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Measuring health outcomes of adolescents: report from a pilot study

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Abstract There is a need to understand the practicality, validity and reliability of using utility measures with children and adolescents. We designed a pilot study in order to help guide the selection of an appropriate healthrelated quality-of-life (HRQoL) questionnaire for adolescents to be used in the context of a large randomised controlled trial (RCT) of family therapy versus standard treatment for adolescents aged 11-17 years. The pilot study was carried out on a school sample of adolescents in the same age range as the RCT. Adolescents were asked to fill in three HRQoL questionnaires: the standard EQ-5D, the licensed Health Utilities Index HUI, and the childfriendly version of the standard EQ-5D: the EQ-5D for youth (EQ-5D-Y). This report explores the problems with the language and concepts embodied within those HRQoL questionnaires and open discussion regarding how we can value the health of adolescents for cost-utility analysis in a larger study.

Keywords EQ-5D · HUI · Adolescents · Children · Utility measures · Health-related quality of life

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Introduction

For the purpose of an economic evaluation alongside a large randomised controlled trial (RCT) focusing on adolescents aged 11–17 years, we needed to make a decision on the best way to assess health-related quality of life (HRQoL) in order to inform resource allocation decisionmaking in the health care context [11]. The SHIFT trial (project reference 07/33/01) intends to determine whether there are differences between family therapy (FT) and treatment as usual (TAU) for adolescents who are seen after an episode of self-harm with respect to repetition rates of self-harm, cost-utility, suicidal ideation, and HRQoL. The related economic evaluation within the trial will examine the incremental cost utility of FT versus TAU in the management of self-harm.

There is a debate in the health outcomes literature regarding who the most appropriate respondent should be when assessing children's health-related quality of life (HRQoL). Parents are generally expected to provide more reliable responses on more complex, psychologically oriented measures [13]. In some cases, parent-proxy reports may be the only practical option where children are unable to provide reliable information on health-related concepts. From a theoretical perspective, children's self-reported values may be preferable because HRQoL is subjective and representing a person's own perceptions/evaluation of life [14]. However, research has shown that the assessment of HRQoL by children using self-report questionnaires is possible as long as they are able to understand and interpret questions and to give reliable and valid answers [16]. So, when precisely can a child provide answers about his/her

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own health? Whilst most children have learnt to read by 6–8 years of age, this may not be sufficient to fully understand a HRQoL questionnaire. The key age of maturity and cognitive ability remains unclear, with conventional wisdom suggesting that children aged 11+ years can self-complete whereas children aged less than 11 require proxies. Guyatt et al. [5] showed that clinicians could obtain additional information from parents when questioning both children and parents of children under 11 years of age. The study however showed that parents provided a limited amount of supplementary information beyond that obtained through questioning children over the age of 11.

Economic evaluations of competing health interventions involve the assessment of the incremental costs and benefits associated with a new intervention compared with standard practice. They are necessary to aid informed decision-making in the presence of a fixed budget. There are different types of economic evaluation, depending on the unit of measurement employed to assess the benefits. This study is concerned with a specific type of evaluation known as cost-utility analysis (CUA). Here, benefits are assessed using utility- or preference-based instruments [1]. The most commonly used utility-based HRQoL instruments assessing interventions for the child and adolescent population include the EQ-5 D^{TM} [18] and the Health Utilities Index HUI[®] [4]. In addition, a child-friendly version of the standard EQ-5D, the EQ-5D-Y has been developed [6]. The feasibility, reliability, and validity of this questionnaire are currently being evaluated, and utility values are expected to be assigned in the near future, which makes this instrument particularly interesting to consider. Further information on recent studies utilising the EQ-5D-Y is given in the next section.

