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Valuing Child and Adolescent Health States for Use in Economic Evaluation: A Good Practices Report of an ISPOR Task Force

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Abstract (242 words)

Economic evaluations of interventions that target or include children require health state utilities (HSUs). Despite the availability of preference-weighted measures for children, methods for valuing child health states and estimating child utilities are not as well established as those for adult HSUs. The objective of this Task Force was to develop emerging good practice recommendations for valuing child and adolescent health to generate HSUs for use in economic evaluation.

This Task Force identified and described the interrelated methodological choices regarding valuation of child health to generate HSUs. The Task Force considered available evidence related to four key issues: (a) whose preferences should be sought; (b) whose health is imagined; (c) which method should be used; and (d) the comparability between adult and child utilities.

Best practices may vary depending on the modeling context, characteristics of the health states, and the health technology assessment setting in which the HSUs will be used. For any individual study, methods will be informed by empirical evidence, value judgments, and recommendations from healthcare decision-makers. Rather than recommending an approach that would apply to every study, this Task Force presents options to consider when determining the preference elicitation approach to generate utilities for child health states, along with strengths and limitations of each. Given that child HSUs can impact the outcomes of a cost-utility analysis and subsequent decisions about healthcare resource allocation, this Task Force recommends that researchers be transparent about methodological choices and their impact on HSUs.

Keywords: health state utilities, HSU, children, adolescents, child utilities, child HSU, time trade-off

Highlights (120 words)

- Although methods for eliciting preferences for adult health states are well established, valuing child health states is more challenging. This Task Force aimed to develop emerging good practice recommendations for valuing child health states to generate utilities for use in economic evaluation.

- Evidence and recommendations are summarized across four key methodological issues regarding preference elicitation: whose preferences should be sought; whose health is imagined; which method should be used; and comparability between adult and child utilities.

- Best practices may vary depending on the modeling context, characteristics of the health states, and the health technology assessment setting in which the health state utilities will be used. Recommendations are provided for issues to consider when selecting methods for valuing child health states.

I. Introduction

Cost-utility analysis (CUA) is used to assess the value of healthcare interventions in terms of incremental cost per quality-adjusted life year (QALY) gained. Health state utilities (HSUs) are required for the calculation of QALYs. HSUs reflect preferences for a particular health outcome or health state on a cardinal scale where 1 represents full health, 0 represents dead, and negative values represent worse-than-dead states.[1] Accurate estimation of HSUs is important because these values can have an impact on the outcomes of a CUA and subsequent decisions about healthcare resource allocation.[2]

Like CUAs of treatments for adults, evaluations of health interventions for children also require HSUs, and there is a growing body of research on methods for estimating child HSUs. For example, there are generic preference-weighted measures designed to assess health-related quality of life (HRQoL) and estimate HSUs for children, such as the EQ-5D-Y-3L[3] and the CHU9D,[4,5] which are accompanied by preference weights that enable the estimation of QALYs. Condition-specific preference-weighted measures have also been used to derive HSUs for children.[6] In addition, HSUs can be estimated through direct preference assessment (e.g., time trade-off [TTO] or standard gamble [SG]) of a child's actual health state[7,8] or vignettes describing children's health states.[9]

Despite the availability of preference-weighted measures for children, methods for valuing child health states and estimating child HSUs are not as well established as those for adult HSUs. Some health technology assessment (HTA) agencies have specific recommendations regarding valuation methods for adult HSUs.[10] For example, some specify that HSUs should be based on general population preferences, elicited using choice-based techniques. However, limited guidance is available on generating utilities for children's health states.[11] In 2024, the Netherlands' Zorginstituut became the first HTA agency to recommend a

measure for generating child HSUs,[12] suggesting that researchers use the EQ-5D-Y-3L[3] and its Dutch preference weights derived from adult preferences.[13]

Designing a stated preference elicitation study to estimate child HSUs presents unique methodological challenges that differ from the issues encountered in studies focused on adult HSUs. Whilst it is possible to use the same methods for valuing child health states that would be used for adult health states, there are reasons why these methods may diverge. Researchers need to consider whose preferences are relevant, which perspective and elicitation methods to use, and how to interpret child HSUs relative to adult HSUs. Methods used to generate child HSUs and QALYs vary widely,[14-16] and the choice of methods has an impact on the resulting HSUs.[17] There is no consensus regarding a "best" method that will apply across all situations. Rather, the choice of methods is informed by empirical evidence and ultimately determined by normative or value judgments (i.e., reflective judgments about what is most important or should take priority). These judgments may vary across countries and decision contexts (e.g., the specific treatment, the medical condition, and the target population).

Good practice recommendations for valuing child health states would be informative to researchers selecting preference-weighted measures, conducting studies to generate child HSUs, and using child HSUs in a CUA, as well as to decision-makers involved in reimbursement, pricing, healthcare resource allocation decisions, and development of guidance concerning children. Therefore, the objective of this Task Force was to develop emerging good practice recommendations for valuing child health to generate HSUs for use in economic evaluation.

Most existing patient-reported outcome (PRO) instruments and HTA activity for children and adolescents have focused on children aged 5 years and above. Throughout this report, the

term “children” is used broadly to refer to children under 18 years old,[18] and the term “adolescents” is used to refer to the subgroup of children in the older part of this range (i.e., approximately 12–17 years old). While the scope of our recommendations is not restricted to children over 5 years old, generating HSUs for preschool children involves additional complexities that are not directly addressed. These issues require further consideration and additional research into instruments intended for children younger than 5 years old.[19-22] In addition, this Task Force report does not address measurement issues associated with PROs for children, which have been addressed in a previous ISPOR Good Research Practices Task Force[23] and other publications.[15,24] This Task Force report was initiated and developed following previously described methods.[25]

IIA. From Whose Preferences Should Children’s Health State Utilities Be Derived?

