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Highlights

What is already known about the topic?

There is little guidance or recommendations around the methods for generating health state utility values for children and adolescents in technology appraisals.

What does the paper add to existing knowledge?

This review examines previous NICE technology appraisals to identify the methods used to generate utility values for child and adolescent health states

The review finds that most assessments (33 of 40) involved the use of adult EQ-5D, and few used a child or adolescent specific preference-based measure (10 of 40).

This raises the issue of whether adult specific measures are appropriate and are the best approach for valuing the health of children and adolescents.

A review of the methods used to generate utility values in NICE technology assessments for children and adolescents

Objective: This review summarises and critically examines methods used to generate utilities for child and adolescent health states in previous NICE (National Institute for Health and Care Excellence) technology assessments.

Methods: We identified all NICE Technology Appraisal (TA) and NICE Highly Specialised Technologies (HST) guidance where the licensed indication for the technology included people under 18 years.

Results: The review includes 40 NICE technology assessments. Most assessments generated utility values using EQ-5D scored using the adult version of the EQ-5D either exclusively (n=16) or alongside other utility measures and direct elicitation methods of patient own utility (n=17) and seven did not use the EQ-5D. Ten assessments used both adult and children population-specific measures: Health Utilities Index Mark 2 (n=6); a children and adolescents specific preference-based measure for atopic dermatitis (n=1); the youth version of the EQ-5D (EQ-5D-Y) generated using mapping and valued using the UK EQ-5D adult tariff (n=2), and the EQ-5D-Y using the EQ-5D adult tariff (n=1). The cost-effectiveness analyses used age adjustment (utility subtractions, weights and published mapping formulae) from adult EQ-5D UK population norms to reflect general population or disease-free health for children and adolescents (n=9), and one assessment assumed full health (utility value of 1).

Conclusion: The review found very limited use of child and adolescent population-specific measures to generate health state utility values for children and adolescents in technology assessments submitted to NICE. Often they use an adult specific measure to reflect the health of children.

1.0 Introduction

Economic evaluation is now an important component of decision-making in health care systems across the world. Methods for these analyses must be appropriate for decisions relevant to many different populations including children, adolescents, working age adults and retired people. The evaluation of technologies for children and adolescents presents particular methodological challenges, one of which is in the assessment of health-related quality of life (HRQoL) [1]. For example, children and adolescents may be less able to accurately report their own health, and this may require a mixture of proxy-report and self-report of their health according to what is appropriate for their age and cognition. This raises the issue of what is and should be done to measure and value benefits of technologies for children and adolescents for economic evaluation.

The National Institute for Health and Care Excellence (NICE) Guide to the methods of technology appraisal 2013 ("Methods Guide") includes a reference case which specifies the methods considered by NICE to be the most appropriate for the purpose of technology assessment in children, adolescent and adult populations[2]. The reference case includes the use of EQ-5D to generate quality adjusted life years (QALYs) for adult populations. The Methods Guide further states that HRQoL should be self-reported directly from patients, or, if that is implausible, their carers[2]. However, the Methods Guide is not as prescriptive for children and adolescents:

"When necessary, consideration should be given to alternative standardised and validated preference-based measures of health-related quality of life that have been designed specifically for use in children. The standard version of the EQ-5D has not been designed for use in children. An alternative version for children aged 7–12 years is available, but a validated UK valuation set is not yet available". (page 42)

Of note is that the age range for the use of the EQ-5D-Y in the above NICE guidance statement is less than that stated in the user guide for the instrument (self-assessment at ages 8 to 15). Regardless, the NICE Methods Guide clearly allows a range of different preference-based measures to be used to generate utility values for the assessment of technologies for use in child and adolescent populations. There is a large body of literature reporting that different measures generate different utility values when used in the same adult patients (for an overview see[3]), suggesting that using different measures to assess interventions for child and adolescent populations may not be compatible with the requirement to make decisions in a consistent manner. This raises issues of how best to estimate utility values reflecting the health of children and adolescents and incorporate the child-to-adult transition in models. The appropriate estimation of utility values involves multiple considerations: which dimensions of HRQoL to include (and the basis of the selection); whether the dimensions of HRQoL vary by age (for example different dimensions for adolescents and infants); whether the health state of the child is self-reported by the child or proxy-reported by their carer (which will differ by age and cognition); valuation of the health state classification system including which technique (for example time trade-off); whose values (for example, representative sample of the UK adult population or adolescents); and from which perspective (for example, adult perspective – imagining what it would be like for you now to experience the health states, or child perspective – for example imagining what it would be like for a 10 year old child to experience the health states).

