 2-4-year-olds (referred to as the adapted EQ-5D-Y), together with the broader suite of EuroQol instruments, enables the measurement of HRQoL across the lifespan, which is essential for assessing the effectiveness of new interventions in clinical trials [1, 2].

Although testing has found the adapted EQ-5D-Y-3L to be reliable in this age range, no value set currently exists, preventing the use of HRQoL data generated from it to estimate QALYs [1, 4]. Failure to capture QALYs risks Health Technology Assessment (HTA) bodies overlooking this age group when making resource allocation decisions. Given the minor changes to the descriptors in health states (Supplementary Fig. 1), it is unclear whether the value sets developed for the EQ-5D-Y-3L, derived from adults’ preferences based on their views of a hypothetical 10-year-old child [2], can be applied directly to the adapted EQ-5D-Y-3L [5].

Research to date has produced mixed evidence on whether the stated age of a child influences values for child HRQoL. Qualitative research found that participants placed greater importance on mobility and the ability to look after oneself when considering a 15-year-old child, compared to a 10-year-old [6] suggesting that preferences about child health may differ by child age. In contrast, quantitative studies have shown little to no impact on results from the latent scale discrete choice experiment (DCE) and VAS values by varying the age framing. Notably, none of these studies included the valuation of health states in children below the age of 5 years [6–8]. Variations in values by child age suggest the potential need for an age-specific value set for the adapted EQ-5D-Y-3L for 2-4-year-olds.

Although there are several HRQoL instruments designed for measuring HRQoL in the 2–4 year age range, such as PedsUtil [9], CHU9D [10], and EQ-TIPS [11], only HUPS provides a value set [12]. The HUPS values are obtained by mapping to the HUI2/3 scoring system, which was developed based on adult preferences for hypothetical health states [12]. Thus, HUPS values do not reflect the possibility that adults’ preferences for child health states may be age-specific [12]. There is a lack of guidance from HTA bodies on how valuation studies should be conducted in children under 5 years of age [13–15]. Valuing HRQoL in children aged 2–4 years raises key questions: [16]. (1) Whose preferences should be used? Should the preferences of the general population continue to be used, or should alternative approaches be considered—such as prioritizing the preferences of parents/caregivers, child health experts, or older children? (2) What should the perspective of the valuation task be? The framing used may involve asking the adult what their preferences are while considering a young child, or alternatively, asking the adult what they think a young child’s preferences would be. Alongside this framing, the adult could be asked to take the perspective of a hypothetical child, a child they know, their own child, or themselves as a child. (3) What age framing should be used? For example, for the adapted EQ-5D-Y-3L for 2–4-year-olds, this could be set as children aged 2–4 years, or a 3-year-old as the midpoint. Finally, (4) what health or non-health considerations do adults think about when making their valuations? Do adults intentionally or unintentionally consider spillover effects - such as the impact of poor child health on parents/carers or the impact on the child’s developmental goals, future education, work, and socioeconomic prospects etc. - when valuing health states? This evidence fills a critical gap being called for internationally [17]. Understanding these factors is important because it helps us to interpret the values generated and identify any unwanted impacts that may be included—either explicitly or implicitly—in valuation tasks. This also helps avoid potential double-counting by decision-makers. By recognising which unwanted impacts are present, we can gain insight into how valuation tasks or questions might need to be reframed or redesigned to mitigate these effects.

This study aimed to establish the feasibility of using a DCE to value health states described by the adapted EQ-5D-Y-3L for 2–4-year-olds, and to use the think-aloud methodology to explore participants’ views on relevant preferences, valuation perspective, age framing, and spillover effects—examining how these views may differ based on parental status.

Although anchoring onto the utility scale is required to generate a value set for QALY estimation, this study primarily focused on qualitatively exploring the feasibility of valuing health state preferences for very young children as a first step toward the provision of anchored utilities for use in QALY estimation.

Methods

Study design and theoretical framework

An exploratory qualitative study design involving a think-aloud process to test a DCE, followed by a semi-structured interview, was used to explore parents/caregivers’ and non-parents’ thoughts, choices, and views on the valuation of young children’s health states [18, 19]. This study was conceptually grounded in cognitive interviewing methodology, which views think-aloud techniques as a way to reveal the cognitive processes participants use when interpreting and responding to complex tasks. In the context of health-state valuation, this approach aligns with welfare economics and utility theory, which assume that participants’ stated preferences represent the relative value of different health states. Guided by this lens, our analysis focused on how participants comprehended the tasks, drew on their experiences, made judgments, and formulated responses. This framing enabled us to interpret misunderstandings or the use of heuristics not as noise, but as meaningful insights into how valuations were constructed for very young children. A phenomenological approach also underpinned this study, recognising that parents/caregivers and non-parents may differ in their perspectives due to varying experiences of and exposure to young children [20].

This study was granted ethical approval. This study was conducted and reported in accordance with the COREQ (Consolidated Criteria for Reporting Qualitative Research) checklist [21]. This work builds on an existing think-aloud study aimed at understanding the valuation of health states for older children [22, 23]. as part of the QUOKKA research programme [24]. Strategies to ensure qualitative rigour are described below.

Research team, reflexivity, and qualitative rigour

All interviews were conducted by X, a cis male PhD candidate who is not a parent. X has experience in conducting interviews with research participants and has been formally trained in interviewing and qualitative research. Interviews were double-coded by X and Y. Y is a non-parent cis female PhD candidate with formal training in qualitative research. Both coders actively reflected on how their non-parent status could shape their interpretation of key themes and took steps to critically engage with these perspectives throughout the analysis. The final analytical framework was discussed and refined in collaboration with the broader team to ensure a balanced and comprehensive interpretation.