In order to help guide the selection of utility measures for use in the SHIFT trial, we designed a pilot study focusing on adolescents in the same age range as the trial population. Using EQ-5D, the HUI, and EQ-5D-Y, the study addresses the following two questions: Is it a challenge for adolescents aged 11+ years to answer questions about their own health? Is there a specific HRQoL questionnaire that is more suitable for this age group? The key criteria used to compare the three measures involve the assessment of completion rates and young peoples' difficulties in understanding the language of the questionnaire. It is outside of the scope of the current paper to assess the appropriateness of using utility values developed for use in adult studies by adults (as is the case in the EQ-5D) on the child and adolescent population. For more information on this area, a discussion around the methodological challenges of eliciting health state valuations from the paediatric population is presented in a recent article by Ungar [19].

This current paper presents the pilot study findings. It does not, however, inform the development of measures for child or adolescent health. It also does not comment on the conceptual differences between the HUI and EQ-5D and whether these measures capture all the relevant domains of HRQoL to children. The objective of this study was to investigate problems with language and comprehension associated with the completion of the aforementioned HRQoL questionnaires.

The remainder of this paper proceeds as follows. In the next section, we describe the current research on the use of utility measures in younger population. In Section 'Study design', we present the study design, followed by the results in Section 'Results'. Section 'Discussion' discusses the results and concludes.

Background

A recent review by Tarride et al. [17] assessed the use of utility measures in the younger population. The authors reviewed the published literature reporting utilities among children and adults across selected conditions common to paediatric and adult populations. The review included 77 studies covering the following health conditions: asthma, cancer, diabetes mellitus, skin diseases, and other chronic diseases. The authors found that in the majority of cases utility values were estimated using HUI or EQ-5D. The authors found 23% of the studies evaluated utilities in children and 21% evaluated utilities for both children/ adolescents and adults. The majority of studies included in the review assessed the utility of children within the area of oncology. The authors surmise that researchers in paediatric medicine should be encouraged to conduct utility measurements in their patients, as the empirical evidence shows differences in the utility values between children and adults depending on methods used to elicit utility values and whether proxy respondents are used.

Another more recent study by Oostenbrink et al. [12] carried out a head-to-head comparison of the HUI and EQ-5D questionnaires. The authors utilised experts' opinion in order to classify seven standardised descriptions of children with permanent sequelae after having bacterial meningitis using both the EQ-5D and the HUI classification systems. An expert panel of paediatricians working within university hospitals or general hospitals in the Netherlands were given these seven hypothetical descriptions and were asked to imagine being a child in these states. The authors hypothesised that the EQ-5D classification would be practically more superior and that the HUI classification would be more precise and more discriminative. They also assumed that both instruments would roughly produce the same quality weights. The study findings were as follows: in terms of the practicality, the EQ-5D was found to perform the best as it had the least missing responses; they also found that the HUI quality weights were substantially

lower than the EQ-5D ones for all descriptions. Although the adolescent population was not utilised in this study, it confirms the need for the assessment of these two questionnaires in an adolescent population in carrying out CUA.

Since its recent development, the EQ-5D-Y has been utilised in four studies. Using the EQ-5D-Y and a proxy version (administered to parents of children included in their study), Jelsma and Ramma [8] compared the HRQoL in children attending open schools and children with disabilities attending a special school in Cape Town, South Africa. Approximately 20% of eligible participants provided complete data (n = 567 sets of child/adult responses from the former group and n = 61 from the latter group). The authors found that the association between adult and child scores were fair to moderate in the domains between the two groups. They also found that the difference in the scores between children with special needs and typical developing counterparts were similar in the following domains: Doing usual activities, Pain or discomfort and Worried, sad or unhappy. Children with special needs reported more problems in the Mobility and Looking after myself domains. Based on their study findings, the authors conclude that if HRQoL is to be used as a clinical outcome in resource allocation, then it is preferable to include the children's values as proxy report did not appear to be highly correlated with the child's own perceptions. In addition, they also warn that children in dysfunctional health states might report better values, because of resilience. This might result in higher values being attached to poor health states and thus correspondingly smaller resource allocation to paediatric health services.