There is a growing range of preference-based measures available for use with children and adolescents including the HUI2[4] (Health Utilities Index Mark 2) (self-assessment at ages five and above), the CHU9D[5-8] (self-assessment at ages 7 to 17), 16D[9] (self-assessment at ages 12 to 15), 17D[10] (self-assessment at ages 8 to 15), EQ-5D-Y[11-13] (self-assessment at ages 8 to 15), AQoL[14 15] (Assessment of Quality of Life) (self-assessment for adolescents) and AHUM[16] (Adolescent Health Utility Measure). One option to generate utility values for children and adolescents is to generate utility values for adults, using self-report EQ-5D, and assume that those estimates would be the same for children and adolescents living with the same condition and health severity. Whilst this maintains comparability between assessments for children, adolescents and adults, it may not be appropriate to expect that children experience the condition in the same way as adults. Another option is to use child measures that enable them to self-report their health where possible and to use proxy-report where this is not possible. Whilst this potentially ensures a more accurate representation of the child's and adolescent's experience, it raises issues of comparability between assessments and methodological issues around the combination of self-report, proxy-report and adult measures once the child progresses into adulthood. Both approaches also require a decision to be made on normative valuation issues raised earlier, including whose values are used for the health states and using which perspective.

This review examines previous NICE technology assessments to identify the methods used to generate utility values for child and adolescent health states in different patient groups.

2.0 Methods

2.1 Search strategy

The NICE advice and guidance website were accessed on 29th October 2019. Filters were applied to the NICE guidance list to retrieve all 474 Technology Appraisals (TA) and 11 Highly Specialised Technologies (HST) guidance. HSTs are new and emerging healthcare technologies with 20 months or less to marketing authorisation. The licensed indication for the technology for people under 18 years were identified from the overview or technology section of the guidance.. The HST and TAs follow the same NICE guidance on the methods of appraising a technology[2]. This review is based on the publicly available Evidence Review Group (ERG) or Assessment Group (AG) reports, and committee final appraisal and final evaluation determination on how the technology should be used in the NHS in England. Company submission documents that are available on NICE's website were retrieved and reviewed when more detail was required on the methods of estimating child utility values in the company's models.

2.2 Included studies

Figure 1 shows the selection of assessments. A total of 39 NICE Technology Appraisals (TAs) and 8 NICE Highly Specialised Technologies (HST) reports were identified. Seven were excluded because the economic analysis was not based on a cost-utility analysis. Technology assessments where the committee guidance covered both adult and children and adolescents were included, even in cases where the economic models simulated only adults, since the choice of estimating cost effectiveness only for adults may have been reached after a review and discussion of alternative approaches including generating utility values for children and adolescents. We intended to identify and record any such deliberation. Therefore, 40 technology assessments were included in this review. Twenty-four were single technology appraisals (STAs), eight were multiple technology appraisals (MTAs) and 8 were highly specialised technology appraisals (HSTs). We examined all submitted models in these technology assessments.

2.3 Data extraction

The extraction included: the assessment process used (STA, MTA and HTA); date of publication of the guidance; health condition; health technology; details of the evidence provider (for example an economic model from the sponsor or an independent assessment group); source of the utility data (including sample size, population, setting); population used to generate utility weights (for example representative sample of the UK population); valuation method (for example time trade-off); adjustments made to utility values (for example for age and gender profiles); methods of mapping to a utility value (where data were not directly obtained with a preference-based HRQoL); any other approaches to estimate utility values in absence of data or reported values in the wider literature; model structure (for example ages of the population upon entry into the model, time horizon of the model), utility values used for children and adolescents for all event states (for example disease free and with disease); and written text concerning children and adolescent health utility values in the committee discussion section of the guidance and assessment reports.

3.0 Results

Table 1 summarises the methods used to estimate utility values in the technology assessments.

3.1 Sources of utility data

Figure 2 shows the data sources of self/proxy-reported data used to establish utility values used in technology assessments: 16 assessments used utility data from existing observational studies, 2 used population trials conducted exclusively in children and adolescents and other types of sources, 11 assessments used a mixture of adult trials and other types of sources, 6 assessments identified utility values from clinical trials, 3 used observational studies combined with estimates from clinical experts (for example experts complete the EQ-5D for illustrative vignettes), 1 assessment was a meta-analysis of utility values, 1 used authors' assumptions of utility values. The two assessments that used children and adolescent population trials did not measure HRQoL using a preference-based measure, and to generate child and adolescent utility values both assessments retrieved information from observational studies.

