A Swedish child-friendly pilot version of the EQ-5D instrument—the development process

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Methods: We modified the existing Swedish EQ-5D adult version to make it child-friendly. Within a multidisciplinary research group, we investigated linguistic and interpretation issues by performing face-to-face and group interviews with children and adolescents aged 6–17 years. Results: The first modification of the adult language was to change single words into words intelligible to and used by children [e.g. changing ‘depression’ (depression) into ‘ledsen’ (sad)]. The second related to whole expressions (using verb-form in the headings of dimensions). Conclusion: The advantage of being able to collect much the same data from children and adolescents, for example in population surveys covering all ages and in chronic childhood diseases, as for adults might outweigh possible disadvantages of modifying existing HRQoL instruments. The Swedish child-friendly EQ-5D pilot version resulting from this development process is further tested for feasibility and construct validity in a clinical interview study; initial results are reported in a subsequent paper.

Keywords: child health, EQ-5D, health-related quality of life, interview, Sweden

Introduction

Measurement of children’s health status may be performed by asking the child directly or by the use of proxies, usually parents. The lower age limit at which a child may understand the concepts and answer the questions adequately is debatable and depends on the type of survey in addition to the child’s maturity. A non-interview situation requires a certain level of literacy that varies not only across groups, but also within ages. Several methodological issues have been raised concerning the description and valuation of health status in children as well as choice of study designs. A number of instruments measuring health-related quality of life (HRQoL) have been developed which are especially designed for use in younger age groups. Another option is to revise instruments used among adults with the intention of making them child-friendly, which enables the collection of similar HRQoL data in children, adolescents and adults.

The generic utility HRQoL measure EQ-5D has been widely used in adult settings both in population and in clinical studies, and the feasibility, validity and reliability of the EQ-5D instrument among adults are well known. With the EQ-5D, respondents may classify their own health status in five dimensions (mobility; self-care; usual activities; pain/discomfort; anxiety/depression) and within three levels of severity (no problems, moderate or severe problems) as well as scoring their own current self-rated health status on a visual analogue scale (VAS) from worst to best imaginable health state (0–100).

Even though the EQ-5D is explored for use among adults, some studies have also found this instrument feasible to employ among children. The lowest age for the use of the adult version of the EQ-5D is not determined and the use in children’s settings of values established by adults is debatable, but most instruments are not employed for self-completion at ages below 8 years. However, as pointed out by Hennessy and Kind, using instruments aimed for adults among children may not yield information that can be consistently interpreted if the language and concepts embodied in the instrument are not correctly understood. Hennessy and Kind have modified the original British version of the EQ-5D into a child-friendly version.

In Sweden, the EQ-5D is commonly used in clinical studies and in population surveys, and increasingly as a health outcome measure in the health care system. There is a growing interest in including children and adolescents in EQ-5D studies. A parent’s proxy version of the EQ-5D has been included in a national child population-based survey.
of the instrument, and on informal discussions with Swedish children of different ages scrutinizing the Swedish version of the instrument, our intention was to modify the existing Swedish adult version for use in younger age groups. The target age group is 8–16 years. Self-reporting by children aged less than 8 years cannot be implicitly relied to. The upper age-limit depends on the study context and the intended ages. For example, the adult version is used in Swedish population studies from 16 years. A child-friendly version should be suitable for alternative modes of self-report administration such as postal survey, face-to-face interview and self-completion in the presence of an interviewer.

The aim of this article is to describe and discuss the development process of a Swedish child-friendly pilot version of the EQ-5D instrument. In the methods section, the working process and inclusion criteria for the study population are detailed. In the next section, the results of each development phase are described and discussed in context. The article ends with an overall discussion. In a subsequent article, we present the results from the clinical interview study where the child-friendly pilot version is initially tested for feasibility and construct validity.

Methods

In the development process, we investigated both linguistic issues and interpretation of expressions and words among children. We aimed at modifying the existing Swedish EQ-5D adult version so that children would be able to understand it. However, experiences from the development of the UK child-friendly version suggested that in some aspects more conceptual adjustments might also be necessary, for example in the mobility dimension. We focussed on the similarities and dissimilarities with respect to both the process in UK and the guidelines for EQ-5D language adaptations, forward–backward translation, in order to develop a Swedish child-friendly version.