The primary researcher's personal experiences and perspectives may have influenced how interviews were conducted, how participants' responses were probed, and how data were interpreted. For example, he may have had less instinctive understanding of the lived experiences of parents, which could have shaped the interpretation of their views on valuing health states for a 3-year-old. To mitigate potential influence on responses, the researcher engaged in ongoing reflexive practice, including maintaining a reflexive journal and documenting any assumptions or reactions throughout the study. Additionally, the analysis was discussed with a co-coder and the wider research team to ensure that findings were grounded in participants' accounts rather than the researcher's preconceptions, supporting the credibility and confirmability of the results.

Strategies to ensure the trustworthiness of the findings included the following: Credibility was enhanced through triangulation using multiple researchers, reflexivity on the researchers' backgrounds, prolonged engagement with participants via interviews lasting approximately one hour, and maintenance of an audit trail. Transferability was supported through a detailed description of participant demographics and context, purposeful sampling, inclusion of illustrative quotations, comparison with existing literature, and explicit acknowledgment of the study's generalisability limitations. Dependability was addressed via a detailed audit trail, inter-coder agreement, transparent methods, and step-wise replication during coding. Finally, confirmability was promoted through reflexivity statements and triangulation across coders and the wider research team.

Sampling and data saturation

Participants were recruited during August 2023, with all interviews conducted and completed in September 2023. A market research agency (Focus People) was used to identify and recruit eligible participants across Australia. A pragmatic sample size of 16 was sought based on prior qualitative DCE think aloud studies, which found 15–20 participants being sufficient in identifying key themes, with the intention to add more participants if saturation of ideas were not achieved [6, 25]. Participants were screened for eligibility and were provided with a study information form before providing informed consent to participate in the study. Eligibility criteria included (1) 18 + years old, (2) residing in Australia, (3) English speaking, and (4) access to a laptop with a working camera and microphone. Purposive sampling was used to achieve a balanced distribution of parents/caregivers and non-parents, as well as a wide range of ages and an even spread of gender [26]. Participants were provided a monetary voucher as a token of appreciation for their time.

Data saturation—defined here as the point at which no new codes or themes were identified—was reached after three rounds of coding, as no additional concepts emerged across consecutive rounds and all themes were consistently applied.

Data collection

Interviews were conducted online via the video conferencing platform, Zoom [27]. The interview structure and content were pilot tested with the authors. Participants were first asked to report their own HRQoL using the EQ-5D-3L and EQ VAS [28] as a way to introduce the concept of HRQoL. The think-aloud method was explained, and participants were provided with an unrelated example think-aloud DCE. A think-aloud method involves asking participants to verbalise and articulate their thought processes while completing the task [18, 19]. The interviewer would remind the participant to continue verbalising their thought process aloud if the participant was silent for too long, and would ask open-ended questions (e.g., "Why did you choose A instead of B?") if the participant gave an answer without providing their thought process. The participants completed a set of six choice tasks, randomly ordered for each participant, while considering a hypothetical 3-year-old and thinking aloud. The tasks did not specify a duration for the time spent in each health state. A 3-year-old was simply chosen as an intermediary age for the two to four range. Participants were asked to select the health state that they preferred, or thought was better. In this case, the DCE attributes reflect the five domains of the adapted EQ-5D-Y-3L. The twelve health states of the adapted EQ-5D-Y-3L selected for the DCE were chosen from a similar think-aloud study using the EQ-5D-Y-3L [6]. (Supplementary Fig. 2) and were expected to engage and stimulate the participants' thought processes due to the variation in dimensions and levels. An example of the task is provided in the supplementary material (Supplementary Fig. 3). Following the think-aloud task, the participants completed a semi-structured interview where an interview guide was used to ensure all key questions were covered and to provide consistency across all interviews and minimize interviewer influence (Supplementary A). This approach helped ensure that participants, regardless of parental status, were asked questions in a comparable way while still allowing them to elaborate on their thoughts and experiences. Finally, participants completed basic demographic questions and questions related to the experience of completing the DCE valuation tasks, which were on a 5-point Likert scale (1 being best, 5 being the worst): difficulty of the tasks, understanding of the task, confidence in imagining a hypothetical 3-year-old, and confidence in completing the task. A descriptive analysis of these findings will be presented.

Data analysis

Interview data were analysed with the seven-stage framework analysis [29]. Stage 1–2: The audio recordings were transcribed, and the two coders familiarised themselves with the transcripts. Stage 3–4: An iterative process was used to develop the analytical framework where each coder coded three transcripts independently per round (6 rounds total). After each round, the coders compared themes identified and discussed the overall analytical framework. The study took an a priori position of structuring the analysis around its pre-specified aims. Accordingly, a combined deductive–inductive approach was used: deductively, the key aims guided the definition of higher-order themes, and inductively, additional themes were allowed to emerge naturally from the data to capture unanticipated insights. In developing the analytical framework, the process was guided by the Situated Cognitive Framework, which considers how participants' decision-making is influenced by the immediate task context and available information [30]. Stage 5: The analytical framework (Table 1) was then discussed and agreed upon with the wider research team (triangulation of information) before being applied to all transcripts. Stage 6–7: The data were then charted and interpreted with a phenomenological theoretical approach [20]. NVivo 14.0 software was used for the framework analysis [31].

Results

A total of 17 participants (9 parents/caregivers and 8 non-parents) completed the think-aloud interview, with an average completion time of 54 min (Table 1).

Framework analysis

The analytical framework comprised four higher-level themes, developed using a combined deductive–inductive approach to capture both pre-specified aims and unanticipated insights (Table 2). Codes and sub-categories were synthesised within these themes to create a structured and conceptually coherent framework, enabling a clear and transparent representation of patterns across participants. The four higher themes were: Heuristics for simplifying or structuring choices, Age-based contextual lens, Perspective and framing influences, and Spillover considerations.