3.2 Methods used to generate utility values

Figure 3 shows the HRQoL measures used to generate utility values in technology assessments. The majority of assessments (n=33) included utility values generated using the adult version of the EQ-5D either exclusively (n=17) or alongside other measures to estimate utility values (n=16). Seven assessments did not use the EQ-5D, with five choosing the HUI3 as its main instrument and the other estimated a utility index from the EORTC QLQ-C30. Sixteen assessments used more than one HRQoL measure to generate utility values for all health states in the economic model. Utility values were mainly based on the EQ-5D but the economic models also had utility values generated using the Health Utilities Index Mark 2 (HUI2) (n=6) and Mark 3 (HUI3) (n=5), the SF 36 (n=1) or calculated from direct elicitation using vignettes such as Standard Gamble (SG), Time-trade-off

(TTO), or rating scale (n=5). Four out of nine assessments that used only children and adolescents in the economic model (no adults) applied different HRQoL measures across different health states and age ranges, while the other five assessments used only the EQ-5D.

Three assessment used only HUI3, although one explored alterative values with EQ-5D (HST 11). Another used HUI3 in combination with clinical advice on the disutility for a health state (HST3), and two assessment used only the HUI, but estimated different health states with alternative versions (HUI2 and HUI3). One assessment did not use a preference-based measure to generate utility values and used one item from a cancer-specific patient reported outcome measure, the EORTC QLQ-C30, and treated this as a utility index on a linear gradient with the worst possible response equivalent to dead at 0 and the best was equivalent to full health at 1 (TA 23).

Ten of the 40 assessments (25%) included child and adolescent population-specific measures to estimate utility values for health states in the models, though nine of these also used at least one other method to generate utility values. Six submissions used the HUI2, one submission used a preference-based measure of quality of life in children and adolescent atopic dermatitis alongside the EQ-5D (TA 82), and two assessments included mapping to the EQ-5D-Y, and one used the EQ-5D-Y exclusively (TA 588). Utilities were generated from the EQ-5D-Y using the UK EQ-5D adult value set.

Eleven assessments used mapping to generate utility values, where 2 assessment mapped to the HUI3, 6 assessments used mapping to estimate EQ-5D utility values from a condition-specific measure and 3 assessments mapped to the EQ-5D-Y with utilities generated using the EQ-5D adult value set with 2 mapped from a condition-specific measures and 1 from The Pediatric Quality of Life Inventory (PedsQL) (TA 588). Regarding the latter assessment, the appraisal committee considered two approaches to estimating infant utilities, a vignette study based on EQ- 5D-Y assessments by healthcare professionals and the mapping of PedsQL data to EQ-5D-Y, and did not prefer one of the approaches to the other.

3.3 Utility values for general population health states

The choice of general population or disease free health state values directly affects the HRQoL gain attributable to a treatment intervention in models, and this impacts on the cost-effectiveness of treatment. Table 2 illustrate the range of utility values reported for general population and disease free health states and mild conditions and how values were established in the absence of child and adolescent HRQoL data.

The range of utility values used for children and adolescents with no disease ranged from 0.87 to 1.0. In the absence of data, the authors assumed these values or extrapolated to children and adolescents from the relationship between age and HRQoL in the adult general population (see section 3.4).

3.4 Adjustments to utility values

Where adjustment of adult utility values were used to estimate children and adolescent values it was mainly to reflect the natural decline in HRQoL associated with older age although other forms of adjustment did take place which was typically regression analysis to adjust the HRQoL of disease states for patient characteristics. All age-adjustments in the assessments increased the health utility of children and adolescents compared to adults by increasing the health utility of children and adolescents rather than decreasing the utility of adults. In seven assessments the utility value for children in full health aged under 16 years was extrapolated from published formulae derived from the relationship between adult HRQoL (measured by the EQ-5D) and age [17 18]. The formulae was established using censored regression models[18] and ordinary least squares models[19] of the relationship between utility values, age and sex although the only regression coefficient used for the extrapolation was age. In one assessment, logistic regression with age as the only explanatory variable interpolated utility values for age 0 onwards using UK EQ-5D general population values available from 18-75 year olds (TA538). Fourteen assessments were based on utility subtractions or weights from age-specific adult EQ-5D UK population norms and in six assessments children and adolescents under 19 were given the same value regardless of age. In all these assessments utility estimates were established in samples of adults using an adult instrument and extrapolated beyond the data to children and adolescents. In one assessment disease free EQ-5D utilities were adjusted every 10 years based on the age coefficient of an OLS regression, which meant all children had the same baseline health (TA606). Just one assessment (TA 235) reported using ‘child weights’ for the age adjustment taken from a population-based Childhood Cancer Registry of Piedmont in Italy using HUI3[20].