A Canadian study by Wu et al. [21] aimed to describe and assess how health-related quality of life correlates with sociodemographic and neighbourhood characteristics in children. A survey was used to measure HRQoL of children aged 10–11 years from 148 schools (N = 3,421). The authors utilised the Canadian English child version of EQ-5D, EQ-5D-Y. A mean EQ-5D-Y index of 0.86 was found by the authors. They also found that children from families reporting higher educational attainment reported higher HRQoL. Also, children residing in neighbourhood characterised as providing good satisfaction and facilities reported higher HRQoL.

The aim of this study by Jelsma [7] was to investigate the performance of EQ-5D-Y instrument compared with the standard EQ-5D in assessing the HRQoL of high school children in Cape Town, South Africa. In a sample of 521 respondents, EQ-5D-Y was found to be superior in that there were statistically significant fewer missed item responses. It was found that more missing responses were found in younger aged children, and this was particularly true for EQ-5D general version in comparison with EQ-5D-Y. The authors concluded that EQ-5D-Y performed better than EQ-5D, particularly in the younger children, and should be used in early secondary school. They also found that EQ-5D-Y generated a wider range of responses and might be more responsive than the adult version.

The study by Eidt-Kochet al. [2] assessed HRQoL using EQ-5D-Y in combination with the Cystic Fibrosis Questionnaire (CFQ). The objective of the study was to evaluate the cross-sectional validity of EQ-5D-Y as a generic health outcome instrument in children and adolescents with cystic fibrosis in Germany. Ninety-six patients were included in the study, age ranging from 8 to 17 years. The findings led the authors to conclude that EQ-5D-Y can be considered a cross-sectional valid generic health outcome instrument, which reflects differences in health according to the progression of the lifelong chronic disease cystic fibrosis.

All these studies taken together motivate the need to carry out a pilot study to decide what the most suitable HRQoL measure would be in the context of our peculiar trial population.

Study design

Ethical approval to carry out the pilot study was granted from the University of Leeds ethics board, and written consent was provided by both parents/carers and the adolescents who were involved in the study. Four school classes were involved in the study, two from each year group.

We carried out the pilot study within the classrooms of a secondary school in Leeds (UK in July 2009) to assess the ability of children to deal with the concepts and language of the EQ-5D, HUI, and EQ-5D-Y questionnaires. Individuals from Years 7 (age 11–12) and 8 (age 12–13) were asked to complete each HRQoL measure during a class session under the supervision of a researcher and their teacher. We also included a convenience sample of 11 adolescents related to University of Leeds staff members aged between 11 and 18 years. A sample of 49 adolescents in total was studied.

The Health Utilities Index HUI2 and HUI3

The HUI[®] questionnaire [3] was developed for use with children and consists of 17 self-assessed questions: 15 HUI-based questions and 2 other questions. The 15-item self-administered questionnaire has been designed to ask the minimum number of questions required to classify a subject's health status according to the classification systems of both Health Utilities Index Mark 2 and Mark 3 (HUI2 and HUI3). The two other questions are a global health rating question and 'how was the questionnaire

completed' question. It is assumed to be phrased to elicit responses from a wide variety of subjects aged 5+ years about their health status for various recall periods, from their own perspective. The version used in this pilot study used a 1-week recall period. The domains covered include vision, hearing, speech, ambulation/mobility, pain, dexterity, self-care, emotion, and cognition.

The standard EQ-5D

The EO-5DTM [18] consists of a descriptive system and a visual analogue scale. The EQ-VAS records the self-rated health on a vertical scale where the endpoints are labelled 'best imaginable' and 'worst imaginable health state'. We did not include this in our study as it was not relevant to our purposes with regard to the assessment of questionnaire wording. The descriptive system comprises five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression; each dimension has three levels of severity. EQ-5D is considered suitable for children from 12 years old [6]. However, a survey with secondary school pupils showed that children reported a number of items that they found difficult to understand or answer [6], so the authors concluded the acceptability of this version limited to older children and tested a modified version suitable for younger children.