Choices about whose preferences should inform adult HSUs involve value judgments on whether to target patients with relevant experience or general population samples. The reasons for using either patient or general population samples have been discussed extensively elsewhere; the choice typically depends on the intended use of the HSUs.[26] Determining the appropriate type of respondent becomes even more complex when deriving HSUs for children.[27] These decisions are important because child HSUs can vary depending on whose preferences are elicited, particularly for more severe health states.[28-32]

Studies designed to elicit preferences for generating child HSUs can be conducted with samples of children, adolescents, or adults (**Figure 1**). A recent systematic review of 77 studies eliciting preferences for child health states found that the most common groups from which to elicit preferences are parents of a child with a health condition (27%), adults (23%) and adolescents (23%) from the general population, and adolescents with health conditions (14%).[14] There are justifications for using either child or adult samples, or a combination of

both, in preference elicitation studies. Some might favor child samples because children, not adults, experience these health states. It can also be argued that children have a right to express their views on matters that affect them[33] if these rights are balanced with considerations of age, maturity, and potential risks.[18] However, conducting preference elicitation tasks with children presents significant cognitive, developmental, and ethical challenges (discussed further in Section IIC below), which can be avoided by using adult samples. In addition, adults typically make important decisions for children and society. The inclusion of children in studies eliciting preferences needs to be carefully considered in terms of both potential benefit and harm, and the selected approach will vary depending on the research context and the health states being valued.

A recent Delphi panel study conducted with a range of experts and UK policymakers found consensus that child HSUs should be based on preferences of the general public aged 16 and above for elicitation tasks like TTO that include consideration of mortality, or 15 years old and above for elicitation tasks without consideration of mortality (e.g., discrete choice experiment [DCE]).[34] In three recently published reports of stakeholder discussions in the US, Canada, and Pakistan, respondents expressed similar support for adolescent involvement in valuation of child health.[35-37] Further research is needed on ways to address the ethical, logistical, and analytic challenges of including children or adolescents in preference elicitation studies, particularly when combining their data with responses from adults.

While general public samples are commonly used, some members of the public support eliciting preferences for child health states from adults with relevant experience because these respondents may "provide more 'accurate' or 'enlightened' responses."[38] For example, these targeted samples could include caregivers of children with or without a relevant medical condition, adults who experienced a medical condition when they were children, or healthcare providers with specific clinical expertise (**Figure 1**).

Adults vary with regard to recent experience with children, and these experiences could impact their preferences. Parents and individuals with personal or professional experience of childhood conditions may have greater insight into how impaired health states might affect a child's life, compared with adults who do not have this experience. However, the perspectives of people with personal experience should be interpreted carefully. Adults reporting their own childhood experiences may have limited insight into children's current experiences. For example, available treatments may have improved since they were young, and staying home from school might not have the same social and emotional impact on children now, because they can now stay connected to friends via electronic devices.

Spillover effects can occur when respondents think about the impact of the child's health on themselves and others, and this can be particularly salient for parents.[39-41] In addition, parents and other carers may adapt to their children's health conditions,[42] which could affect the resulting utilities. Several studies have found that being a parent has an impact on values for child health states, including generic EQ-5D-Y-3L and CHU9D health states[43,44] and condition-specific vignettes.[45] When recruiting a sample to value child health, researchers can consider parenting status to avoid over- or under-representing parents in the study sample relative to the general population, as discussed in a recent Delphi panel.[34]

IIB. Whose Health Is Imagined in Preference Elicitation Tasks?

Health state valuation tasks typically ask people to think about the health of an individual person. Three factors to consider when deciding whose health is imagined in tasks for estimating child HSUs are (1) the life stage of the imagined person, (2) the relationship of the respondent to the imagined person, and (3) the specified age of the imagined person (**Figure 2**). Decisions regarding each of these three interrelated factors should be considered carefully and jointly because they can affect the results of the health state valuation.

Life Stage of the Imagined Person

"Life stage" refers to whether the respondent is told that the health state represents a child, an adult, or a child growing into adulthood. One common approach is for the respondent to be asked to consider a child experiencing the health state and respond based on what they think would be best for that child.[46,47] Alternatively, an adult may be asked to imagine themselves living in a health state without specifying that it is a *child* state,[4,48] which is a more straightforward task than thinking about a person other than oneself, particularly a child. However, the impact of disease and treatment on HRQoL may differ between children and adults, and this framing would not capture the specific impact in children.[49,50] Further, some health state descriptions may clearly relate to children (e.g., ability to play or complete schoolwork), which raises questions about whether adults can truly value these states from a "self" perspective.

For elicitation methods involving duration, such as TTO and DCE with duration, the age of the child varies within a single task. These preference elicitation tasks can be structured so that respondents consider a child aging into adulthood during the time spent in the imagined health state.[51-53] For example, in a TTO valuation with a 10-year time horizon, considering a 10-year-old child, health states span ages 10 to 20 for states perceived as better than dead. Using a lead-time approach for health states perceived to be worse than dead results in an even longer span of time.[54]

An issue related to the choice of life stage is the perspective that the respondent is told to adopt. While it is most common to ask adult respondents to express their own preferences regarding children's health states,[47] it has also been suggested that they could respond based on what they think the child would prefer. These two perspectives may yield different results.[55]

Relationship of the Respondent to the Person in the Health State

Respondents can be asked to consider the health state for themselves ("self-frame" or "own perspective") or another person ("other frame" or "other perspective").[50] The "self-frame" can be used with child[51,56] or adult respondents.[52,57] With child samples, it may not be appropriate or ethical to conduct valuation studies requiring children (especially younger children) to consider their own mortality.[49,50]

In studies with the "other frame," adult respondents are often asked to imagine a child living in a health state. With this approach, a variety of frames are possible, including imagining one's own child living in the health state,[58-62] imagining another known child living in the health state (e.g., "a child you know," "a close family member"),[63] or imagining a nonspecified child living in the health state (e.g., "an 8-year-old child" without further specification of who this child may be).[45,47,64] This aspect of the framing must be considered carefully because it can have a substantial impact on results. For example, respondents imagining their own child may be less willing to trade life-years regardless of health state severity than respondents imagining a different child, resulting in higher HSUs for parents imagining their own child.[43,45] Imagining one's own child may also lead respondents to consider not only the child, but also spillover effects on the rest of the family.[49,65]

