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HEDS Discussion Paper 08/04

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# HEDS Discussion Paper 08/04

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## Health Economics and Decision Science Discussion Paper Series

No. 08/04

**Working with children to develop dimensions for a  
preference based generic paediatric health related quality of  
life measure.**

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## **Abstract**

The use of preference based measures (PBM) of health related quality of life (HRQoL) in National Health Service (NHS) decision making is becoming more common. PBMs allow the calculation of quality adjusted life years which can then be used in economic evaluation as part of the decision making process. Research in the field of paediatric PBMs is lacking. This work is the first stage in the development of a generic paediatric PBM of HRQoL for use in economic evaluation.

To identify the dimensions of HRQoL for inclusion in the instrument, 74 qualitative interviews were carried out with children aged 7-11 years, to find out how their health affects their lives. The children were divided into two age groups (7-9 years and 9-11 years). Each age group was sampled and analysed independently to explore whether these age groups have a common HRQoL framework. Sampling was purposive, trying to balance primarily for level of health within age, with gender and ethnicity as secondary criteria. A wide range of health conditions, both acute and chronic were covered in the interviews and children were successfully able to articulate how their health affects their lives.

Thematic content analysis of the data identified ten dimensions of HRQoL relevant to each population, nine of which were the same in each group, giving 11 dimensions in total for the combined group. The dimensions cover social, emotional and physical aspects of HRQoL in common with other frequently used generic paediatric HRQoL measures, but differ in terms of

including dimensions on sleep, feeling jealous and feeling tired/weak and not including dimensions related to treatment/procedures and wider family or behavioural issues.

**Key Words:** Economic evaluation, quality of life, paediatric, preference based measures

## **Introduction**

Use of economic evaluation to aid resource allocation decision making in the UK National Health Service (NHS) is widespread and has increased over recent years especially since the introduction of NICE (The National Institute for Health and Clinical Excellence) (NICE 2004). Cost utility analysis, a form of economic evaluation, allows comparison of healthcare interventions both within and between disease areas by using outcome measures that combine length of life and QoL into a single summary measure, conventionally the quality adjusted life year (QALY). There are preference based measures (PBM) that are widely used for this purpose in adults, such as the EQ-5D (Dolan 1997) or the SF-6D (Brazier, Roberts & Deverill 2002), however research in the paediatric field is more limited (McCabe 2003). PBMs can improve and assist decision making within the NHS by providing information on the benefits of an intervention in a common metric, allowing decision makers to assess the cost effectiveness of interventions. This paper reports the first stage in the development of a new preference based measure of HRQoL for children.

## **Background**

Adult measures are not really suitable for use in paediatric populations as the dimensions may not be appropriate or pertinent to children and the response scales, wording and format may also not be appropriate. (Eiser & Morse 2001)



Existing generic paediatric HRQoL measures are limited in terms of their use in cost utility analysis. With the exception of the Health Utilities Index 2 (HUI2), they are not preference based, meaning that the calculation of QALYs from them is not directly possible.

Their descriptive systems vary widely in terms of the definition of QoL used and hence their content. (McCabe 2003) It could be argued that some measures contain items that are not relevant for health care resource allocation decisions, for example items on clothes or toys which are related to income rather than health. Some measures have many items, for example the Child Health Questionnaire (CHQ), (Health Act 2007) which makes it difficult to incorporate preferences and hence use the instrument in economic evaluation. (McCabe 2003)

Existing measures also vary in terms of the age they are intended for, some covering a wide age range and some much narrower. (Eiser & Morse 2001) There is very little evidence about whether there are common HRQoL frameworks across age groups, for example, the dimensions of HRQoL important to a 16 year old may be very different to that of a 9 year old. This has long been recognised in the literature. (Petrou 2003)

The content of existing measures is generated from a mixture of literature reviews, expert opinion and interviews with relevant populations, including parents, children, paediatricians or other experts. No paediatric PBM to date has been developed purely from interviews with children. In the past, children

tended to be involved at a later stage, testing the items or wording. It is rare that children are used to develop the descriptive system itself without some other influence, for example prompting with existing literature or items, input of parents or clinicians. Parents have often been asked as proxies about the HRQoL of children, but there is evidence that parent's views are affected by their own health status, knowledge, experience and expectations. (Petrou 2003)

There is evidence that children can provide information about their HRQoL. Riley et al (Riley 2004) report that children can self report on their health, even as young as age 6, with more reliability and validity as age increases, as long as the questionnaire is age appropriate. Whilst this does not specifically provide evidence that they can give information for the purposes of developing the content of a descriptive system, it does suggest that children are able to report on their own health and may understand what we mean by health.