3.5 Approaches taken to incorporate the child-to-adult transition

Many of the assessments had a child and adolescent population that progressed into adulthood as part of the model of cost-effectiveness, reflecting chronic conditions and long term treatment (n=24). In the majority of assessments that incorporated the child-to-adult transition (n=14), children and adolescents had the same utility values for event states as adults and the utility values were estimated using EQ-5D completed by adults. Four assessments had different utility values for adults and children to represent the progressive nature of a disease that started in early childhood. In one assessment the utility of children of four severity stages of disease was stratified by three age bands (1-4 years, 5-12 years, 13 years and older) and the utility values of children 13 years and old were assumed to be applicable to adults (HST 8). Five assessments had different utility values for adults and children and age subgroups were modelled separately.

Eight assessments had economic models with children and adolescents that were not followed into adulthood, beyond the age of 18 years. These assessments mainly estimated child utilities from adult EQ-5D scores (n=6) although other approaches included mapping condition-specific measures to the EQ-5D (n=2), the Dermatology Quality of Life score to the EQ-5D-Y (TA 455), mapping PedsQL scores to the EQ-5D-Y in addition to a vignette study based on EQ- 5D-Y assessments by healthcare professionals (TA588) and estimating utility values from the EQ-5D supplemented with information for some health states from other preference based approaches such as the TTO and HUI. Eight assessments included economic models that simulated only adults when the committee guidance covered the entire patient population (children, adolescents and adults).

4.0 Discussion

The most common method used to generate utility values for children and adolescents was the adult EQ-5D, scored using the UK value set (33 of 40 assessments). Other adult generic preference-based measures were used, including HUI3. Direct elicitation methods of SG and TTO were used, though typically to generate only a subset of health states in the economic model, with EQ-5D being used to generate utility values for other health states. Out of all assessments, only 10 (25%) used child and adolescent population-specific measures to report the description of the health of a child. Nine of these assessments also used at least one other method to generate utility values for some health states in the economic model.

A commentary in 2016 briefly reviewed the approaches to generate utility values in child populations in NICE technology appraisals over time[21] and 'found that most had used adult utilities to inform the model, due to the unavailability of suitable child derived utilities; furthermore, it was clear that there was no trend away from this over time' (p. 349). However, this statement was supported using only three illustrative case studies. Thus, it failed to demonstrate how the evidence warranted its findings. In contrast, this review considers and evaluates in detail all assessments submitted to NICE across both the HST and TA programs through to 2018, compares the methods taken to establish child and adolescent utility values and draws out the implications of the general absence of paediatric utility values for methods of healthcare technology assessment.

In the majority of assessments it was not possible to identify the ages of the respondents to the HRQoL measure used as the source for utility estimates, or easily distinguish who the instrument had been completed by (children, adolescents and adults self-reporting their heath or proxy-reporting by carers) with the information provided. However, EQ-5D is an adult measure not intended for use in children. This suggests that many of the utility values used in the economic models to reflect child HRQoL may be based on adolescent or adult self-reported health for the same condition. In the majority of assessments utility values were based on only adult responses (n=22), but it is not always clear whether they are reporting their own health (they could be proxy-reporting health).

The child and adolescent population-specific measure CHU9D was not used to generate utility values in any submission, despite the large number of licenses granted to use the measure in studies to date. EQ-5D-Y was used in 2 assessments, yet it should be noted that at present a value set for the EQ-5D-Y is not yet available in any country and the EuroQol Research Foundation does not recommended to use the EQ-5D-3L value set as proxy value set for the EQ-5D-Y [22]. This may have influenced the decision not to use it in clinical studies.

The findings raise the question of whether adult self-reported health, scored using a value set generated for adult health states valued by adults using an adult perspective is appropriate for generating the utility values used to reflect child and adolescent health states. The appropriateness of use of adult self-reported health, scored using the standard value set appropriate for adults relies on several assumptions: 1) children, adolescents and adults are affected in a similar way by conditions, that is approximately the same impact on severity of problems in those dimensions; 2) All dimensions of HRQoL that are relevant to inform policy in child populations are relevant dimensions in adults; 3) the value sets for adult health states are applicable to adults, adolescents and children, that is typically the adult general population (not children or adolescents) valuing adult health states (not child health states) from an adult perspective (typically imagining themselves in the health state) will capture the HRQoL of child health states.