The multidisciplinary research group consisted of two health economists (KB leader of the field work and AL), two paediatric nurses (ACE and ME also performing the clinical interviews where the child-friendly pilot version will be tested) and an occupational and environmental specialist (MS).

Working process of developing a Swedish child-friendly pilot version of the EQ-5D instrument

During the development process, we performed face-to-face and group interviews in school classes. We interviewed children in the target group and asked them to identify difficult words and to suggest alternatives. The General Probing Method was used to ask respondents whether the item was comprehensible and clear and alternative suggestions were discussed. We started to modify the original Swedish adult version by revising it item by item and then translated the draft into English in order to compare the result with the UK child-friendly version. We decided on the following working process, each phase of which was discussed and evaluated in the research group:

(i) Face-to-face interview with a 17-year-old girl to investigate understanding among children.
(ii) First draft of a child-friendly version.
(iii) Face-to-face interview with a 6-year-old boy to test comprehension of the first draft.
(iv) Second draft, feed-back from the 17-year-old girl.
(v) Translation into English of the second draft, by a native English-speaker.
(vi) Third draft, to be tested in school classes.
(vii) Testing the third draft in group interviews in school classes, pupils aged 9 years and 12–13 years.
(viii) Development of a pilot version to be tested in a clinical interview study.

Inclusion criteria for participating in interviews

Criteria for participating in face-to-face interviews were representation of the extremes of the target age group for a child-friendly version (7–16 years), and interest and ability to reflect on health issues. The lower-age extreme was tested in an interview with a boy aged 6 years, while realising that children aged 7 years have different levels of literacy but also different levels of maturity. This boy could read, but, the interviewer read the text with him. The 17-year-old girl and the 6-year-old boy were selected from the authors’ neighbourhood to represent the extremes of the target age group in this initial phase before testing the draft in school classes.

A criterion for participation at the area level, i.e. schools, was that the composition of the area should reflect the general population in socio-economic aspects such as housing, ethnicity, level of education, and income. The criterion for group-level participation, i.e. school classes, was that the classes had shown interest in participation in these kinds of studies before and in working in groups discussing different issues with a group leader. Individual level criteria for participation were membership of the target age group and interest and ability to reflecting on health issues, which was the case with the pupils as they were trained in the class. No children were excluded, though activity varied among them.

We used strategic samples and tested the child-friendly pilot version in two classes \((n = 38)\) in a school in a mixed socio-economic suburban area of Stockholm. One class was mixed, with half of the pupils aged 12 years and the other half aged 13 years. The other class had 12 pupils aged 9 years. In total, 21 boys and 17 girls were interviewed (mean age 11.4 years). As the daily teaching was usually based on an interactive process between the teacher and the pupils, there was an environment in the classes where pupils were used to expressing their thoughts aloud. The leader of the fieldwork (KB) guided the test situation and ME participated, observed, and took notes during the discussions.

Results

Face-to-face interview with a 17-year-old girl to investigate understanding among children

We interviewed a 17-year-old girl about her understanding of the concept captured by the EQ-5D dimensions, the wording as well as the layout of the questionnaire. She was told that the child-friendly version would be presented to children aged 8–12 years and that her comments could provide some retrospective aspects of what she thought was understandable at those ages. She was also asked to suggest alternative workings.

Key identified expressions and words in the Swedish adult version to be explored in the interviews and key suggestions for a first draft of a Swedish child-friendly version are summarized in table 1. A general comment from the girl interviewed was that the headings of the dimensions should be phrased as verbs and that a verb should be added in the description of the levels in the dimension usual activities to stress the word performing that is used in the English original, though not in the Swedish adult version.