There is a growing recognition that children have their own unique views and a right to express them in matters affecting them (Article 12 of the United Nations Convention on the Rights of the Child) (UN 2007) and children are now taken more seriously as providers of data, with researchers actively seeking their views.

In general, quality of life (QoL) and patient reported outcome (PRO) measures more generally have been developed using a top down approach, in that they

use the literature and views of experts. (Fitzpatrick, Davey, Buxton & Jones 1998) Recently the involvement of patients and lay people has been encouraged in developing PRO measures. (Food and Drug Administration 2006) By involving the population the measure is intended for, a greater content validity and relevance is likely to be achieved. It also gives a greater insight into the language and terminology used by the target respondents, ensuring the vocabulary of the measure is appropriate. (McColl 2005) These are strong arguments for using children as the population to develop a descriptive system.

This paper reports on the first part of research to develop a new generic paediatric PBM of HRQoL for use in paediatric health care resource allocation decisions. It is the first paediatric PBM that has been developed using bottom up methods with children only.

The main constraint in designing a descriptive system for economic evaluation is that the health states defined by the system should be amenable to valuation. Health state classification systems that have dimensions with ordinal levels fit this criteria well. The most widely used generic descriptive systems range from five to nine dimensions. (Brazier, Ratcliffe, Salomon & Tsuchiya 2007) This is a practical constraint on the number of dimensions within a descriptive system as it is unlikely that respondents would be able to handle a larger number when undertaking valuation exercises. Non PBMs of HRQoL do not have to operate within these constraints and hence can have much larger descriptive systems. This research aims to identify all the

dimensions of HRQoL pertinent to children and future work will reduce these to meet valuation constraints.

There is no agreement in the literature on a definition of QoL or HRQoL, although QoL is often defined as multidimensional, covering physical, emotional and social domains. (Eiser & Morse 2001) Many existing adult and paediatric instruments cover these areas (Dolan 1997), (Brazier et al 2002), (Landgraf 2005). This work takes the perspective that the measure is for paediatric health care resource allocation decisions, therefore it needs to capture how health affects children's everyday lives by capturing changes that are important, appropriate and relevant to children due to a change in health. It is being developed as a HRQoL measure, in that the dimensions are related to health and not other areas such as income or family environment. It explores the consequences of a health problem on a child's life, rather than being symptom based.

The measure is being developed for children age seven to eleven years as this avoids some of the developmental issues that would occur with children under five and keeps the focus within a reasonably tight age span.

## **Methods**

The main aim of this study was to identify the dimensions of HRQoL relevant to this population for the purposes of developing a generic PBM of HRQoL. A second aim was to explore whether there is a common HRQoL framework across age within this group.

## **Sampling**

Qualitative interviews were undertaken with children aged seven to eleven years in two schools in Sheffield. The schools were chosen in collaboration with the Children and Young People's Directorate at Sheffield City Council and were chosen to represent the diversity of children in Sheffield in terms of ethnicity and social class. The characteristics of the schools are given in Table 1 along with comparative Sheffield and National data. Both schools have an equal mix of gender and sit either side of the median in terms of a key indicator of deprivation - eligibility for free school meals, and total special educational needs. The percentage of ethnic minority children and percentage with a first language other than English are above the median for Sheffield and the UK in both schools.