Heuristics for simplifying or structuring choices

For all choice tasks, there were similar patterns in the responses by both parents/caregivers and non-parents across all six choice sets (i.e., most participants picked the same health state for each task) (Table 3). Participants generally understood the tasks, found them feasible, and reported confidence in taking the perspective of a 3-year-old (Fig. 1). However, completing the valuation tasks also engaged specific heuristics, as participants adapted their decision-making to manage the cognitive and emotional demands. Some found the tasks emotionally challenging ("depressing," "sad," "awful") when considering a young child in poor health, while non-parents often struggled due to limited experience or knowledge of young children. These challenges appear to have prompted participants to rely on simplifying strategies such as focusing on the most important domains. Such strategies illustrate a situated approach to cognition, in which participants' judgments were shaped by the task demands and the particular scenario rather than by abstract rules.

Participants used a variety of heuristics to simplify or structure their decision-making, such as reducing the number of domains considered (e.g., ignoring domains that were identical between options or deemed less important), assessing overall severity, comparing the number of differing issues between choices, or considering which health state could be treated or supported.

Table 1 Demographic information on the sample of Australian adults participating in the think-aloud DCE valuation study of adapted EQ-5D-Y-3L for 2-4-year-olds

	Parental Status (*N* (%))	
	Parent (9)	**Non-parent (8)**
Gender		
Male	5 (56%)	3 (38%)
Female	4 (44%)	5 (62%)
Age Group		
20–29	2 (22%)	2 (25%)
30–39	3 (33%)	2 (25%)
40–49	2 (22%)	2 (25%)
50–59	2 (22%)	2 (25%)
Education*		
No qualification	0 (0%)	0 (0%)
Completed year 12 and/or Cert III	3 (33%)	2 (25%)
Diploma or Advanced Certificate	4 (44%)	2 (25%)
Bachelor's Degree or Higher	2 (22%)	4 (50%)
Income*		
<$26,000p/y	0 (0%)	0 (0%)
$26,000-$65,000p/y	3 (33%)	2 (25%)
>$65,000p/y	6 (67%)	5 (63%)
Prefer not to say	0 (0%)	1 (13%)
Employment status*		
Full time	5 (56%)	5 (63%)
Part-time	0 (0%)	1 (13%)
Self-employed	0 (0%)	1 (13%)
Full time carer	3 (33%)	1 (13%)
Unemployed	1 (11%)	0 (0%)
Marital Status *		
Single	3 (33%)	3 (38%)
Domestic partnership	0 (0%)	1 (13%)
Married	5 (56%)	4 (50%)
Divorced	1 (11%)	0 (0%)
State		
VIC	3 (33%)	2 (25%)
NSW	2 (22%)	1 (13%)
QLD	1 (11%)	1 (13%)
SA	2 (22%)	1 (13%)
TAS	0 (0%)	1 (13%)
ACT	0 (0%)	2 (25%)
WA	1 (11%)	0 (0%)
Work experience with children		
Yes	1 (11%)	3 (38%)
No	8 (89%)	5 (62%)
Number of own children		
1	5 (56%)	-
2	4 (44%)	-
Own children's age		
< 4	5 (56%)	-
>5	4 (44%)	-

* Variables derived and modified from Australian Bureau of Statistics [32].

When evaluating the overall severity of the health states, some participants highlighted the importance of severity levels, noting that multiple moderate (level 2) issues could be preferable to a few severe (level 3) issues—potentially explaining why all participants chose B as preferred in choice set A (11332 vs. 22222; Table 3). A few participants linked domains together, which may have shaped the participants' perception of the overall severity of the health state ["*pain can be managed to a certain degree but if they're not worried, sad or unhappy they would be in a better place to deal with that pain*" ID 6 – Parent]. Which domain was given more weight varied with some participants prioritising physical domains (i.e., usual activities, helping look after themselves, mobility), and a majority prioritising the sad, worried, or unhappy and the pain or discomfort domains ["*I was thinking more from the point of view of the bottom two rows being the most important. So, whether they're sad, happy or worried, and whether they are in pain or discomfort*" ID 14 – Parent], with a few participants swapping the domains they considered most important in between the tasks.

Age-based contextual lens

Participants' perceptions of 3-year-olds may have influenced how they evaluated health states. Some non-parents viewed children at this age as too young to understand or verbalize complex emotions such as anxiety or depression ["*thinking a three-year-old being anxious or depressed, I think you're too young to even know what those feelings are and experience them*" ID5]. Others described 3-year-olds as being in an intermediate stage between dependence and independence and noted that certain health issues were considered normal for this age. These perceptions sometimes led participants to minimise the weight of specific domains, particularly physical domains such as mobility, helping with self-care, and usual activities. When assessing 'some' or 'a lot' of pain, participants also suggested that younger children might experience pain more intensely than older children or adults, due to a lower tolerance or threshold.

Perspective and framing influences

There was a wide range of thoughts on whose preferences should be sought for the valuation of young children's health states, which were reflected in the various themes (Table 4).

There was some support for a representative sample of the general population to get a wide range of perspectives for fairness. There was an emphasis on seeking parents/caregivers' perspectives, mostly suggested by parents/caregivers themselves, for the reasons of "*they know more*" and "*are more experienced*", and therefore, "*are likely able to give a more accurate ranking on behalf of the children*" (ID 14). On a similar note, there were a handful

Table 2 Analytical framework codebook

Higher Theme	Themes	Sub-themes (if identified)
Heuristics for simplifying or structuring choices	Child-centred decision criteria	
	Attention to overall severity	
	Reducing number of states considered	
	Linking to medical condition	
	Comparing number of issues across states	
	Consideration of treatability/supportability	
	Importance of levels within domains	Some issues spread across domains judged better than few severe issues
		No issues and some issues treated as equivalent
	Connecting domains when evaluating health states	
	Task feasibility	Emotional challenges imagining a young child in poor health
		Limited experience or knowledge of young children
Age-based contextual lens	Limitations in communication and expression	
	Intermediate dependence (child seen as partly dependent, partly independent)	
	Variability in social engagement	
	Challenges distinguishing normal vs. problematic (some problems are considered normal for this age)	
	Perceived severity and variability of health states (health states may be judged less severe or interpreted differently for 3-year-olds.)	
	Perceived cognitive and emotional limitations in children	
Perspective and framing influences*	Whose preferences were preferred for valuation of child health states*	General adult population
		Parents/caregivers of children
		Non-parents
		Children
		Professionals
		Individuals with lived experience
	Perspective framing*	Framing difficulties
		Variation in framing between a known child and a hypothetical child
		Perspective-taking (Who was imagined)
	Age framing*	Target of consideration (who participants thought about)
		Preferred age-framing
		Differing views on age framing
Spillover considerations*	Future spillover effects	Anticipated natural improvement over time
		Lifelong impact of health
		Impact on child development
		Consideration of future life experiences
	Caregiver spillover effects	Caregiver burden
		Financial impact
		Emotional impact
		Caregivers' ability to support or attenuate the child's quality of life
	Beyond the description of the task or health state provided	Anticipated health improvement over time
		Availability of health resources and treatments
		Recognition that some health issues are typical for children