The English word problem is translated as ‘problem’ in the Swedish adult version. This word is in some sense commonly used in the Swedish context as an adjective to describe
especially a child’s behaviour or personality—’ett problombar’, used by adults, but children are aware of the concept and find it stigmatising (in English a problematic child/a child with problems). Hence, the comment was that nobody wants to answer a question that make you feel like ‘ett problombar’ (a problematic child) since the stigmatisation implies that there is nothing to do for or with such a child. An alternative suggestion was ‘svårighet’, more like difficulties in English as that word implies that the problem could be solved.

The English word pain is translated into ‘smårt’; however, it is questionable whether a younger child would understand

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### Table 1 Modifications for a first draft of a Swedish child-friendly version of EQ-5D

<table>
<thead>
<tr>
<th>Expressions where the term is used in the Swedish adult version</th>
<th>Terms in adult Swedish and English versions</th>
<th>Terms in child-friendly Swedish and English* versions</th>
<th>Explanations for the modifications</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Jag kan gå men med viss svårighet’</td>
<td>‘måttlig’/’vissa’</td>
<td>‘lite’/’en del’</td>
<td>‘måttlig’/’vissa’ not used by children</td>
</tr>
<tr>
<td>‘Jag har vissa problem att tvätta eller klä mig själv’</td>
<td>‘svåra’/’högst’</td>
<td>‘svåra’/’mycket’</td>
<td>‘i högsta grad’ not used by children</td>
</tr>
<tr>
<td>‘Jag har vissa problem med att klara av mina huvudsakliga sysselsättningar’</td>
<td>‘tvätta eller klä mig på’</td>
<td>‘tvätta mig eller klä på’</td>
<td>‘problem’ could be stigmatising</td>
</tr>
<tr>
<td>‘Jag är orolig eller nedstämd i viss utsträckning’</td>
<td>‘sandigande’/ ‘confined to bed’</td>
<td>‘mycket svårt att gå’</td>
<td>In UK study confined to bed was difficult to understand and inappropriate for children at school. Hence, Swedish child-friendly followed UK change.</td>
</tr>
<tr>
<td>‘Hygien’ (as heading)</td>
<td>‘hygien’</td>
<td>‘ta hand om sig själv’</td>
<td>‘hygien’ was considered a clinical term.</td>
</tr>
<tr>
<td>‘Jag behöver ingen hjälp med min dagliga hygien, mat eller påklädnings’</td>
<td>‘tvätta eller klä mig själv’</td>
<td>‘tvätta mig eller klä på mig själv’</td>
<td>The straightforward expressions for washing/dressing in Swedish adult version level 2 used for child-friendly level 1.</td>
</tr>
<tr>
<td>‘Huvudsakliga aktiviteter’ (as heading and in levels of severity)</td>
<td>‘huvudsakliga’/’usual’</td>
<td>‘vanliga’/’usual’</td>
<td>‘huvudsakliga’/’usual’ not used by children.</td>
</tr>
<tr>
<td>‘Smärt/besvär’ (as heading and in levels of severity)</td>
<td>‘ont’/’smärt’</td>
<td>‘ont’/’sma ¨ rtor’</td>
<td>‘ont’/’sma ¨ rtor’ not used.</td>
</tr>
<tr>
<td>‘Oro/nedstämdhet’ (as heading and in levels of severity)</td>
<td>‘orolig/ledsen/olycklig’</td>
<td>‘orolig/ledsen/olycklig’</td>
<td>‘orolig/ledsen/olycklig’ not used by children.</td>
</tr>
</tbody>
</table>

Key expressions and words identified in the Swedish adult version to be explored in the interviews:
a: Developed by Hennessy and Kind

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that word, the girl interviewed said it sounded too clinical. An alternative suggestion was ‘ont’ (hurt). The dimension anxiety/depression caused even a greater consideration. It was suggested to emphasize the phrase I feel in the heading, in Swedish ‘jag känner’. The argument was similar to that mentioned concerning the potential stigmatisation of some children by using I am, implying that their situation is not possible to change, whereas a feeling is something that you feel, but need not have forever.