If the child is not specified, respondents will make their own assumptions about who the child is, and these assumptions tend to be quite heterogeneous. The child they choose to imagine may be their own child, a child they know, or a nonspecific child, and these choices could influence the resulting utilities.[45]

Age of the Imagined Person

The age of the imagined child can be presented as a specific age (e.g., "an 8-year-old child"),[47,52,53,57,59] a range of ages (e.g., a child in the range of ages 8–12), or a distribution across a range of specified ages (i.e., several specific ages, each assigned to a subset of

respondents).[63,66,67] Some studies have found minimal or no differences in values reported for different child ages,[68,69] though one study found that respondents provided larger disutilities for 1-year-olds than for 8-year-olds.[70] It is possible for a health state to describe a "child" without specifying the age, but this could introduce heterogeneity because each respondent would make their own assumptions about the child's age or not consider a specific age. When choosing which age to specify, several factors can be considered. For example, when valuing condition-specific health states, the age can be selected based on the typical age range of children with the relevant medical condition[67] or mean ages in relevant clinical trials.[45]

Combining the Three Factors

Decisions for each of the three factors described above can be combined in various ways. Many studies to date have not explicitly specified all three dimensions. For example, in the valuation protocol for the EQ-5D-Y-3L health states, adult respondents are instructed to respond "considering your views about a 10-year-old child" (i.e., specifying both life stage and age) without stating the relationship between the respondent and the imagined child.[47]

Selection of the appropriate framing will depend on a range of factors, such as research goals, the child population represented in the health states, and local HTA guidance. Further research is needed to develop best practices and better understand how respondents, researchers, and policymakers are considering these frames.

IIC. Method Used to Elicit Preferences

The methods commonly used to generate utilities for adult health states, such as TTO and SG,[1] are also used to value child health states. The TTO and SG elicitation techniques focus directly on placing health states on the cardinal utility scale anchored to 1 (full health) and 0 (dead). These methods can be used to value health states described via PROs for children,

vignettes describing child health states, or an actual child's current health state. When valuing health states associated with generic measures such as the EQ-5D-Y-3L, value sets used to generate HSUs for all possible states are derived from regression modeling of the resulting preference data.[47] Variants of TTO have been explored to avoid asking adolescents to give up years of life,[71] but their use is not widespread. For example, parental TTO, in which adult respondents consider trading years of their own life to prevent illness for their child, has also been proposed as an alternative,[65,72] but interpretation and usefulness of the results are unclear.

In contrast to TTO and SG, choice modeling approaches such as DCEs and best-worst scaling (BWS) focus on determining the relative importance of dimensions and severity levels within each dimension of a health state. Additional steps are required to place health state preferences on the utility scale anchored to 0 and 1, such as including a duration attribute in the DCE or the supplemental use of TTO as an anchoring task. DCE approaches may be useful for collecting relative importance data and estimating utilities for preference-weighted measures, but they are not well-suited for valuing children's actual health states or vignettes that are not structured according to attributes and levels. Visual analog scales (VAS) can be used to rate health states on a 0 to 1 scale, but it is debatable whether VAS values are appropriate for generating QALYs,[1] and the VAS approach is not typically recommended in HTA guidelines as a method for deriving HSUs.

Table 1 summarizes key elicitation methods that can be used to generate child HSUs. When selecting and using any of these elicitation techniques for valuation of child health states, the choice is interlinked with decisions about *whose preferences* will be elicited in the valuation study (Section IIA) and *whose health* should be imagined (Section IIB). Detailed descriptions of the elicitation methods have been published previously.[1]

Additional Issues to Consider When Selecting Methods for Eliciting Preferences from Children and Adolescents

Preference elicitation from children and adolescents raises unique challenges. A key question is whether children and adolescents can provide valid and meaningful preferences, and if so, at what age.[50] While some studies have sought preferences from children as young as 8 to 11 years old,[28,56,73-75] there is no generally accepted consensus regarding the minimum age at which children can provide reliable HSUs, and this age is likely to vary depending on the elicitation method and children's level of cognitive development. Many researchers are hesitant to use complex stated preference methods with children and adolescents, particularly methods like SG and TTO that require consideration of mortality.

When deciding whether to include children in studies to elicit preferences for generating HSUs, researchers should consider the children's cognitive ability, reading level, and developmental stage. Childhood is a time of rapid cognitive development affecting risk-taking, perception of time, ability to imagine hypothetical health states, and development of moral judgment.[76,77] Adding to the complexity, child development may differ for those with health conditions.[78] Other concerns are whether children have enough life experience to provide HSUs, how preferences from children experiencing poor health may be affected by adaptation, and whether these preferences are stable over time.[79]

In addition to cognitive and developmental issues, there may be ethical concerns with asking children and adolescents to complete tasks that involve consideration of death and reduced life expectancy, particularly with younger children. For example, TTO tasks, where years of life are sacrificed to avoid ill health, may cause distress and complicate ethics approvals (see Section IIA), though TTO has been used with child samples,[80,81] and variants of TTO have been explored to avoid asking adolescents to give up years of life (e.g., Ratcliffe et al).[71]

While DCE and BWS exercises may alleviate some of these concerns, they still entail cognitively challenging tasks,[14] and their use would require additional information to anchor the values on the 0 to 1 utility scale involving consideration of death. For example, DCE- and BWS-modeled utilities (reflecting ordinal preferences from child respondents) can be anchored to the utility scale using TTO responses from adults,[82] but these anchors are based on adult rather than child preferences. Alternatively, duration can be included as an attribute within the DCE itself,[6,83,84] although this would require consideration of mortality, which raises the concerns described above. Existing preference elicitation methods were developed for use in adults, with little focus on developing or redesigning these methods for use in children. Research on the appropriateness and feasibility of the various preference elicitation tasks in children is limited, and further research is needed.