Themes and sub-themes developed through inductive approach, unless specified. * Represent deductive themes

Table 3 DCE responses of parents/caregivers and non-parents for six adapted EQ-5D-Y-3L health state sets

		Adapted EQ-5D-Y-3L health state sets					
ID	**Parental status**	**11,332 (A) vs. 22,222 (B)**	**13,213 (A) vs. 32,331 (B)**	**11,113 (A) vs. 11,121 (B)**	**31,231 (A) vs. 32,313 (B)**	**33,323 (A) vs. 21,133 (B)**	**33,311 (A) vs. 11,133 (B)**
1	Yes	B	A	B	A	A	A
2	No	B	B	B	A	B	A
3	Yes	B	A	B	A	B	B
4	Yes	B	A	A	B	B	A
5	No	B	A	B	A	B	B
6	Yes	B	B	B	A	B	B
7	No	B	A	A	A	B	A
8	No	B	B	B	A	A	A
9	No	B	A	B	B	A	A
10	Yes	B	A	B	A	B	B
11	No	B	A	B	A	A	A
12	Yes	B	A	B	A	A	A
13	Yes	B	A	A	A	B	B
14	Yes	B	B	B	A	A	A
15	No	B	B	B	A	B	B
16	Yes	B	A	B	A	B	A
17	No	B	A	B	A	B	B
A	Yes	0 (0%)	7 (78%)	2 (22%)	8 (89%)	3 (33%)	5 (56%)
B		9 (100%)	2 (22%)	7 (78%)	1 (11%)	6 (67%)	4 (44%)
A	No	0 (0%)	5 (63%)	1 (13%)	7 (88%)	3 (38%)	5 (63%)
B		8 (100%)	3 (38%)	7 (88%)	1 (13%)	5 (63%)	3 (38%)

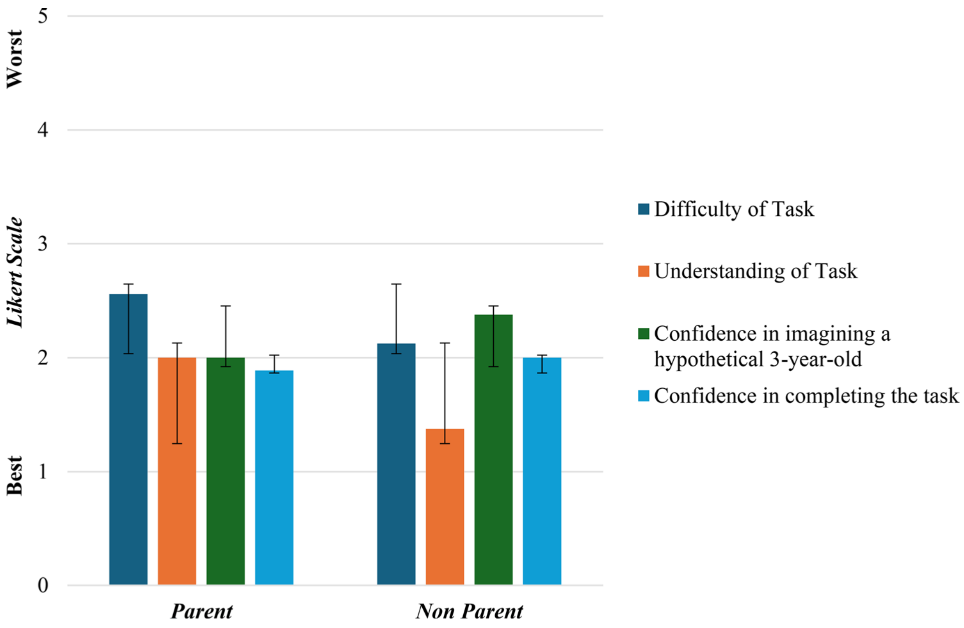

Fig. 1 Participants' feedback on their experience completing the DCE valuation tasks for states described using the adapted EQ-5D-Y-3L for 2-4-year-olds. Five-point Likert scale ranging from 1 (best) to 5 (worst); 1 indicates highest confidence/understanding (least difficult) and 5 indicates lowest confidence/understanding (most difficult). Mean scores with standard deviations shown

of reasons not to include non-parents due to having less experience and possibly a lack of interest or understanding of young children's lives. Equally opposing views on seeking parents' preferences, expressing that parents are too biased in their decision making. There was a preference from most participants for including individuals with direct experience of children, whether personal or professional. Inclusion of children was suggested but generally regarded as infeasible for this age group.