The child-friendly version of the EQ-5D

The EQ-5D-Y is a modified version of the standard form of the EQ-5D that has been tested in a survey of more than 3,000 children and young people aged 7–17 [20]. The modifications consisted of the language used to be comprehensible to younger children [20]. Therefore, *self-care* was changed to *looking after myself*, *moderate pain* to *some pain*, *performing my usual activities* to *doing my usual activities*, *I am confined to bed* to *I have a lot of problems walking about*. A recent validity study [15] showed that the EQ-5D-Y is easy to fill in, has few missing values, and is highly feasible for children as a HRQOL measure. However, the very low proportions of missing values may be due to assistance from an investigator or somebody at home.

All three questionnaires were edited in an attractive manner using *Comic sans MS* font on coloured paper. The questionnaires were stapled together and presented in the following order: standard EQ-5D, HUI, and EQ-5D-Y (a copy of the questionnaire is available from the authors upon request). In addition, children were asked to circle any particular words or questions they found hard to understand or answer; they could also ask for oral clarification. All 3 questionnaires applied were UK versions for this pilot study.

Results

The age range was from 11 to 18. The majority of study participants were 12 years old (57%) and mostly from the school sample (78%). Approximately 53% of the adolescents who participated in the study were women (see Table 1). We present the percentage of completion for each questionnaire in Table 2. No missing data were observed for any of the questions in the EQ-5D. The HUI has the highest rate of missing data, and from the feedback we got from the adolescents at school they had difficulties interpreting some of the questions. Words and phrases that caused problems in the questionnaires were identified; a number of pupils also asked for verbal clarification from the researcher. Approximately ten adolescents who took part in the study requested verbal clarification whilst they were completing the questionnaires. Three adolescents misunderstood questions related to the pain dimension in the HUI. This relates to question 8 in the HUI 'Which one of the following best describes the pain and discomfort you have experienced during the past week? (a) Free of pain and discomfort; (b) Mild to moderate pain or discomfort that prevented no activities; (c) Moderate pain or discomfort that prevented some activities; (d) Moderate to severe pain or discomfort that prevented some activities; (e) Severe pain or discomfort that prevented most activities'. It was also relevant to question 15 in the HUI questionnaire: Which one of the following best describes the pain or discomfort you have experienced during the past week? (a) Free of pain and discomfort; (b) Occasional pain or discomfort. Discomfort relieved by non-prescription drugs or self-control activity without disruption of normal activities; (c) Frequent pain or discomfort. Discomfort relieved by oral medicines with occasional disruption of normal activities; (d) Frequent pain or

Table 1 Descriptive statistics

	Frequency	Per cent (%)
Sex		
Female	26	53.06
Male	23	46.94
Age		
11 years old	3	6.12
12 years old	28	57.14
13 years old	12	24.49
14 years old	2	4.08
15 years old	1	2.04
16 years old	0	0.00
17 years old	2	4.08
18 years old	1	2.04

Table 2 Completion of the three health-related quality-of-life questionnaire by questions

	Ν	%
Standard EQ-5D		
Fully completed questionnaires	49	100
Completion by dimension		
Mobility	49	100
Self-care	49	100
Usual activities	49	100
Pain discomfort	49	100
Anxiety depression	49	100
Health Utilities Index HUI		
Fully completed questionnaires	36	73.47
Completion by question		
HUI 3		
Vision A	46	93.88
Vision B	47	95.92
Hearing A	47	95.92
Hearing B	47	95.92
Speech A	47	95.92
Speech B	47	95.92
Emotion	47	95.92
Pain	47	95.92
Ambulation	46	93.88
Dexterity	47	95.92
Cognition A	42	85.71
Cognition B	47	95.92
HUI 2		
Self-care	47	95.92
Emotion	47	95.92
Pain	47	95.92
Overall health	42	85.71
Child-friendly version of EQ-5D		
Fully completed questionnaires	44	89.80
Completion by dimension		
Mobility	45	91.84
Looking after myself	45	91.84
Doing usual activities	45	91.84
Having pain or discomfort	44	89.80
Feeling worried, sad or unhappy	44	89.80