IID. Comparability and Consistency Between Child and Adult Health State Utilities

When designing studies to elicit preferences for child health states, it is important to consider the potential differences between child and adult HSUs. The classification systems used in preference-weighted measures developed for adults may not reflect the experiences of children, which raises questions about the content validity of adult measures applied in child samples. In addition, the relevant attributes of HRQoL may change as children progress through stages of maturation and development.[85,86]

Studies that compare valuations of corresponding health states for children and adults usually report differences.[31] Several studies have found that utilities tend to be higher for child health states than for corresponding adult health states, with fewer worse-than-dead values for the child states.[17] This difference has been observed with utilities for various EQ-5D health states,[87-89] as well as for disease-specific vignettes.[45,63] However, this pattern is not consistent across all studies,[90] and there is variation among respondents within studies. The difference

between utilities of corresponding adult and child health states depends on several factors, including characteristics of the health states and the respondents. For example, differences between child and adult utilities tend to be greater with more severe health states.[43,45,87,91] Parents tend to attach higher utilities than nonparents to child health states.[43,45,87] Adult respondents valuing child states may be affected by the consideration of long-term impact of childhood illness.

There are also individual differences in how respondents interpret the TTO valuation task for children. Some respondents have reported a general reluctance to trade time from children's lives,[92] and some adults are more reluctant to shorten the life of a child than to shorten their own life.[43] Years of life may be perceived as more precious for children than adults.[87] These tendencies would lead to higher utilities for children than adults. These differences in utility could result in smaller QALY gains for children than for adults for HRQoL-improving technologies, which could impact decision-making on children's access to effective treatment.

In contrast, some respondents trade more time when valuing severe child health states to minimize children's suffering.[43,45] In addition, choices between different durations (as in a TTO task) could be impacted by time preferences (i.e., distant vs. more immediate time periods),[89,93,94] and this may vary depending on characteristics of the respondents (e.g., adults vs. adolescents) and who is imagined in the health state (e.g., the respondents themselves vs. a hypothetical child).

Several studies have used qualitative methods to examine how respondents make decisions when valuing child health states, and the results provide insight into the differences between child and adult utilities. There is some indication that respondents may prioritize different dimensions of health for children and adults,[40] and the same health states may be viewed as

having different types of impact for children and adults.[43] Valuation of child health states could also be influenced by adults' implicit values around equity and the notion of "fair innings," suggesting that everyone is entitled to live for a normal span of years.[95] Another important factor is that respondents are often not given guidance about which child to imagine in the health states (see Section IIB). Without specific guidance, respondents will vary regarding whom they imagine when valuing child health states, which can lead to heterogeneity in resulting utilities.[40,43,45]

In summary, while utilities for child health states may tend to be higher than utilities for corresponding adult states, the difference between child and adult utilities is complex, variable, and influenced by a range of factors. These issues should be considered when designing studies to estimate child HSUs and when using these values in economic models, particularly long-term models that span multiple age groups and require HSUs for both childhood and adulthood. For example, if child and adult HSUs are used in the same model but have different characteristics, then a longitudinal model may exhibit an artefactual change when transitioning from the child to adult HSUs, even if the underlying health remains unchanged.[17] These issues of consistency and characteristics of HSUs across the lifespan are important for decision-makers who require a comparable basis for assessing cost-effectiveness across both children and adults. Further research is needed to explore these challenges, and it would be beneficial if HTA and public health bodies were actively involved in discussions about the extent to which child HSUs should be directly comparable to adult HSUs or reflect unique characteristics of child health states.

III. Selecting the Overall Approach to Generating Child Health State Utilities

The methodological choices discussed in this Task Force report are summarized in **Figure 3**. In addition, a summary of the Task Force findings and recommendations for good practices

in methods for generating child HSUs is presented in **Table 2**. The methodological choices summarized in **Figure 3** and **Table 2** cannot each be considered in isolation (see **Table 3** for examples of how these choices can be combined). For example, the questions of 'whose preferences' and 'whose health is imagined' must be considered jointly, since asking children to imagine a child of a different age may be too complex. The selection of the respondents and the preference elicitation method in child health state valuation studies also require joint consideration, since not all methods are equally suitable for all types of respondents. In addition, the choices of who to imagine in the health states and the elicitation method cannot be separated, because different combinations can generate different results.[14,88,96] Finally, comparability and consistency of child HSUs with adult HSUs are affected by all these decisions.

The goal of study design decisions should be to generate appropriate and accurate HSUs for modeling and decision-making, not to influence the magnitude of HSUs or utility decrements. There is no gold standard approach, and the methodological decisions will be guided by a wide range of factors, including the age range of the child population, the latest empirical evidence, economic modeling requirements, cultural and socioeconomic issues in the target country, and preferences of local HTA bodies and other decision-makers.

The content of the health states that will be valued will also shape methodological decisions. For example, rare diseases and temporary health-related events often require vignette-based methods rather than a generic instrument,[9] and this methodological choice would affect the elicitation decisions (e.g., which elicitation method, whose preferences, and who is imagined in the health states). With any preference elicitation study, it is important to consider the limitations and implications of the selected method, and there may not be a single optimal solution.

Consultation and involvement of people from the general public and those with relevant experience, such as patients, caregivers, and clinicians, in study design can help ensure the research yields appropriate and meaningful results. A checklist for assessing the reporting of studies to generate HSUs for children (RETRIEVE) is available, and this may be helpful for ensuring that all relevant issues are considered when reporting and evaluating these studies.[97]

While HTA bodies and decision-makers currently provide little guidance specific to methods for eliciting preferences to generate child HSUs,[11] future guidance is expected, given rapid progress in the emerging literature on child HSUs and the number of new technologies being developed for use in children. The flowchart and recommendations in **Figure 3** and **Table 2** provide an overview of the methodological issues that can be considered alongside emerging local HTA guidance when generating and selecting these HSUs.

IV. Conclusions

The field of child HSUs has been very active in the last 5 years. While considerable progress has been made, the field remains in its infancy. This Task Force has identified gaps in available evidence and methods research, and these are provided in **Appendix A**. Several issues were beyond the scope of this Task Force, including assessment of spillover effects and additional considerations for generating HSUs for infants and very young children, and it is hoped these important issues will be addressed in future research and task forces.