All parents of children in both schools were sent a letter explaining the nature of the study, an information leaflet and a consent form asking to approach their child to take part. Parents were asked to rate the health of their child using five levels (excellent, very good, good, fair and poor). This information was then used for sampling. The children were split into two age groups; Y3+Y4 (seven to nine years) and Y5+Y6 (nine to eleven years) and a sampling frame was applied to the two groups separately. From the returned consent forms children were sampled purposively. The primary sampling criteria was age, followed by level of health to try and ensure that the views of a full range of experiences of health was covered. Secondary criteria were gender and ethnicity. The two groups were sampled and analysed

independently to explore whether they share the same HRQoL frameworks, in terms of the dimensions they generate.

## **Interviews**

Children were interviewed in school in a suitable place such as the library or the dining room, so they could concentrate and no one else could hear them. Children received an information leaflet and read through this with the interviewer and had the opportunity to ask questions. A warm up exercise was undertaken to make the child feel relaxed and comfortable which involved making a name badge with a sticker. Children were asked if they preferred to do the interviews in a one to one situation or a small group, as talking about health problems can be a sensitive area.

A semi structured interview was held, which asked about any health problems children had and how they affect their life, using a topic guide developed to include probing to make sure both acute and chronic health problems were recognised as valid and that all areas of children's lives were thought about, for example, how their health affected their lives (at home and school). The format of the interview was firstly to ask the child about any health problems they had and then ask for some basic descriptive information, in order to engage them and get them thinking about their health. Then, when the child had described the nature of the health problem, further questions were asked as to how their health affected their lives. Probing was necessary in the interviews, both for making sure the child thought about how their health affected them in all areas of their lives such as home and school, and also to

make sure all their health problems were included. This was achieved using prompts such as how does this affect you at school, have you been to the doctor, do you take any medicines and have you been off school recently due to your health. The interviews were designed to understand and explore the consequences of a health problem on the lives of children, rather than just the symptoms a health problem may produce. These consequences then form the dimensions of HRQoL. The use of closed questions was avoided, even though children prefer this type of questioning, since it is poor interview technique and limits the data obtained. Instead, open questions, for example “how did that affect you” and “why did it make you feel like that” were used, in order to encourage children to give more depth and explanation to their answers.

All interviews were carried out by the author, recorded and transcribed verbatim and continued until saturation was reached. The position of the researcher was neutral, in that no influences from existing paediatric measures of HRQoL were brought to the interviews. It was left to the children to determine how they felt their health affected their lives.

Ethical approval and research governance for the study was obtained from The University of Sheffield.

## **Analysis**

The analysis was guided by the research question; how does health affect children’s lives, and the aim was to identify dimensions of HRQoL.

Thematic content analysis was undertaken using Framework, an approach developed by the National Centre for Social Research (Ritchie & Lewis 2005). This provides a systematic thematic way of summarizing and classifying data. It involved several stages, the first was to review the data by rereading and relistening to all the interviews in order to become more familiar with the data. During this process, recurring themes and ideas were identified as they occurred and a thematic framework was devised by grouping these into main themes and sub themes. All interviews were then coded according to this framework, with the aid of NVIVO software. (QSR International) The data were charted, producing a matrix of sub themes and respondents, where each row in the matrix was a respondent and each column was a sub theme. This matrix summarized and synthesized each sub theme, taking care to retain the terminology and language of the children. All data was charted in this way. Each sub theme was then reviewed and explanations behind the affected areas of HRQoL explored. Relationships between themes and sub themes were explored and mapped and dimensions were generated by exploring the consequences of a health problem on a child's life. For example, an ear infection may mean that the child cannot hear well, which then means that they cannot hear as well in lessons, affecting their schoolwork. In this case, school work would become a dimension. Dimensions were intended to be mutually exclusive.

The analysis was overseen by an experienced and independent qualitative researcher, who reviewed the charting and mapping process.



## **Results**

### **Response**

School A had a 9.5% response rate and school B a 35% response rate from the parents. Thirty three interviews were carried out with seven to nine year old children and forty one interviews were carried out with nine to eleven year olds, giving a total of seventy four interviews on seventy five children (one was carried out as a pair). All children requested the interviews be one to one apart from one pair. Tables 2 and 3 show the characteristics of the groups. A good balance of gender and ethnicity was achieved, however there were few children with fair or poor health due to a lack of children with these levels of health in the sample.