discomfort; frequent disruption of normal activities. Discomfort required prescription narcotics for relief; (e) Severe pain or discomfort. Pain not relieved by drugs and constantly disrupted normal activities. However, the wording of the suggested answers in the pain and discomfort domain in EQ-5D (a) I have no pain or discomfort; (b) I have moderate pain or discomfort; and (c) I have extreme pain or discomfort did not appear to pose a problem for them. The cognition dimension relating to Question 11 in the HUI was also highlighted as a problem

Table 3 Completion of the EQ-5D-Y questionnaire by age group

Completion by dimension (number of missing)	12 years old $(n = 28)$	13 years old $(n = 12)$	Total
Mobility	2	2	4
Looking after myself	2	2	4
Doing usual activities	2	2	4
Having pain or discomfort	3	2	5
Feeling worried, sad or unhappy	3	2	5
Total by age group ^a	12	10	22

^a None of the other age groups missed any of the questions: 11 years (n = 3), 14 years (n = 2), 15 years (n = 1), 17 years (n = 2), 18 years (n = 1)

for adolescents' understanding. Question 11 from the HUI questionnaire asks: Which one of the following best describes your ability, during the past week, to remember things? (a) Able to remember most things; (b) Somewhat forgetful; (c) Very forgetful; (d) Unable to remember anything at all. They picked up 'somewhat forgetful' as a term that they did not know the meaning of and would thus not be able to appropriately answer the question. For both the HUI and the EQ-5D questionnaires, 'anxiety' and 'anxious' were terms that needed verbal clarification. Finally, in terms of EQ-5D, verbal clarification was also sought for the meaning of 'confined to bed'. Upon explanation that this meant 'not being able to get out of bed', adolescents were able to indicate an appropriate answer. Questionnaire completion by age group is presented in Tables 3 and 4. For the EQ-5D-Y, missing data were observed for 12- and 13-year-olds, only. Regarding HUI completion, 12-, 13-, 15-, and 17-year-olds missed out at least one question. The 13-year-olds had the most missing data compared to any of the other age groups. The 12-yearolds did not have problems completing the majority of questions contained in the HUI. Four of the questions contained in the HUI were problematic for some 12-yearolds; for 2 of these, only one individual could not complete the question.

Table 5 describes the proportion of participants falling within each level and dimension for the three HRQoL instruments. The highest proportion of problems was reported for the 'Emotion' dimension both in the HUI3 and in the HUI2 questionnaire. However, a small sample of participants reported problems in the analogous dimension for EQ-5D (*Anxiety/Depression*) and EQ-5D-Y (*Feeling worry, sad, or unhappy*). Meanwhile, all the HRQoL measures described very similarly reports of problems related to the *Pain and Discomfort* dimension. Noticeably, the proportion of responses for each level of severity in the *Pain* and *Emotion* dimensions in the HUI3 and the HUI2 were quite different. In particular, *Pain* in the HUI2 was