As this field continues to develop, we recommend transparency in the reporting of study methods. Researchers conducting studies eliciting preferences to generate child HSUs need to ensure that all methodological choices are clearly considered, justified, and reported so that those who are using and evaluating the HSUs understand the methods and assumptions underlying the values. In addition, we encourage HTA bodies to carefully consider the

methodological choices we described for child HSUs (Sections IIA–IIC) and provide guidance or normative judgments on these issues where appropriate.

This Task Force has identified and described the interrelated methodological choices regarding the elicitation of preferences for generating child HSUs. Recommendations have been provided in **Table 2**. While the choice of methods for any study valuing child health states should be informed by empirical evidence, these decisions also require value judgments. Therefore, it is not possible to fully prescribe "best practices" in isolation from recommendations from healthcare decision-makers who rely on child HSUs. Best practices may vary depending on the modeling context, characteristics of the health states, and the HTA setting in which the HSUs will be used. This Task Force presents reasonable options to consider, along with the strengths and limitations of each, rather than recommending a single choice that would apply to every study.

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VI. Disclosure Section

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Conflict of Interest

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Government at the University of Oxford. The views expressed in the paper are those of the Task Force and do not necessarily reflect the views of the employers of the authors.

VII. Tables and Figures

Table 1. Suitability of Common Preference Elicitation Methods for Generating Child Health State Utilities

Elicitation method[e]	Applicable and useful for eliciting preferences from three age groups?[a]			Enables direct generation of utilities[b]
	Pre-adolescent children	Adolescents (approximately 12–17 years old)	Adults	
BWS	?	Yes	Yes	No
DCE	?	Yes	Yes	No
DCE with duration	No	?	Yes	Yes
Standard gamble	No	?	Yes	Yes
TTO	No	?	Yes	Yes
VAS	?	Yes	Yes	No[d]

Abbreviations: BWS = best-worst scaling; DCE = discrete choice experiment; TTO = time trade-off; VAS = visual analog scale

Yes = The elicitation method is suitable for this situation.

No = The elicitation method is generally not suitable for this situation.

? = Insufficient evidence is available to know whether the method is suitable for this situation. Further research is needed.

[a] The ratings of "yes," "no," and "?" in these columns are based on the subjective judgments of this Task Force. These judgments were informed by our research experience and literature gathered to support the current manuscript, rather than a systematic review of the evidence.

[b] A "yes" in this column means the method yields a utility value on the 0 (dead) to 1 (full health) scale, with no additional information required.

[c] Although ranking is not generally used to estimate a utility, there is a method for deriving a utility from ranking if "dead" is included as a state in the ranking task.[98]

[d] Results of a VAS are generally not considered to be utilities. However, by using an upper anchor of full health and including "dead" as a state in the VAS task, it is possible to estimate values for health states on the full health to dead scale.[1]

[e] For each of the methods listed here, variations exist in the specific format of the task that may be relevant to consider. For example, there are different ways of presenting TTO tasks, especially with respect to eliciting values <0, the time horizon, and the differences in the order in which TTO choices are presented (e.g., "ping-ponging" vs. titration/bisection).

Table 2. Summary of Task Force Findings and Recommendations

Section of this Task Force report	Summary of findings and recommendations

IIA: Whose preferences?	• Consider whether samples should consist of general population respondents or respondents with relevant experience (e.g., patients, parents, adults who experienced the condition as a child; see **Figure 1**). HTA guidelines often state a preference for HSUs derived from general population samples.
	• It is possible to elicit preferences for child health states from either adults or children. There are justifications for using either type of sample or a combination of both.
	  ○ Child respondents may be considered because children, not adults, experience these health states, and children have a right to express their views on matters that affect them. There appears to be growing interest in adolescent valuation (alongside adults) of child health among various stakeholders.
	  ○ There are cognitive, developmental, and ethical challenges of conducting preference elicitation tasks with children. For these reasons, preference elicitation studies valuing child health states are most commonly conducted with adult samples, and this approach is usually effective.
	• The inclusion of children in studies eliciting preferences to generate HSUs needs to be carefully considered in terms of both potential benefit and harm, and the preferred approach will vary depending on the research context and the health states being valued.

IIB: Whose health is imagined?	• Consider three factors when deciding whose health is imagined in tasks for valuing child health states. The decision for each of these factors can affect the resulting HSUs.
	  1. Life stage of the imagined person: Respondents may be told that the person living in the health state is a child, an adult, or a child growing into adulthood (depending on the time horizon of the elicitation task).
	  2. Relationship of the respondent to the imagined person: Respondents can be asked to consider the health state for themselves or another person.
	  3. Specified age of the imagined person: The age of an imagined person can be presented as a specific age, a range of ages, or a distribution across a range of specified ages.
	• If any of these factors are not specified in the elicitation tasks, respondents will make their own assumptions about who is living in the health states, and these assumptions can be quite heterogeneous.
	• Selection of the appropriate framing will depend on a range of factors, such as research goals, the child population represented in the health states, and local HTA guidance.

IIC: Method used to elicit preference	• For studies eliciting preferences for child health states from adults, methods that estimate HSUs on the cardinal scale anchored to 0 and 1 and are commonly used to value adult health states are recommended (i.e., TTO, SG, and DCE with a duration attribute). • For studies eliciting preferences from children, methods that do not involve consideration of mortality are a suitable option (e.g., DCE). The results can be used to generate HSUs on the cardinal scale anchored to 0 and 1 using anchoring methods informed by adult responses in preference-based tasks involving mortality (e.g., TTO or SG). • Methods that require consideration of mortality (e.g., trading years of life in a TTO task) should be used with caution in children and adolescents because (1) younger children may lack the cognitive development and understanding required for these tasks and (2) there are sensitivities and ethical implications around raising these issues with this population.