**First draft of a child-friendly version**

Based on comments and suggestions from the interview with the 17-year-old girl and experiences from the UK modification, a first draft was created in an interactive process in the research group. In this first draft in the pain/discomfort dimension, the Swedish word ‘sma¨rtor’ used in the adult version for pain was retained (table 1). This was in order to investigate whether the 17-year-old girl was right in thinking that ‘sma¨rtor’ was not a word that children could understand. Following the UK version, we decided also to add ‘olycklig’ (unhappy) for further assessment of the mood dimension (table 1).

**Face-to-face interview with a 6-year-old boy to test comprehension of the first draft**

The main impression from the comments by the 6-year-old boy was that when he was asked what he thought the phrases meant he repeated some of them in a more direct way. He also reacted by jumping around, saying, ‘watch me this is what I meant’ when asked about the meaning of the mobility dimension. He had some problems with the words ‘aktiviteter’ (activities) and ‘sma¨rtor’ (pain) and the interviewer had to explain their meanings. Activities were explained as what you usually do during the day and then understood. The alternative word for pain suggested by the 17-year-old girl, ‘ont’, was also the word the interviewer spontaneously used as explanation, and the boy then understood ‘sma¨rtor’. When the interviewer asked about when someone feels sad, the answer was when someone has been injured or when someone has died. He did not relate to the word ‘olycklig’ (unhappy) but used the word ‘ledsen’ (sad) instead.

**Second draft, feed-back from the 17-year-old girl**

A second draft (table 2), including alternative phrasing for some dimensions, was created, based on the experiences from the interview with the 6-year-old boy and discussed in the research group with feedback from the 17-year-old girl. The most troublesome issue was whether to include a third word in the mood dimension as done in the UK child-friendly version. We contacted a child psychiatrist with experience of both clinical practice and child health questionnaire studies. The consensus was that the concept in the mood dimension is well captured by the words ‘orolig’ and ‘ledsen’ (worried and sad).

**Translation into English of the second draft**

A native English-speaker fluent in Swedish, and experienced in surveying children’s health with questionnaires, translated the second draft from Swedish into English, in order to investigate the differences between these two child-friendly versions. This work was commented on by a native Swedish-speaker fluent in English. The result of the translation procedure (table 2) presented no indications for revising the second draft, and the addition of a Swedish word for unhappy was not supported.

<table>
<thead>
<tr>
<th>Expressions where the term is used in the Swedish adult version</th>
<th>Terms in child-friendly Swedish version</th>
<th>Explanations for the modifications</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Jag har vissa problem att tvätta eller klå mig själv’</td>
<td>‘svårighet’/‘svårt’</td>
<td>The use of ‘svårighet/svårt’ (problem) was supported in the Swedish-English translation process.</td>
</tr>
<tr>
<td>‘Jag har vissa problem med att klära av mina huvudsakliga sysselsättningar’</td>
<td>‘rörlighet’</td>
<td>Discussed using a word on levels stressing mobility (‘rörlighet’) more than walking (‘ga˚ ’) as in the Swedish heading, decided to not change ‘ga˚ ’ to ‘rörlighet’.</td>
</tr>
<tr>
<td>‘Huvudsakliga aktiviteter’ (explanation of activities)</td>
<td>‘det du brukar göra på dagarna...’</td>
<td>Adding explanation to the word activities</td>
</tr>
<tr>
<td>‘Huvudsakliga aktiviteter’ (examples)</td>
<td>‘familje- och fritidsaktiviteter’</td>
<td>Added ‘familje- och fritidsaktiviteter’ as this is an example in the adult version which is also appropriate for children.</td>
</tr>
<tr>
<td>‘Sma¨rtor/besvår’</td>
<td>‘ont’</td>
<td>In second draft ‘ont’ was used.</td>
</tr>
<tr>
<td>(as heading and in levels of severity)</td>
<td>‘olycklig’</td>
<td>The necessity of adding ‘olycklig’ (unhappy) was supported neither by a child psychiatrist nor in the Swedish-English translation process and hence not included.</td>
</tr>
<tr>
<td>‘Oro/nedstämdhet’</td>
<td>‘ledsen’</td>
<td></td>
</tr>
<tr>
<td>(as heading and in levels of severity)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Third draft, to be tested in school classes

A third draft to test in school classes was now established, with the design of the questionnaire modified by spacious text with bigger capitals and instructions that were more straightforward. The design of the page with the VAS followed the overall modified design and the instructions were re-written in a clearer format compared to the adult version, including the substitution of ‘hälsa’ for ‘halsotillstånd’.