### **Interviews**

Children concentrated well during the interviews, the warm up exercise worked very well and children seemed to feel relaxed and at ease with the interviewer. The consent process was very helpful for explaining to children what the research was about and what was involved and some children raised questions prompted by this. Some children commented that they had enjoyed the interview. No children asked to stop the interview and no bad feedback or experiences were reported. Interviews varied in length from 4 to 26 minutes.

Saturation was reached in both age groups. Despite increasing the number of interviews and specifically trying to target children with poorer health, no new themes or issues emerged. The total number of interviews was more than

was needed, but this has increased the confidence that saturation was reached.

A range of health problems arose in the interviews, covering both chronic conditions such as asthma, epilepsy, allergies and eczema, and acute conditions such as flu, infections and headaches. Some were minor and some more serious, for example some cases of eczema required hospital treatment. Some conditions also arose that involved hospitalisation, including pneumonia and muscle growth problems. Many conditions required treatment via the GP, such as hay fever, ear infections and chicken pox and some required hospital visits, such as losing feeling in the legs, severe asthma and broken bones.

## **Analysis**

The analysis generated ten dimensions which are broadly similar between the 2 age groups, with the exception of the final dimension. They are listed in Table 3. The results reported here are from both groups.

### **1. Worrying**

This dimension stemmed from feelings of worry about their health or illness and what was going to happen to them, both in the short and long term, for example worrying about whether their health would get worse and worrying that they would always have the health problem. There was also worry because of the physical symptoms, for example when breathing was restricted due to an asthma attack or bleeding from eczema. Some children worried about what was going to happen to them, for example if they had an

allergy, they were worried about what would happen if they had a reaction. The younger children tended to talk more about being scared or nervous, sometimes from people looking at them because of their health and they were also scared because of the physical effects of their health. Older children just talked about it in terms of being worried. For example:

Child: Sometimes it's hard to breathe, when you're breathing up or down sometimes a little ... (unclear)... sometimes when I get tired it's hard.

Interviewer: It's hard to breathe, how does that make you feel?

Child: A bit worried.

Interviewer: A bit worried, why do you get worried?

Child: Cos sometimes like err you don't know what to do.  
(B127, male, 11, very good health)

Child: Because sometimes I worry what's going to happen to me.  
(B12, male, 8, very good health)

Child: I felt like really, really worried, worry me, like, um it felt really scratchy and itchy just really worried like it's never gonna stop and it's never gonna go away.

(B33, female, 8, fair health)

## **2. Feeling sad or unhappy**

There were several reasons for feeling sad, miserable, upset or unhappy.

Some children said it was because they felt unwell and experiencing the physical symptoms made them feel sad. Some children felt sad when they couldn't do things they would normally do, like going to school, seeing their friends or doing activities they normally did. Some children felt sad when they were teased because of their health. All these reasons occurred in both age groups and the language was the same apart from older children using the term miserable in addition to sad, unhappy and upset.

Child: I just felt unhappy because I'm missing things that I normally do on the weekend.

(A22, female, 10, excellent health)

Child: Yeh it stopped me skipping cos I can't skip with one arm.

Interviewer No, how did that make you feel?

Child: Upset because I like skipping.

(A8, female, 8, good health)

Interviewer: And can you tell me about that, what's it feel like, when you get the chest pains.

Child: It just gets all squeezed up and I just keep on rubbing it and it just feels, it just feels hurt and I don't want it to happen but it just does happen.

Interviewer: And how does it make you feel?

Child: Unhappy, actually.

Interviewer: Unhappy, why does it make you feel unhappy?

Child: Because it hurts and I don't want it to hurt actually.  
(A13, female, 9, good health)

### **3. Feeling angry, annoyed or frustrated**

This dimension arose from a variety of reasons for feeling angry, annoyed or frustrated. In some cases, physical symptoms caused children to feel annoyed or frustrated. Some children also got annoyed because their health affected their everyday activities or things that they did, including sleeping, eating and being able to concentrate. Some younger children also mentioned being annoyed because of having to apply medication and also having to go to hospital for tests.