Section of this Task Force report	Summary of findings and recommendations
	• Older adolescents may be able to complete tasks requiring consideration of mortality. The age at which these tasks are appropriate is not clear based on existing evidence.
IID: Comparability and consistency between child and adult utilities	• When designing studies to elicit preferences for child health states, consider potential differences between utilities for child and adult health states. • Studies that compare values of corresponding health states for children and adults usually find differences. • The extent of these differences depends on a range of factors such as health state severity, respondent characteristics, and valuation task interpretations. • These issues should be considered not only when designing studies to estimate child HSUs, but also when using these values in economic models, particularly long-term models that span multiple age groups and require HSUs for both childhood and adulthood.
Additional recommendations	• **Transparency from researchers**: Researchers reporting or generating HSUs for child health need to ensure that all methodological choices are clearly considered, justified, and reported so that those who are using and evaluating the HSUs understand the methods and assumptions underlying the values. • **Implications of methodological decisions**: In studies reporting or generating HSUs for child health, researchers should make an effort to ensure that users understand the likely effect of methodological choices on the characteristics and properties of the resulting HSUs, as well as the implications of those characteristics for the estimation of QALYs. For example, discussion sections of child HSU publications should provide guidance on the appropriate use and interpretation of the reported HSUs. • **Policymakers**: We encourage HTA bodies to carefully consider the methodological choices we described for child HSUs (Sections IIA–IIC) and provide guidance or normative judgments on these issues where appropriate.

Abbreviations: DCE = discrete choice experiment; HSU = health state utility; HTA = health technology assessment; QALY = quality-adjusted life-year; SG = standard gamble; TTO = time trade-off

Table 3. Four Examples of Preference Elicitation Approaches for Generating Child Health State Utilities with Various Combinations of Study Design Decisions

Study design questions	Whose preferences	Who is imagined living in the health states?			Which elicitation method
		Life stage	Relationship of the respondent to the imagined person	Specified age of the imagined person	
Example 1[a]	Adult	Pre-adolescent child	No relationship specified	10 years old	DCE with TTO
Example 2[b]	Adult	Adult	Self	Own current age	TTO
Example 3[c]	Parent	Pre-adolescent child	Their own child	Child's current age	SG
Example 4[d]	Adolescent	Adolescent	Self	Own current age	BWS

Abbreviations: BWS = best-worst scaling; DCE = discrete choice experiment; SG = standard gamble; TTO = time trade-off

[a] Example 1 corresponds to the published EQ-5D-Y-3L protocol.[47] This example uses DCE and TTO methods with an adult sample, imagining a 10-year-old child living in the health states, with no specified relationship between the respondent and the child.

[b] Example 2 is a study using DCE with duration with an adult sample imagining themselves living in the child health states at their own current age, as in the study deriving the CHU9D value set for the Netherlands.[99]

[c] Example 3 is a study using SG methods with a sample of parents imagining their own child living in the health states at the child's current age.[62]

[d] Example 4 is a study using BWS methods with an adolescent sample imagining themselves living in the health states at their current age, followed by a TTO task with adults to anchor the ordinal BWS preferences to the cardinal utility scale, as in the study deriving the adolescent CHU9D value set for Australia.[100]

Figure 1. From Whose Preferences Can Children's Health State Utilities Be Derived?