Table 4 Illustrative quotes regarding whose preferences should be sought for the valuation of the adapted EQ-5D-Y-3L for 2-4-year-olds

Themes	Illustrative quotes*
General adult population	*"It would be great to do it [DCE valuation task] across a wide demographic, the socioeconomic demographics as well. Because I feel it will have varied outcomes dependent on those environments"* **ID 4 [Parent]** *"I always think it's good to get a broad range, for accuracy"* **ID 7**
Parents/caregivers of children	*"Probably just parents, I would say, because people without children don't really have any idea about kids. Of course, I think there needs to be professionals involved and if they're non-parents, then that's fine, but I don't think asking the general population, like non-parents about a child's health is, yeah, no, I don't think they should be involved […]. You don't really know what it's like to have a child or until you have one. You think you do, but you don't."* **ID 13 [Parent]** *"At that age, I think probably the parents are the ones who would know better about what … what's best for their child […]. I think you need to have that close experience with children to be able to …accurately …give that priority ranking."* **ID 14 [Parent]**
Adults and children	*"I think it's important to get both perspectives of a child and an adult […] I don't feel like you could ask a three-year-old what they prefer because I feel that they wouldn't know"* **ID 5** *"It would be good to get the children to do it, but again, I don't know how you'd be able to do it. The questions for me, even I had trouble trying to compare things […] it would be good to see what they think because they've got their own thoughts."* **ID 15**
Experience with children & professionals	*"I also think school teachers and childcare workers and people that deal directly with young kids. […] I've got nieces and nephews, and I actually care about, even though I don't have my own human kids, I still have a connection with my nieces and nephews and take an interest in what's what."* **ID 17** *"Child psychologists or […] a paediatrician, child doctor, they would probably the best ground runners to determine then where and what was needed from here on."* **ID 7**
Non-parents	*"A perspective of just common person who have seen a few things around and don't relate it to somebody you know or your own, just as general thinking. So, I would go with the same approach because if I go to parents, then based on their circumstances, their responses would vary quite a lot."* **ID 9**
Lived experience of health	*"Opinion of adults who had been through those situations as a younger child"* **ID 3 [Parent]**

*To enhance readability of the quotes non-essential information within quotes has been replaced with ellipses […]

In relation to perspective framing, some of the non-parents stated they would have responded differently to the task if they were asked to think about a child they know, whereas all the parents/caregivers stated that their responses would not have differed if they were asked to think about their own child or a hypothetical child.

Despite framing the task in terms of a hypothetical child, participants tended to think of a child they know. In almost all cases, parents/caregivers thought of their own child/ren. Parents/caregivers who had healthy children used their child as a reference point to think about a hypothetical 3-year-old, compared to parents/caregivers who had children with existing health conditions, who thought of their child instead of a hypothetical child. Similarly, some of the non-parents thought of a child that they know as a reference point.

The age of the child that participants actually thought about was either 3 years (as stated in the task) or in the age range of about 2 to 5 years, with some participants stating they would have preferred to have thought of an age range.

Almost all participants suggested that their responses to the valuation task would not have changed when considering a child aged 2 or 4. Conversely, most participants said that their responses to the valuation task would be very different if thinking of a much older child (i.e., a child aged 10 or older). Some reasons participants provided explanations for why they might respond differently, such as putting more emphasis on the physical domains (i.e., mobility, help looking after self, and usual activities) and the fact that older children have more capacity to manage or deal with pain or mental difficulties.

Spillover effects

Future spillover effects were observed and raised by several participants regardless of parental status (Table 5). Given the hypothetical child's young age, many considered how the health state might impact the child's developmental progression or needs as they aged, as well as the impact on future life experiences such as education, social connectivity, and employment.

Caregiver spillover effects, primarily observed and reported by parents/caregivers, encompass both the broad burden of a child's health on caregivers—such as increased involvement—and specific impacts, including financial and emotional costs. Some also considered the extent to which caregivers could support or attenuate aspects of the child's health, particularly in the 'helping look after self,' 'usual activities,' and 'mobility' domains.

The majority of participants pulled in information beyond the description or health state provided. Some believed that aspects of health could be improved, and others considered what healthcare resources might be available or not available to help optimise or manage aspects of the young child's health state.

Table 5 Illustrative quotes regarding the type of spillovers effects found when completing a latent scale DCE valuation of the adapted EQ-5D-Y-3L for 2-4-year-olds

Themes	Sub-themes	Illustrative quotes*
Future spillover effects	Health will naturally improve over time	*"a lot of problems with movement, that's something that can I think be solved fairly easily; they'll probably be able to walk, run and jump soon."* **ID 8**
	Lifelong impact of health	*"But I suppose with the socialising one, or with the running or anything like that, it felt like that also included in the future, where I suppose it would affect them daily"* **ID 2** *"You are talking medication that could be life long and develop into an addiction when they are older […] if it's really strong medication."* **ID 16 – Parent**
	Impact on development	*"I was probably thinking today …and how that will impact their developmental health state in the future."* **ID 4** *"I suppose longer term impacts…on how the child is going to develop or how the child is going to progress throughout their life […] If it's not addressed at that early stage and they're unhappy and sad and not getting any joy from life that could manifest into some real significant issues … when they're older."* **ID 16 – Parent**
	Life experiences considered	*"The problems with mobility, it sounds to me like would they be wheelchair-bound or something along those lines, if they're having problems now, what can they accomplish in life? […] normal things like graduating, […] going to school, […] travelling, there's always going to be boundaries"* **ID 1 – Parent** *"Being able to get a job, to get money, to be able to afford cost of living. […] Would they be able to survive and look after themselves without family around them"* **ID 17**
Caregiver spillover effects	Burden on caregiver	*"A lot of problems with usual activities. I think that's quite a big difficulty in a child's life and for the parents."* **ID 10 – Parent** *"I did think about parents as well […] for example, if your child can't walk and they're in a wheelchair, then that's a huge thing for you as a parent."* **ID 13 – Parent** *"I was thinking of what would I be looking for or prefer if I was the parent of that child […] because obviously it would have a huge impact on the parents"* **ID 5**
	Financial cost	*"Finances, because it will cost money for whatever we need to do. I mean, mental health, physical health, everything as an adult, it costs so much money."* **ID 15**
	Emotional burden	*"I thought about the parents because I've seen firsthand a colleague […] and the trouble that she went through, the pain she went through. It was very tough. […] I thought about that, those impacts, like what parents go through and what the support family go through. Everybody's involved, of course. […] But parents are the one who are impacted the most, both financially, emotionally, physically"* **ID 9**
	Caregivers can support or attenuate quality of life concerns	*"Having lots of problems with movement […], they don't know any better. A lot of problems with helping look after themselves, you're there, you'll help them. And the same with the usual activities, if they can't do something and you're there to help them, they don't know any better."* **ID 6 – Parent** *"Usual activities, you have a lot of problems. It is not ideal, but you might get some help around it. Helping with washing. This, again, not ideal, but you can get some help around it. Walking, running, jumping, you can get some help around it."* **ID 9**
Beyond the description of the task or health state provided	Health can be improved	*"They've got a lot of problems helping look after themselves, and that's something that can be taught."* **ID 10 – Parent**
	Health resources and treatments are available	*"With pain and discomfort, we could go down the route of with a doctor and medication and we can alleviate that"* **ID 6 – Parent** *"If there was a deficit in one area straight away, my mind would think, okay, but we can go and see an OT or we can go and see a physio and they can help with this issue."* **ID 10 – Parent** *"So for me, the key factor only there is their emotive state, which is worried or sad or unhappy, which I think, for a three-year-old, can be altered in a positive environment."* **ID 4 – Parent**
	Child has some issues as part of natural development	*"A three-year-old is not expected to be able to be fully confident with walking, running and jumping […]. It is also normal for them to have problems helping look after themselves, like washing themselves, dressing, and going to the toilet by themselves; that's normal."* **ID 8**