Table 4 Completion of the HUI questionnaire by age group

	11 years old $(n = 3)$	12 years old $(n = 28)$	13 years old $(n = 12)$	14 years old $(n = 2)$	15 years old $(n = 1)$	17 years old $(n = 2)$	18 years old $(n = 1)$	Total by question
Completion by quest	ions (number of	f missing)						
HUI 3								
Vision A	0	1	2	0	1	0	0	4
Vision B	0	0	2	0	1	0	0	3
Hearing A	0	0	2	0	1	0	0	3
Hearing B	0	0	2	0	1	0	0	3
Speech A	0	0	2	0	1	0	0	3
Speech B	0	0	2	0	1	0	0	3
Emotion	0	0	2	0	0	0	0	2
Pain	0	0	2	0	1	0	0	3
Ambulation	0	1	2	0	1	0	0	4
Dexterity	0	0	2	0	1	0	0	3
Cognition A	0	3	3	0	1	0	1	8
Cognition B	0	0	2	0	0	0	0	2
HUI 2								
Self-care	0	0	2	0	1	0	0	3
Emotion	0	0	2	0	1	0	0	3
Pain	0	0	2	0	1	0	0	3
Overall health	0	4	3	0	0	0	0	7
Total by age group	0	9	34	0	13	0	1	57

rated at level 1 for 100% of the population, whereas *Pain* in the HUI3 was reported up to level 3 with level 2 being 8.3% and level 3 being 5.6% of the respondents. Regarding the *Emotion* dimension, the distribution of answers over the three levels was also very different: level 1 for the HUI2 being 78% of adolescents' answers but less than 59% for the HUI3.

Discussion

This pilot study provided an opportunity to examine the performance of three questionnaires in measuring health status among adolescents. Whilst the wording in the *pain* and *discomfort* domains in EQ-5D did not appear to pose a problem for adolescents, it did present a difficulty for the HUI questionnaire. Therefore, we would attribute adolescents' difficulty to the length of the responses suggested with the latter than to problems comprehending the vocabulary. Typical of a general population sample [15], the results showed a low reporting of severe problems in all the dimensions for the three instruments. Differences in reports were nevertheless found for similar health-related dimensions within the HUI2 and the HUI3. A potential explanation may be found within the terminology used for

severity levels not being equivalent between the HUI2 and the HUI3: levels 2 and 3, respectively, meaning *mild to moderate* and *moderate* in the HUI3 but *occasional* and *frequent* in the HUI2. High ceiling effects were observed in most of the dimensions of the three instruments. Ceiling effects up to 100% were found in the *Self-care* dimension for EQ-5D, EQ-5D-Y, and the HUI2, and in the *Ambulation* and *Dexterity* dimensions for the HUI3. The limitations of HRQoL instruments to detect moderate impairments and the poor ability to discriminate between respondents in general population have already been commented elsewhere [10, 15].

EQ-5D had the least amount of missing data followed by EQ-5D-Y. The HUI had the largest number of missing data and also more adolescents required help in completing this questionnaire compared with the other two questionnaires.

We checked the literature for evidence of the psychometric performance of the children-friendly version of EQ-5D (EQ-5D-Y). The literature on this is still limited. The SHIFT trial will survey adolescents aged between 11 and 17 years. As older adolescents have been found able to complete the adult version of EQ-5D [6] and EQ-5D-Y is recommended for children aged 8–14 [15], we would need to collect both the standard EQ-5D and EQ-5D-Y to cover the age range of the trial.

Table 5 Percentage of responses by dimension and level for measures

Instrument	(%) of responses for each level of severity ^a						
	Level 1	Level 2	Level 3	Level 4	Level 5	Level 6	
HUI 3 $(n = 36)$							
Vision A	88.89	11.11	0.00	0.00	n/a	n/a	
Vision B	88.89	11.11	0.00	0.00	n/a	n/a	
Hearing A	97.22	0.00	2.78	0.00	0.00	n/a	
Hearing B	97.22	2.78	0.00	0.00	0.00	n/a	
Speech A	97.22	2.78	0.00	0.00	n/a	n/a	
Speech B	97.22	2.78	0.00	0.00	n/a	n/a	
Emotion	58.33	38.89	2.78	0.00	0.00	n/a	
Pain	86.11	8.33	5.56	0.00	0.00	n/a	
Ambulation	100.00	0.00	0.00	0.00	0.00	0.00	
Dexterity	100.00	0.00	0.00	0.00	0.00	0.00	
Cognition A	86.11	8.33	5.56	0.00	n/a	n/a	
Cognition B	88.89	8.33	2.78	0.00	0.00	n/a	
HUI 2 $(n = 36)$							
Self-care	100.00	0.00	0.00	0.00	n/a		
Emotion	77.78	16.67	5.56	0.00	0.00		
Pain	83.33	16.67	0.00	0.00	0.00		
Standard EQ-5D ($n = 49$)							
Mobility	95.45	4.55	0.00				
Self-care	100.00	0.00	0.00				
Usual activities	97.73	2.27	0.00				
Pain discomfort	88.64	9.09	2.27				
Anxiety depression	95.45	4.55	0.00				
EQ-5D Y $(n = 44)$							
Mobility	95.92	4.08	0.00				
Looking after myself	100.00	0.00	0.00				
Doing usual activities	93.88	6.12	0.00				
Having pain or discomfort	85.71	14.29	0.00				
Feeling worried, sad or unhappy	97.96	2.04	0.00				