We were anxious about comprehension of the word health since in Swedish (‘hälsa’) it has two different connotations. One is health, the other is as a verb, meaning to greet someone, often particularly to shake hands. In order to investigate the understanding of health and activities we wanted to stress these words in the test.

Testing the third draft in interviews in school classes, pupils aged 9 and 12–13 years

We told the pupils that the purpose of the test was to investigate whether this questionnaire was understandable by children, and that there were no right or wrong answers and that we were not testing the pupils in any way, but needed their help. In order not to collect information on the pupils’ own health but to investigate their comprehension of the questionnaire, we had decided to ask the pupils to act as proxies. We then also avoided the need for ethical permission entailed by asking children about their own health. ME read a short chapter from a well-known Swedish book about a boy aged 8 years, named Eddie: Eddie had got an asthma attack and had to visit the doctor, who explained to Eddie what had happened to him and how he could live with his asthma. In the instruction sentence, Eddie’s name was written and in the levels we changed I to him etc. After reading the story, KB explained the EQ-5D by reading the five dimensions and the VAS aloud from an overhead picture and then asked whether they understood the task.

Among the older pupils (12–13 years), there were no problems, whilst among the younger (9 years) some had to repeat the instruction as a question to make sure they had understood. The pupils were then asked to individually rate Eddie’s health by ticking one box in each dimension and to mark on the VAS how good or bad they thought Eddie’s health was. After completion, we all sat down in a circle on the floor, including the teacher who had been told not to participate during the whole test. The performances were almost identical in the two classes except that among the youngest there were some pupils who had difficulties with reading. We decided to go to children’s desks to ask them to read some of the sentences, and explain what was said, to test whether they could read and understand what they had read. We helped the three pupils who had problems by reading the text with them.

To investigate comprehension of the word ‘hälsa’ (health), the first question asked was ‘What does “hälsa” mean?’ Among the 12–13-year-olds the common answers were ‘How you feel’, ‘Good health is when you are alert, can run/jump—bad health is when you are tired’, ‘Health may be how the body feels’, ‘There is no difference in asking how is your health or how do you feel’. One child said ‘How you feel means more like being sick or sad, health is something more’. We asked ‘What does ‘frisk’ mean?’ (in English healthy). They answered ‘Healthy means that you are not sick’, ‘Sick means that you have fever, allergy, headache, feel sick etc’. The pupils were asked whether they knew any other word that should be better to use than ‘hälsa’ (health). Since they had no suggestion, KB stressed the question by suggesting ‘frisk’ (healthy) instead. There was consensus among the pupils that the questionnaire did not ask about ‘frisk’ (as opposite to sick), but concerned something more—health. The discussion was almost the same among the 9-year-old pupils, and here nobody thought that the Swedish word ‘frisk’ should be used instead. One child ‘informed’ us after a while that ‘hälssa’ also means saying hello to someone. We further asked the pupils how they understood the phrasing and intention of each dimension and level and if they had any alternative to the words used. There were no specific comments concerning the dimension mobility. Examples of the dimension self-care were ‘When you can take care of yourself you can take care of your hygiene, eat and cut your food and dress yourself’. One child among the younger said: ‘...but I feel sorry for those who can’t and the parents don’t help’. Concerning the usual activities dimension there was a debate among the elderly pupils ‘whether Eddie could participate during the PE lessons as he could not run so fast because of his asthma’, ‘He cannot overstrain himself’. Some pupils asked for an alternative between Level 1 and 2 in Eddie’s case. The discussion was almost the same among the younger pupils. As we were anxious whether the word activities would be understood by younger children we asked specifically about that. The pupils said that the teacher used this word and they understood the meaning (‘what you do’). The word hobby was exemplified with ‘playing computer games or playing football, what you like to do’. Examples in the dimension pain/discomfort from the elderly pupils were ‘Having pain or discomfort is when you feel discomfort’, ‘Jobbigt’ in Swedish, ‘Having asthma is a discomfort’, ‘Eddie’s discomfort may be his itching eyes, because of the asthma, which is a discomfort’, ‘If you break your leg you get pain in the beginning, then only discomfort due to the itching plaster, for example’. An example from the younger class was ‘To have discomfort means that you have difficulties with something, for example breathing’. The dimension anxiety/depression caused no more discussion or ambiguity than other dimensions. A comment among the elderly pupils was ‘Eddie cannot be with his dog because of his asthma, he can not run and play with the dog. That can make you feel sad. But you do not have to feel sad if you can’t run—it depends on whether you want to run’. Both older and younger pupils were asked ‘What is meant by feeling worried or sad?’ and then exemplified with ‘I have asthma and I am worried about having an attack’. Another example was ‘If your parents do not come home at the time they have promised you feel worried’. They were also asked about the meaning of the word depression in order to capture their understanding of different nuances in the mood dimension. The example was ‘When you get a crisis’. They did not suggest using the word in the questionnaire.