*To enhance readability of the quotes non-essential information within quotes has been replaced with ellipses […]

Discussion

This is the first study to qualitatively explore the valuation of a EuroQol measure for very young children and provides evidence to inform the development of methods for producing value sets for instruments in this age group. Participants stated that their preferences regarding the health states would likely differ if asked to consider an older child, aged 10 years old, rather than a 3-year-old. These findings are comparable to other qualitative studies where adults stated their preferences would differ when considering different aged children [6], although this is not supported quantitatively [7]. One possible explanation for this misalignment is that preferences across age groups may differ for only a few health states or domains, resulting in only marginal differences in health state ordering. Alternatively, these differences may "wash out" in large-sample valuation models. Existing research has only examined differences down to age five, highlighting the need for further studies of preferences regarding health in younger age groups.

Although participants were asked to imagine a hypothetical child, most imagined a child they knew, and this did not appear to affect their preferences. Asking participants to consider 'a child' rather than 'a hypothetical child' may be the most optimal approach, as participants naturally envision a child regardless.

Whose preferences should be used

Despite the wide range of perspectives on whose preference should be sought to generate a value set for 2-4-year-olds, there was a general consensus that parents or individuals with experience with young children would be more appropriate. Nevertheless, the question of whose preferences are relevant is inherently normative. Traditionally, preference weights for adult health states have been derived from the general adult population using the 'taxpayer argument,' but this approach may not be suitable for valuing child health states. A systematic review by Bailey et al. (2022) highlighted the variability of whose preferences are currently used for paediatric health state valuation, with most studies relying on adults, while some incorporate parents, healthcare providers, or the child/adolescent themselves [33].

Although this study was conducted in an Australian context, the issues we address regarding the valuation of health state in younger children are relevant in other setting. Firstly, seeking preferences from the general population would maintain consistency for adult and paediatric valuation studies, however, the issue of whether most adults can imagine the health states of a young child remains. It should be noted that this argument on expertise and experience of what is being valued applies to any value set development. For example, participants' familiarity with the population (such as age) or a particular health state could influence perceived severity and the resulting values.

Secondly, those with experience with young children may be more informed but may also come with their own biases. Thirdly, collecting preferences from both the general adult population and a parent sample allows flexibility in selecting the most appropriate responses – whether prioritising only the parent sample or using a combined approach. This also enables transparency by allowing users to compare differences between the two groups. A key consideration is whether preferences for health states of young children differ between non-parents/those without experience and parents/those with experience of young children, and how much it impacts the values generated.

Further research is needed to explore these differences, alongside careful consideration of what constitutes 'experience with children'. If meaningful differences exist, a normative decision will be required. A fourth option of children valuing their own health states is considered unfeasible for 2-4-year-olds due to a lack of understanding, as raised in the interviews. Using older children to complete valuation tasks concerning younger children's health states is possible, although this would invoke similar issues to adults valuing a child (i.e., valuation of someone else's health). Noting that there is strong support from key stakeholders in the United States [34], the UK [35], and Canada [36]. for preferences to be elicited from either parent/caregiver and/or adolescent to value child health states.

Management of spillover effects

Spillover effects in valuation tasks may introduce inconsistencies in the values assigned to certain health states. Spillover effects could influence both the relative importance assigned to different dimensions (dimension ordering) and the overall range or magnitude of the utility scale. Therefore, it is crucial for those conducting or using valuation studies to understand the types of considerations participants make and the extent to which spillover effects influence participants' valuation of health states of young children. Understandably, caregiver spillover effects appear mostly when looking at a sub-sample of parents/caregivers completing the valuation task, likely due to personal understanding or experience in how a child's health state directly impacts themselves as caregivers. Accounting for caregiver/family spillover effects appears important, given consideration of the spillovers tends to result in a more favourable CUA result for paediatric intervention [37]. Additional qualitative research could be conducted with the primary aim of exploring how different spillover effects influence specific health state dimensions. Consensus on the most appropriate method/s used to account for these spillovers is also needed. For example, caregiver spillover effects could be quantified and then incorporated or adjusted for in the analysis post-hoc, depending on the objectives of the valuation study.

Limitations

Some participants felt the instrument's dimensions were not well-suited to 3-year-olds, as age-typical issues, like limited mobility, were viewed as normal rather than problematic. This may suggest that the instrument was not performing optimally by identifying issues where none existed, or alternatively that participants overlooked the guidance notes intended to support age-appropriate interpretation. The 'helping look after themselves' was a particularly difficult and confusing domain to understand for some non-parents. Further developing lay summaries for what is meant by the dimensions in the context of a 2-4-year-old could be useful to support both the valuation and measurement/reporting of the instrument. It may also indicate a need for further conceptual work on the adapted EQ-5D-Y classification system itself.