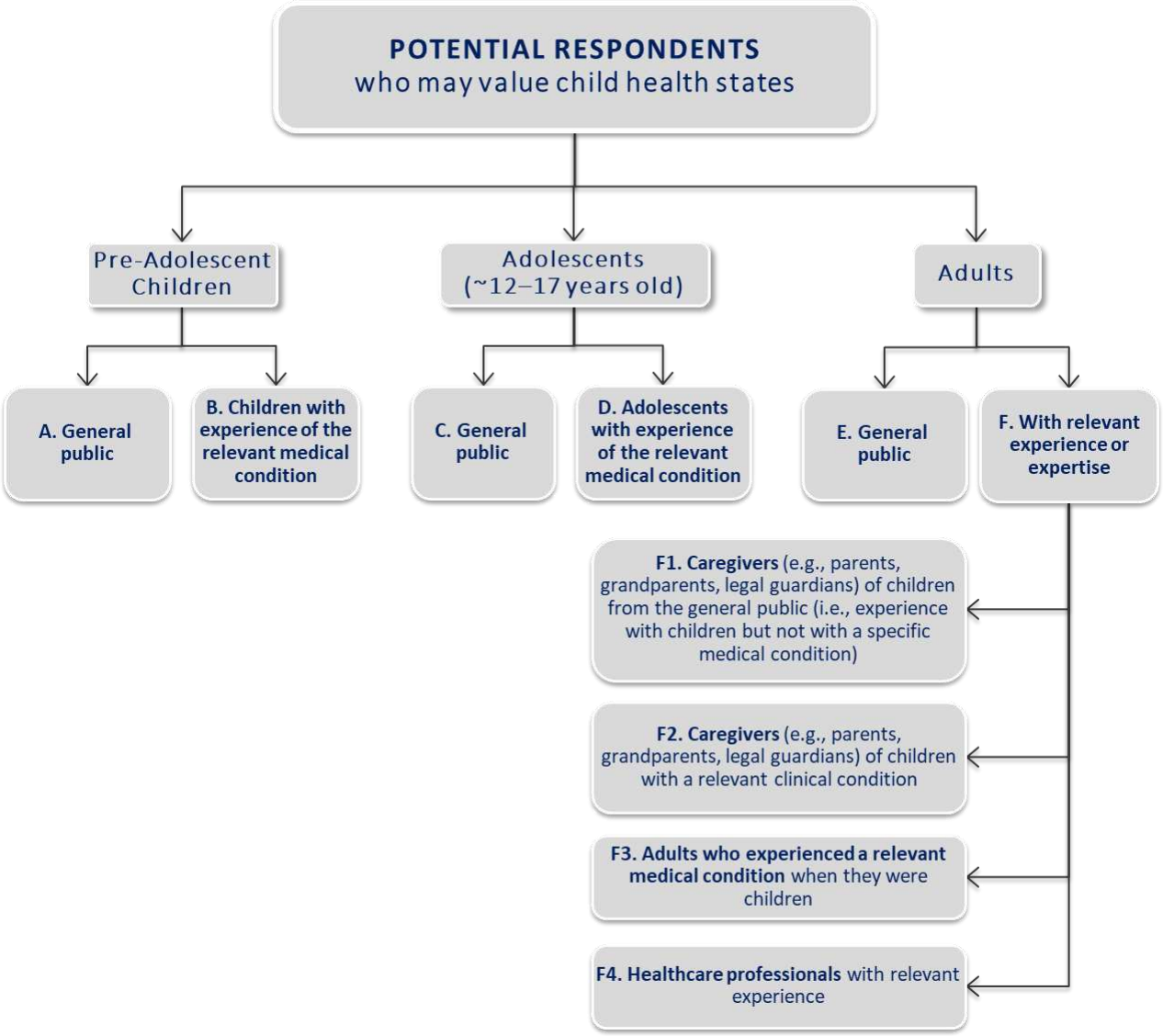
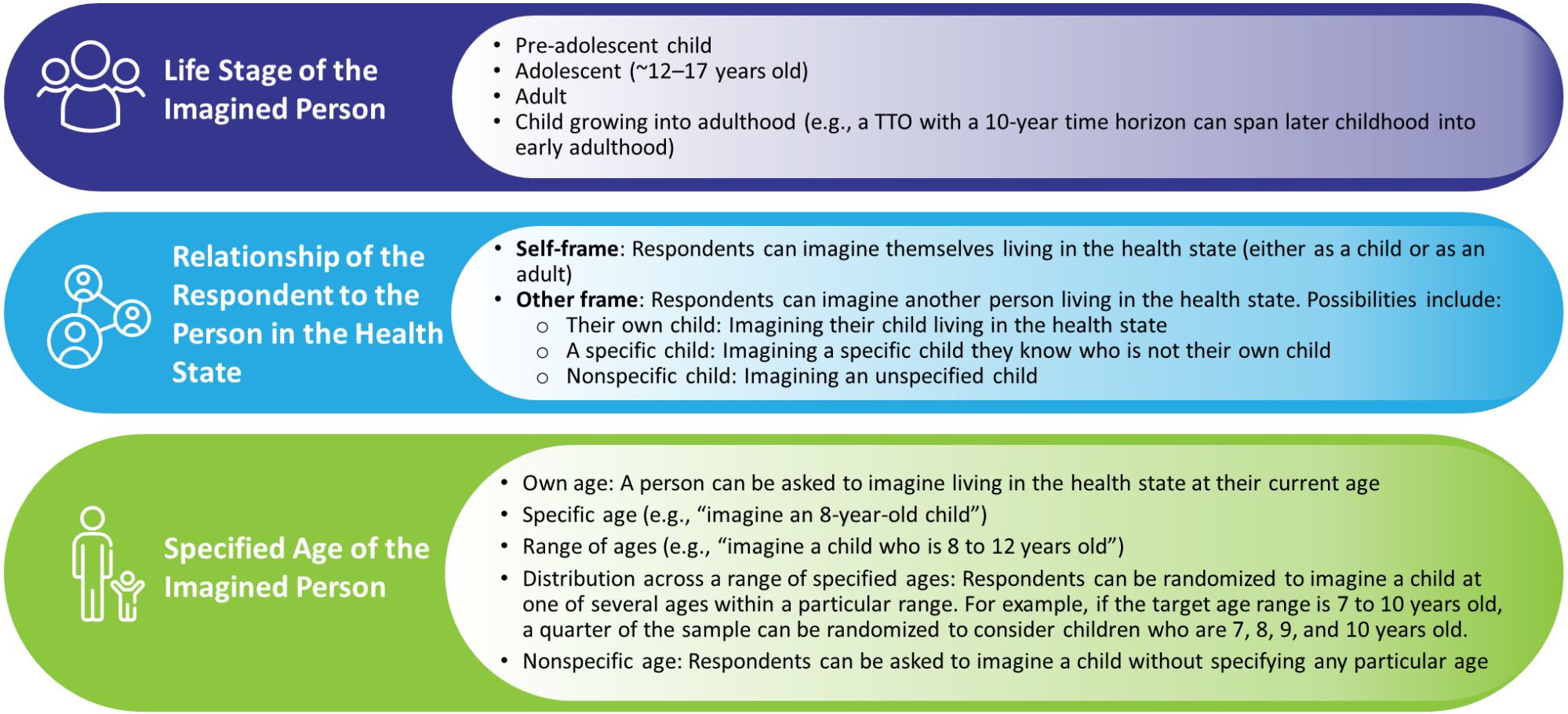
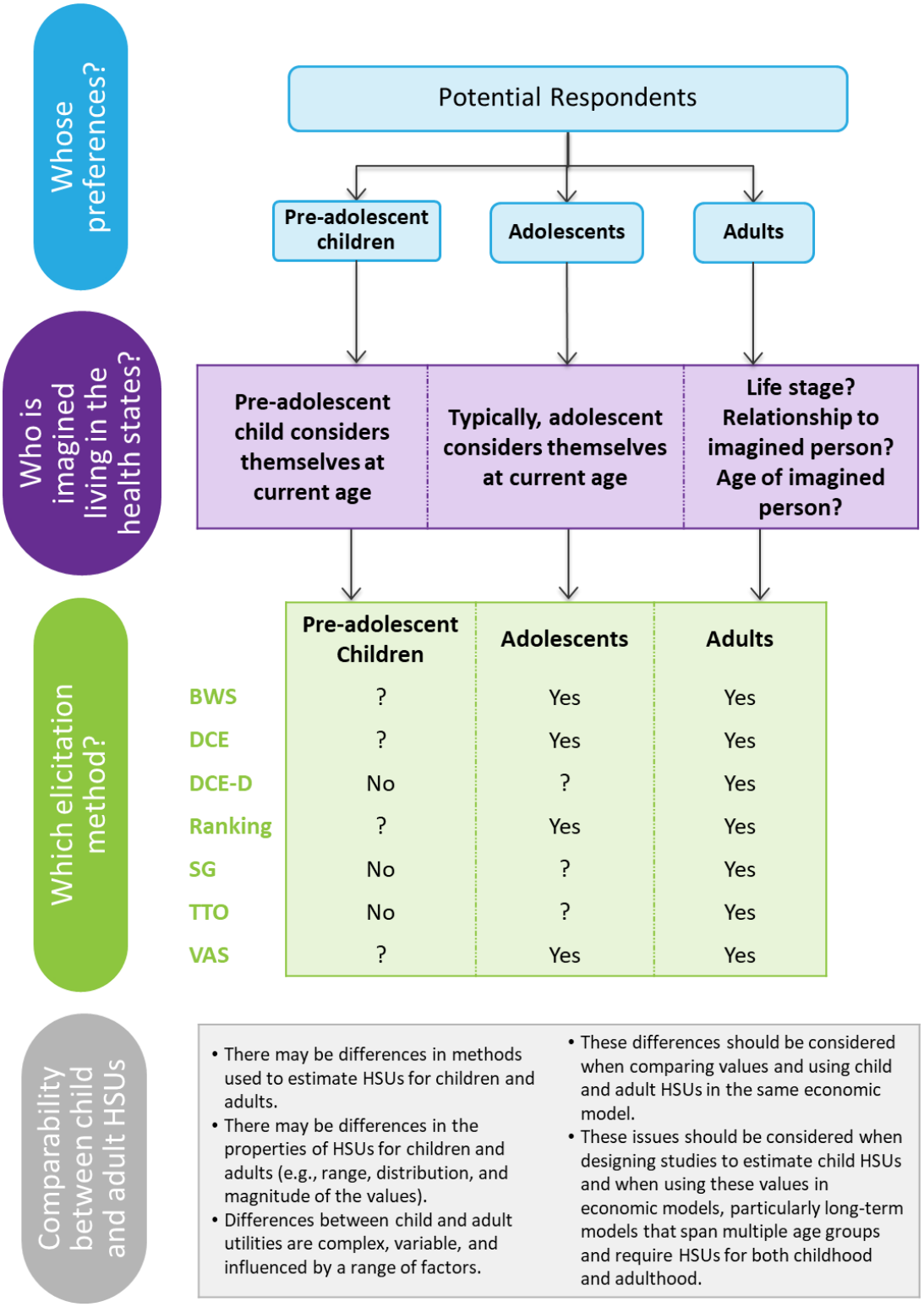