Interviewer: You couldn't breathe. And what does that feel like when you can't breathe?

Child: I get really frustrated.

Interviewer: Why is it frustrating?

Child: Because you wanna breathe and I can't breathe.

(A17, male, 9, very good health)

Child: I had to get into the bath and put a glove on and then I had to put a plastic bag on and then you've got soap and I it's just really annoying because I couldn't really do very much and, then I couldn't play football and then like I couldn't do very much stuff basically and I didn't like it.

(B97, female, 10, excellent health)

Child: It was really annoying I couldn't go to sleep at night, cos I was coughing.

(B3, male, 8, good health)

#### **4. Hurting/pain**

Many different health problems led to pain of different degrees. Sometimes pain came about through itchy skin, for example, when talking about spots on

their skin. In other cases pain came about through physical symptoms like a sore throat, an asthma attack, tummy ache, headaches or coughing. Other children talked about the pain of treatments they have to have in hospital. Others talked of pain when they undertook specific activities, such as pain when they walked on their sore feet. The same reasons and issues came up in both age groups and both age groups used the same terminology, describing it as hurt or pain.

Child: Umm it's like whenever you swallow there's like it's horrible it's like a dry but sharp pain  
(B106, female, 11, excellent health)

Child: It's like, it was like I couldn't breathe properly and when I tried to breathe in it really hurt my chest.  
(B110, female, 11, good health)

## **5. Learning/schoolwork**

There were many issues to do with school and they all led to the same outcome, in that problems around concentration, being absent from school because of health and not being able to manage work, led to schoolwork and learning being affected. Some children said that their physical symptoms meant they were not able to concentrate, which meant they couldn't learn. This included pain or itching or being tired. Other children said that when they were off school because of their health, it affected their learning as they were

missing their lessons, or in some cases it was because they were unwell at school and had to miss lessons. Some children described how problems with vision, hearing and speech all led to them having difficulty in lessons, so it affected their schoolwork, for example not being able to hear the teacher or see the board properly. The same issues arose for both age groups, however the younger children talked about their work or school work, often naming specific parts of it such as writing or drawing, whereas the older children tended to extend this by saying it affected their learning in general.

Child: I'd just sit down and be coughing a lot and disturb the class, I wouldn't be learning because I'd be concentrating on my cough instead of learning.

(A18, male, 10, good health)

Child: cos I can't concentrate on my work its like, it all just goes all over blurry so I close my eyes and then I look back and it goes ok but then like it hurts my eyes.

(B97, female, 10, excellent health)

Child: It affects me kinda like speaking because all your mouth dries up, dries up and you can't really open your mouth.



Interviewer: And what does that affect when you can't speak, how does that affect you?

Child: I can't answer any answers at school or anything.

(B7, female, 8, excellent health)

## **6. Daily routine (eating, bathing, dressing, getting ready, moving around)**

There were many issues around children's daily routine, including being able to have a bath and wash themselves, being able to get dressed and get ready for school. Some children found it took longer to get ready for school as they had to take their medication. Some children had problems undertaking other daily tasks including picking things up, and getting out of bed. In addition, issues arose around not being able to eat, for example if children had a sore throat or stomach ache, then they would not be able to eat what they normally would. Some children did not eat so they wouldn't be sick and some children lost their appetite when their health was not good.

Some children had problems moving around, for example going up and down stairs or getting around places. The issues were the same in both age groups. Neither age group talked about a daily routine, but instead talked about the individual tasks that they would normally have to do as part of their everyday life. The younger children sometimes broke it down into smaller tasks, for example specifically talking about difficulties with cleaning their teeth, rather than a more general getting ready in the morning.

Interviewer: How did it affect you when you had your leg like that in the things that you do everyday?

Child: Well it's hard to get up the stairs, that was the main thing so I had to crawl up the stairs but...  
(B122, male, 10, good health)

Interviewer: And how does it affect you at home?

Child: Umm it takes a bit longer to get ready for school.

Interviewer: Why's that?