Methods for anchoring health state preferences were not explored in this study. Anchoring of preferences for health states in this age group is a key area to be resolved if value sets are required to support QALY estimation and should be the subject of future theoretical and empirical research.

Although efforts were made to ensure an even distribution of parental status, age, and gender, the small sample lacked representation for adults over the age of 60 and those with only secondary qualifications or less, limiting the generalisability of the overall findings. It is possible that these groups may comprehend and respond differently to the tasks. For example, a 65-year-old with experience as both a parent and a grandparent may view the health states of 3-year-olds differently from a younger parent.

Although self-reported ratings of task difficulty and understanding may not accurately reflect response quality, they were primarily used to support the qualitative findings. Triangulation indicated that non-parents struggled due to limited knowledge of children, whereas parents found the task challenging because of the emotional difficulty of imagining their own child in poor health.

Only 12 health states were explored, so some interactions may not have been captured, potentially masking differences between parents and non-parents. However, this is not a major concern given the study's focus on understanding reasoning processes rather than estimating preferences. A follow-up valuation study with a larger sample will examine these differences quantitatively.

Conclusion

Latent scale DCE appears to be feasible for obtaining stated preferences of dimension importance for the adapted EQ-5D-Y-3L for 2–4 year olds. Many participants expressed the view that valuation tasks may be more appropriately undertaken by individuals with experience of young children. Those using the information may, however, prefer to separately see and compare preferences of those with experience of children alongside a general population sample more traditionally used to generate value sets. Framing the task for participants to consider a child aged 2–4 years appears both preferred and feasible, as participants tend to naturally think of a child they know, regardless of the instructions provided. It is important for those conducting or using results from valuation studies to understand that participants completing valuation tasks involving health states in young children are likely to also consider caregiver burden and future outcomes for children as spillovers. Our findings may have implications beyond the specific instrument used in this study (adapted EQ-5D-Y-3L for 2-4-year-olds) to the valuation of health states in young children more broadly.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12955-025-02456-x.

Supplementary Material 1

Acknowledgements

EQ-5D-Y was modified with permission by the ©EuroQol Research Foundation. In this publication it will be referred to as the 'adapted EQ-5D-Y for 2–4-year-olds'. Reproduction of this version is not allowed. For reproduction, use or modification of the EQ-5D (any version), please register your study by using the online EQ registration page: www.euroqol.org.

Author contributions

AVH, AY, BM, KD, and ND made substantial contributions in the conception and design of the work. AVH and RJ substantial contributions to the acquisition and analysis of the data. All authors contributed to the interpretation of the data. AVH drafted the manuscript, and all authors substantially revised it. All authors have approved of the submitted version and have agreed both to be personally accountable for the author's own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

Funding

This research was funded by an Australian Government Medical Research Futures Fund (MRFF) grant (1200816) and a EuroQol Research Foundation grant (EQ Project 111-2020RA). AVH is supported by a Research Training Program Scholarship provided by the Australian Commonwealth Government and the University of Melbourne.

Data availability

The transcripts used and analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval

This study was approved by the University of Melbourne (UoM) Human Research Ethics Committee (Ref#2023-26964-43277-3) on 2nd August 2023. This study was conducted in accordance with the National Statement on Ethical Conduct in Human Research (2007, updated 2018).

Consent in publication

Not applicable.

Financial disclosures

None reported.

Competing interests

The authors declare no competing interests.

Received: 8 July 2025 / Accepted: 17 November 2025

References

1. Dalziel K, van Heusden A, Sarvananthar J, et al. A qualitative investigation to develop an adapted version of the EQ-5D-Y-3L for use in children aged 2–4 years. Value Health. 2023;26(10):1525–34. https://doi.org/10.1016/j.jval.2023.06.004.
2. Ramos-Goñi JM, Oppe M, Stolk E, et al. International valuation protocol for the EQ-5D-Y-3L. PharmacoEconomics. 2020;38(7):653–63. https://doi.org/10.1007/s40273-020-00909-3.
3. Devlin N, Roudijk B, Viney R, Stolk E. EQ-5D-Y-3L value Sets, valuation methods and conceptual questions. PharmacoEconomics. 2022;40(Suppl 2):123–7. https://doi.org/10.1007/s40273-022-01226-7.