n/a Not applicable

^a Numbers of levels are 3 for EQ-5D dimensions, 4 to 6 for HUI 3; 4 or 5 for HUI 2 – the highest level for each dimension is the most severe

However, EQ-5D-Y was not yet ready to derive utility scores at the time we needed to decide on the HRQoL questionnaire to be surveyed in the SHIFT trial, namely early September 2010; therefore, we choose to measure HRQoL in the SHIFT trial using the standard version of EQ-5D. In the SHIFT trial, HRQoL will be collected at baseline prior to randomisation via face-to-face researcher administration, at 6 months follow-up via postal administration and at 12 and 18 months follow-up at the researcher's visit to the participants' home in order to assess the effect of each intervention on health outcome. We will therefore address problematic questions related to wording understanding with the help of a researcher being present to explain wording to adolescents for three of the four individual data collection points. Regarding the high ceiling effects of EQ-5D, the specific context of adolescents with self-harm problems will offer an opportunity to test the instrument's reliability in a different clinical context. Furthermore, previous studies showed that EQ-5D was able to discriminate between severity subgroups and captured improvements in mental health over time [9].

Our findings for this pilot study are limited to the population that has been surveyed: English-speaking pupils between 11 and 18 years of age. It is thus possible that the issues of comprehension are country specific. The pilot study was not carried out on adolescents with mental health issues despite the trial population being self-harming young people; it would be interesting to analyse in the future the trial collected data to check whether mental health issues such as self-harming appear to have an effect on HRQoL questionnaire completion and understanding. It would have been useful to provide instrument designers with insights into how to develop more ageappropriate HROoL measures, and not simply identify the measure that had been previously developed for, and tested with, children; unfortunately, this pilot study had to deal with limited resources in terms of availability of respondents, funding, and time. Similarly, exploring ordering effects on completion of questionnaires was unfortunately not part of the pilot study design. The choice of the standard version of EO-5D over the two other HRQoL questionnaires because of full completion may therefore be related to this questionnaire being the first within the pilot booklet. This paper provides new elements to support ongoing research for a reliable and valid child's version of HRQoL questionnaire such as the EQ-5D-Y. It also emphasises that there is an urgent need of instruments deriving child-specific utility measures to assess the cost-effectiveness of medical treatments and interventions among children.

Children appear not to be a homogenous group and this explains the challenges related to the measurement of their health status. Here, we provided some evidence on completion rates and problems with language understanding in three commonly used HRQoL measures, although the difficulty of measuring HRQoL in an age-appropriate way still remains. HRQoL measures reliable for children would benefit much from multidisciplinary research, particularly if health economists were interacting with specialists of children cognitive/developmental abilities; there is a conceptual background necessary to understand the various types of difficulties that young children and early adolescents may have with measures written for adults. In particular, a collaborative pilot study running a series of cognitive debriefing sessions with children of different age groups might be informative in order to list the different types of problems by age group and for each measure, allowing for within and between group comparisons by age and by measure.

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