All pupils completed the VAS. Some had changed their mind and had drawn a second line. One child had drawn ‘a snake’ of the line, but it ended at 85. The explanation as to why they had marked a certain point on the scale was in most cases adequate, often relating to ‘Eddie has some problems with breathing, for example, and therefore he is not at 100’. A comment on the expression ‘best imaginable health state’ was ‘You have to be an athlete to reach that state’. One of the older children shyly asked why the bottom of the scale was not ‘dead’. Then another child commented, ‘Sometimes it is better to be dead—I know a person who now is dead and he wanted to die, and I also think he is in a better state now’.

We did not perceive that the pupils, older or younger, had difficulties in understanding the phrasing or the intention of the questionnaire. We did not get any suggestions to replace one word by another. It was more like reflections in terms of the general meaning of a word or a phrase, exemplified in different appropriate ways. In addition, the scorings and reflections concerning Eddie’s health were appropriate. We
became reassured that most pupils understood the intentions of the words we especially wanted to stress.

**Development of a pilot version to be used in a clinical interview study**

The only further modification was an even more straightforward sentence when explaining the anchor points on the VAS. In a summing-up discussion within the research group concerning the whole process thus far, we decided that the pilot version could now be set. In the descriptive system, the headings of the five dimensions in the child-friendly version are ‘kunna ro¨ra sig’ (mobility); ‘ta hand om sig sjalv’ (looking after myself); ‘göra vanliga aktiviteter’ (doing usual activities); ‘ha ont eller ha besva¨r’ (having pain or discomfort); ‘känna sig orolig eller ledsen’ (feeling worried or sad). The levels of severity are ‘inte svårt’ (no problems), ‘lite svårt’ (some problems) and ‘mycket svårt/kan inte’ (a lot of problems/unable).

**Discussion**

This article describes and discusses the development process of a Swedish child-friendly pilot version of the EQ-5D. We, a multidisciplinary research group, modified the existing Swedish EQ-5D adult version by carrying out face-to-face and group interviews in younger age groups. The adult language was modified in two ways. The first was to change single words into words intelligible to and used by children, e.g. changing ‘depression’ (depression) into ‘ledsen’ (sad). The second related to whole expressions, e.g. using the verb form in the headings of dimensions.

Revising already existing HRQoL instruments used among adults in contrast to developing an instrument especially designed for use in younger age groups raises some concerns. First, do the dimensions included characterize children’s experience? The change of the severe level in the mobility dimension, replacing confined to bed with having a lot of problems walking around indicated that not all concepts are appropriate for an instrument used among younger people. The self-care dimension has been questioned in other studies, as it might be that limitations of self-care among children are more related to age than to health. However, one of the children commented that he felt sorry for those who could not wash and dress themselves and got no help from their parents. That might imply that the level in the Swedish version referring to no problems involves the expression need no help to wash and dress and could make younger children classify themselves as having no problem only if they can wash and dress without any help at all. There might also be other domains that are of importance to children rather than to adults, and hence would need to be expressively included as dimensions, e.g. social functioning and school environment. As we intended to develop a child-friendly version of an already existing instrument, we did not contemplate any other dimensions than those of the EQ-5D, which in most cases are also included in other instruments for younger ages.