Figure 2. Three Factors to Consider When Deciding Whose Health Is Imagined in Preference Elicitation Tasks for Generating Child Health State Utilities



Abbreviation: TTO = time trade-off

Figure 3. Summary of Issues to Consider When Designing or Evaluating a Preference Elicitation Study to Generate Child Health State Utilities



Abbreviations: BWS = best-worst scaling; DCE = discrete choice experiment; HSU = health state utility; SG = standard gamble; TTO = time trade-off; DCE-D = DCE with a duration attribute

Yes = The elicitation method is suitable.

No = The elicitation method is generally not suitable for this situation.

? = Insufficient evidence is available to know whether the method is suitable for this situation. Further research is needed.

VIII. Supplemental Material

Appendix A. Research Gaps in the Generation of Child Health State Utilities Identified by This Task Force

While conducting this Task Force, the following gaps in evidence and methods relating to child health state utilities (HSUs) were identified. These are listed by the principal issues to consider when designing and evaluating a study eliciting preferences to generate child HSUs, as summarized in **Table 2** of the Task Force report. The order in which they appear does not imply their relative importance. These gaps were identified by Task Force members in September 2024. The field of child HSUs is rapidly evolving, and researchers consulting this list in subsequent years are encouraged to check for recent research addressing these gaps.

IIA: Whose preferences?	The choice of whose preferences to elicit for child health is related to the value judgments of those using the HSUs in decision-making. However, the following questions are relevant to that choice and to understanding the implications: • Does the choice of respondents for valuing child health depend on the age of the children whose health is being valued? • Are preferences elicited from children/adolescents systematically different from those elicited from adults for child health states? If so, how would that affect estimated QALY gains? • How do child HSUs obtained from *parents* compare with those obtained from non-parents? • If eliciting preferences from adults who have experience with childhood conditions, do the resulting HSUs depend on whether the adults are parents, healthcare professionals, or others? • Are there interactions between the nature of the child health states of interest (e.g., temporary, acute, chronic, severe, life-limiting), choice of method (e.g., TTO, DCE), and mode of administration (e.g., online TTO with an interviewer is feasible for adults, but little is known about mode of TTO administration with children)? • If preferences are elicited from mixed samples of adults and children/adolescents, how would the data be analyzed, reported, and used in cost-utility analyses? Should the percentage of children/adolescents in the sample be targeted to match the general population?
IIB: Whose health is imagined?	• Is it feasible and ethical to ask children to value health states either as themselves or by thinking about other children? What effect might this framing have on child HSUs? • What influence on child HSUs does the consideration of spillover effects have (e.g., on caregivers)? • How do the various ways of framing "whose health is imagined?" affect the resulting HSUs? While some literature demonstrates differences between preferences elicited when adults imagine themselves experiencing a child health state compared with adults imagining a child experiencing a child health state, there is little evidence comparing other frames.

IIC: Method used to elicit preference	• Can existing methods for eliciting preferences to generate HSUs anchored at 0 and 1 (principally developed for use in adults) be adapted (e.g., using qualitative and quantitative exploration) to be feasible and acceptable to use with children, including younger children? • How does the feasibility of eliciting preferences differ by age (e.g., between 8 and 17 years of age)? • Can new preference elicitation tasks be developed specifically for children? • Do adults apply different rates of time preference to future health scenarios when valuing child health states than when valuing adult states from a 'self' perspective? • Do children have a different rate of time preference than adults when considering future health scenarios, and how does that affect their response to tasks that include duration (e.g., TTO, DCEs that include duration attributes)?
IID: Comparability and consistency between child and adult utilities	• What are HTA bodies' views on the importance/desirability of having comparable HSUs for child and adult health states? • How do differences in preference elicitation methods for child and adult health states affect the resulting HSUs and their use in QALY estimation? • Should factors beyond the usual health state considerations, such as impact on future outcomes or spillover effects on caregivers, be taken into account in child HSUs?
Younger age groups	• What are the additional considerations when generating HSUs for the youngest age groups (i.e., children under 5 years old)? • What additional evidence is required to inform these methodological decisions?

Abbreviations: DCE = discrete choice experiment; HSU = health state utility; HTA = health technology assessment; QALY = quality-adjusted life-year; TTO = time trade-off