There is evidence that each of these assumptions could be challenged. A systematic review published in 2015 challenges assumption 1) where it was concluded that adults, children and adolescents perceive and value health differently[23] and the review recommended further development of child- and adolescent-specific measures. Assumption 2) could be challenged by the fact that adult and child and adolescent measures often have different dimensions, for example anxiety and depression in adult EQ-5D in comparison to worry and sadness for child and adolescent measure CHU-9D. However, it could be argued that the underlying dimension – mental health – is constant across the two and that the same underlying dimensions are equally relevant for children, adolescents and adults. Indeed, the underlying dimension may be the same but worded in child-appropriate and adult-appropriate language. There is also the issue of whether the severity levels are the same and are comparable, even if the underlying dimension is the same. Regardless, even if there are a core set of dimensions that are equally relevant for children, adolescents and adults, the wording of dimensions would need adaptation for children to be able to self-report their own health. Equally whilst the content of measures differs, this is due to the process used to develop a measure. The CHU9D differs in its dimensions to the EQ-5D and also differs to the EQ-5D-Y in the process used to develop the measure. The EQ-5D-Y was generated by adapting the adult EQ-5D content for children[13], whereas the CHU-9D was developed from interviews with children aged 7 to 11 years to generate the dimensions of the classification system[5-7]. Thus, CHU-9D should be seen as an entirely de novo child-specific instrument that does not mirror the dimensions of an adult measure, whereas EQ-5D-Y is an adaptation of an adult instrument using child-appropriate language for use in children. Recent research has challenged assumption 3), finding that health states are valued differently when described using an adult or child perspective, implying that UK EQ-5D adult value sets may not be applicable to EQ-5D-Y[23].

A further consideration is the distinct developmental stages in child and adolescent populations. Children and adolescents are not a single population but present a spectrum of developmental stages in cognitive and linguistic capacities within and across ages. Full health at each stage can be defined by the absence of problems in any dimensions of health on a HRQoL measure. However, important dimensions of health could be categorized differently at each stage, and respondents/proxy-responders could respond differently at each stage despite no underlying change in health. For example, there are different norms for speech-language development at different child ages although failure to meet this standard does not imply a cognitive illness.

The widespread use of adult EQ-5D utility values in NICE assessments may be due to the NICE recommendation of EQ-5D for adults, and a desire for consistency across all assessments, and a belief that the recommended method for adults also applies for children and adolescents. However, it may also be driven by practical and pragmatic concerns. There are significant challenges in collecting self-report or proxy-report health data for child and adolescent patients, in particular for rare conditions, and there is much larger availability of adult EQ-5D data. This may explain why only two assessments were based on trials with only child patients and these trials did not include use of a preference-based measure that could be used to generate utility values. The age of the population may also be a factor. The EQ-5D could be self-reported by older adolescents (or proxy-report if this is not possible) where arguably the dimensions may be both understood and appropriate, and this may achieve consistency with trial data collected with adults.

5. Conclusion

To sum up, this review has summarised the approaches used to generate child and adolescent health state utility values in assessments submitted to NICE, finding inconsistencies in the methods that are used. Some assessments used child and adolescent population-specific measures, others used an adult HRQoL measure (often the EQ-5D). Even within the approaches used that follow NICE guidance for generating adult utility values there are inconsistencies in the approaches used, for example some technology assessments use EQ-5D, others use EQ-5D-Y and others adjust utility values to account for age.

The trend across the assessments is mainly that adult values are assumed to be adequate. This raises some very important questions of underlying principles that need to be answered before any progress on best practice recommendations around utilities for children and adolescents can be made. What are the underlying dimensions of health for children and adolescents, how can these be appropriately measured and then valued? The answers to these questions might point to the need to develop either new measures or extend existing ones. But it could equally lead to us accepting the use of adult EQ-5D responses (or another measure) with adjustment for age, as undertaken for different ages when establishing baseline health-state utility profiles. This raises important questions on the selected methodology for any cost-utility evaluation in child and adolescent populations. Without these issues being addressed there will continue to be variability in the methods used to generate utility values for children and adolescents, and lack of consistency in the evidence considered across different technology assessments.

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