Another concern is the design of the instrument. The Swedish child-friendly pilot version of the EQ-5D requires the child to be able to read him/herself or to be interviewed as the questions are based on text and no pictures are added to facilitate the understanding of concepts. This latter, age-related issue is associated not only with a specific dimension but also with the question at what age we can expect a child to be able to appropriately understand a HRQoL instrument. Our experience was that younger children were not only able to answer the questionnaire but also had the ability to think more conceptually about health issues. However, the level of literacy, readability, is important for self-administration.

Other matters in our study are related to the method used and recruitment of the samples. We used strategic samples for interviews. In the initial phase of the study, when we wanted reflections on the adult version before we started the step to test the third draft in school classes, we could have used alternative methods, for example focus groups. However, during these informal discussions we had collected information, though not in strict focus groups, from children as a base for the decision to initiate the study (first and second drafts). We had an open-ended discussion of the third draft with a total 38 children in the school classes.

The inclusion criterion that the school classes should have shown interest in studies of this kind before and that the children should be able to reflect on health issues might have underestimated trouble with understanding words. However, they had not participated in an exercise with these particular expressions, and with this inclusion criterion we could be more confident that the task was understood. The mixed socio-economic area supports the choice to test the questionnaire in only one school. The results of this development process are likely to be generalized to other children in Stockholm and in other parts of Sweden in the same age groups, strengthened by the variation in socioeconomic area and the age spectrum included in our study. The words used in our pilot version are also found in other Swedish child-friendly HRQoL instruments and are commonly used.

We found it fruitful to perform the work in a multidisciplinary research team in order to capture some different experiences and views, but other professionals would also have been beneficial. One advantage was that all the interviews in school classes were performed by the same two members of the research team, both with different backgrounds, with experience from dialogues with children at different ages. Another advantage was that the testing of the child-friendly pilot version was also performed by one of the persons conducting the interviews.

The way in which a child-specific instrument is developed or an already existing adult instrument is modified depends on the purpose for which the instrument is intended. The advantage of being able to collect much the same data from children and adolescents as for adults, for example in population surveys in all ages and in chronic childhood diseases, might outweigh possible disadvantages of modifying an existing HRQoL instrument. Further studies ought to investigate the comparison between child-friendly versions and adult versions of EQ-5D.

The Swedish child-friendly pilot version is initially being tested in a clinical interview study; first results are reported in a subsequent article, which provides more clarification of the feasibility and construct validity. Further international task force work, in the course of which the Swedish child-friendly version was finalized, is described elsewhere.

Prospective research must investigate the lower age-limit for self-completion from children and in what circumstances a parents’ proxy version would be more adequate. Finally, the issues on whose values should be used and what methods should be employed in children’s setting are of the greatest importance but are beyond the scope of this article.
Key points

- In Sweden, the EQ-5D is commonly used in clinical studies and in population surveys, and increasingly as a health outcome measure in the health care system. There is a growing interest in also including children and adolescents in EQ-5D studies.
- A Swedish child-friendly pilot version of the EQ-5D instrument has been developed by carrying out face-to-face and group interviews in younger age groups.
- Some of the wording of the adult version was found to be too clinical for children, and changed into words intelligible to and used by children.
- More straightforward expressions were used, e.g. using verb-form in the headings of dimensions.
- The advantage of being able to collect much the same data from children and adolescents as for adults, for example in population surveys in all ages and in chronic childhood diseases, might outweigh possible disadvantages of modifying existing HRQoL instruments.

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The EQ-5D is a copyrighted instrument and all requests should be sent to the EuroQol Executive Office in Rotterdam, Netherlands (userinformationservice@euroqol.org).

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