4. van Heusden A, Rivero-Arias O, Herdman M, Hiscock H, Devlin N, Dalziel K, et al. Psychometric Performance Comparison of the Adapted versus Original Versions of the EQ-5D-Y-3L and -Y-5L in Proxy Respondents for 2- to 4-Year-Olds. Pharmaco Economics. 2024;42(1):129–145. https://doi.org/10.1007/s40273-024-01350-6.
5. Devlin N, Pan T, Kreimeier S, et al. Valuing EQ-5D-Y: the current state of play. Health Qual Life Outcomes. 2022;20(1):105. https://doi.org/10.1186/s12955-022-01998-8.
6. Reckers-Droog V, Karimi M, Lipman S, Verstraete J. Why do adults value EQ-5D-Y-3L health States differently for themselves than for children and adolescents: A Think-Aloud study. Value Health. 2022;25(7):1174–84. https://doi.org/10.1016/j.jval.2021.12.014.
7. Ramos-Goñi JM, Estévez-Carrillo A, Rivero-Arias O, et al. Does changing the age of a child to be considered in 3-Level version of EQ-5D-Y discrete choice Experiment–Based valuation studies affect health preferences? Value Health. 2022;25(7):1196–204. https://doi.org/10.1016/j.jval.2022.03.001.
8. Retra JGA, Essers BAB, Joore MA, Evers SMAA, Dirksen CD. Age dependency of EQ-5D-Youth health States valuations on a visual analogue scale. Health Qual Life Outcomes. 2020;18:386. https://doi.org/10.1186/s12955-020-01638-z.
9. Varni JW, Seid M, Kurtin PS. PedsQL™ 4.0: reliability and validity of the pediatric quality of life Inventory™ version 4.0 generic core scales in healthy and patient populations. Med Care. 2001;39(8):800–12.
10. Furber G, Segal L. The validity of the child health utility instrument (CHU9D) as a routine outcome measure for use in child and adolescent mental health services. Health Qual Life Outcomes. 2015;13(1):22. https://doi.org/10.1186/s12955-015-0218-4.
11. Verstraete J, Ramma L, Jelsma J. Validity and reliability testing of the toddler and infant (TANDI) health related quality of life instrument for very young children. J Patient Rep Outcomes. 2020;4(1):94. https://doi.org/10.1186/s41687-020-00251-4.
12. Furlong W, Rae C, Feeny D, et al. Generic Health-Related quality of life utility measure for preschool children (Health utilities preschool): Design, Development, and properties. Value Health. 2023;26(2):251–60. https://doi.org/10.1016/j.jval.2022.07.015.
13. Lamb A, Murray A, Lovett R. The challenges of measuring and valuing quality of life in preschool children: A retrospective review of NICE appraisals. Child (Basel). 2021;8(9):765. https://doi.org/10.3390/children8090765.
14. National Institute for Health and Care Excellence (NICE). NICE health technology evaluations: the manual. London: NICE; 2022.
15. Pharmaceutical Benefits Advisory Committee (PBAC). PBAC Guidelines: Overview and rationale of the economic evaluation. Canberra: PBAC; September 2016. https://pbac.pbs.gov.au/section-3a/3a-1-overview-and-rationale-of-economic-evaluation.html.
16. Devlin N, Roudijk B, Herdman M et al. How should we value health states for infants and toddlers? The case of EQ-TIPS.
17. Matza L, Rowen D, Chandler F et al. Valuing child and adolescent health States for use in economic evaluation: a good practices report of an ISPOR task force in Value in Health on 6 Nov 2025.
18. Kuusela H, Paul P. A comparison of concurrent and retrospective verbal protocol analysis. Am J Psychol. 2000;113(3):387–404. https://doi.org/10.2307/1423365.
19. Ericsson KA, Simon HA. Verbal reports as data. Psychol Rev. 1980;87(3):215–51. https://doi.org/10.1037/0033-295X.87.3.215.
20. Flood A. Understanding phenomenology. Nurse Res. 2010;17(2):7–15. https://doi.org/10.7748/nr2010.01.17.2.7.c7457.
21. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–57. https://doi.org/10.1093/intqhc/mzm042.
22. Yu A, Luo Y, Bahrampour M, et al. Understanding the valuation of paediatric health-related quality of life: a qualitative study protocol. BMJ Open. 2023;13(8):e073039. https://doi.org/10.1136/bmjopen-2023-073039.
23. Yu A, Luo Y, Bahrampour M, Norman R, Street D, Viney R, Devlin N, Mulhern BJ; QUOKKA Project Team. Understanding the valuation of paediatric health-related quality of life: results from a qualitative study. 40th EuroQol Plenary, Rome, Italy. 2023.
24. QUOKKA Research Program. Quality of Life in Kids | QUOKKA Research Program. [Internet]. QUOKKA Research Prog; [cited 2024 Jul 10]. Available from: https://www.quokkaresearchprogram.org
25. Noushad B, van Gerven PWM, de Bruin ABH. Twelve tips for applying the think-aloud method to capture cognitive processes. Med Teach. 2023 Dec 10 [cited 2024 Dec 10];46(7):892–897. https://www.researchgate.net/publication/376396007_Twelve_tips_for_applying_the_think-aloud_method_to_capture_cognitive_processes.
26. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. Adm Policy Ment Health. 2015;42(5):533–44. https://doi.org/10.1007/s10488-013-0528-y.
27. Zoom. Published online 2012. https://zoom.us/.
28. Devlin N, Parkin D, Janssen B. Methods for analysing and reporting EQ-5D data. Cham: Springer International Publishing; 2020. https://doi.org/10.1007/978-3-030-47622-9.
29. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol. 2013;13(1):117. https://doi.org/10.1186/1471-2288-13-117.
30. Cobb P, Bowers J. Cognitive and situated learning perspectives in theory and practice. Educational Researcher. 1999;28(2):4–15. https://doi.org/10.3102/0013189X028002004.
31. NVivo. Published online 2020.
32. Australian Bureau of Statistics. Australian Bureau of Statistics; 2024 Jul 3 [cited 2024 Jul 3]. Available from: https://www.abs.gov.au/.
33. Bailey C, Howell M, Raghunandan R, et al. Preference elicitation techniques used in valuing children's Health-Related Quality-of-Life: A systematic review. PharmacoEconomics. 2022;40(7):663–98. https://doi.org/10.1007/s40273-022-01149-3.
34. Nazari JL, Pickard AS, Gu NY. Findings from a roundtable discussion with US stakeholders on valuation of the EQ-5D-Y-3L. PharmacoEconomics. 2022;40(2):139–46. https://doi.org/10.1007/s40273-022-01222-x.
35. Powell PA, Rowen D, Keetharuth A, Mukuria C. Understanding UK public views on normative decisions made to value health-related quality of life in children: A qualitative study. Soc Sci Med. 2024;340:116506. https://doi.org/10.1016/j.socscimed.2023.116506.
36. Xie F, Xie S, Pullenayegum E, Ohinmaa A. Understanding Canadian stakeholders' views on measuring and valuing health for children and adolescents: a qualitative study. Qual Life Res. 2024 Mar 5 [cited 2024 Oct 23];33(5):1415–1422. https://pmc.ncbi.nlm.nih.gov/articles/PMC11045599/.
37. Lavelle TA, D'Cruz BN, Mohit B, et al. Family spillover effects in pediatric Cost-Utility analyses. Appl Health Econ Health Policy. 2019;17(2):163–74. https://doi.org/10.1007/s40258-018-0436-0.

Publisher's note