Child: Erm, because I've got lots of things to do to get ready I don't have to just brush my teeth and then that's it I have to my (unclear) brush my teeth and then I have to do this special thing with my teeth.  
(B70, male, 10, very good health)

Child: Getting dressed was quite hard.

Interviewer: Was it?

Child: Yeh, cos I had to stretch my arm a bit to get something on, like a jumper, I had to stretch my arm a bit and then it hurted.

(A14, male, 9, good health)

### **7. Feeling weak/weary/tired**

Issues arose around feeling weak and not having any energy to do things, Some children didn't want to do anything because they had no energy, or because of how they felt when they had symptoms, for example, a headache. Some children felt tired and for different reasons, sometimes it was because their health problem made them feel like going to sleep, sometimes it was because their sleep had been affected. Some children had to rest more or sleep more. Older children talked more about having enough energy to do things and feeling weary. Younger children sometimes described feeling drowsy.

Child: I felt really weak so I couldn't really do a lot of activities that took lots of energy cos I didn't really have a lot of energy at that time.

(B110, female, 11, good health)

Child: Well it was like a fluey sort of cold or something, I was really tired and I just fell asleep on the couch. I just sort of felt ill and just stayed on the couch for a week.

(B120, male, 11, excellent health)

Child: Err, well I usually have to have like a rest on the sofa cos it feels really bad and tiring.

(B22, female, 8, good health)

**8. Able to join in activities that they want to (e.g. playing out with friends, sports)**

There were a lot of issues that arose around being able to join in activities that children wanted to do. These activities included playing with or being with their friends, playing out, going on trips, or joining in activities or sports that they wanted to. In some cases children could still play out, but their health made it difficult. Some children had to miss out on sports because they had hurt themselves or they were in pain. In some cases children couldn't do physical activity as it set off their illness. In some cases they could still join in but found it harder. Some children said they couldn't play much because they were in hospital. Other children described how they missed their friends when they were poorly. In some cases this was because they were off school or in hospital. The issues were the same for both age groups.

Child: It affects me because at home I can't do nothing cos I sometimes I like playing with my brother's and sisters on the road or outside and I have to stay inside and do nothing.

(A18, male, 10, good health)

Child: Yeah I wasn't able to join in with things that I normally do like tennis and football and stuff like that.

(B114, male, 11, very good health)

Child: I didn't get to meet with some of my best friends and play games with them.

(B42, male, 9, very good health)

### **9. Sleep**

Sleep emerged as an issue among children for different reasons. Some children found it difficult to get to sleep, some couldn't sleep because they were worried, others because of symptoms, such as coughing or being sick. Some children experienced broken sleep, in some cases this would really affect their sleep as they couldn't get back to sleep and in other cases not so much. Some children really struggled with sleep when all they wanted to do was go to sleep and other children hated going to bed because they knew they would not be able to sleep and would have to lie there alone. This had consequences for the next day, when children felt tired and found it difficult to get up for school and concentrate. Some children couldn't sleep at all and some children woke early. These issues arose in both age groups and were described in very similar ways.

Child: Oh that was horrible, it was absolutely horrible, you couldn't go to sleep at all because when, when...cos if you opened your

mouth and tried breathing out of your mouth you swallowed  
because my mouth would be all dry in the middle of the night  
and I'd have to swallow and it wasn't very nice

(B106, female, 11, excellent health)

Child: Yeah I couldn't sleep cos it really hurt my throat when I slept, so  
I couldn't sleep at all.

(B110, female, 11, good health)

Child: In the night I wake up because I'm scratching it.

Interviewer: And how does that feel?

Child: Horrible because I can't get back to sleep.

(B28, male, 9, excellent health)

Child: when um I kept being sick in the night and then, um, I didn't get  
much sleep then cos I just had to kept waking up and stuff yeh.

(A15, female, 9, good health)

## **10. Embarrassed**

This dimension arose in the older children. Some children said they were teased because of their appearance, in some cases because of their figure. In some cases, children were embarrassed about their appearance and took action to cover it up. Children didn't like crying or being sick at school because they felt embarrassed. Children also talked about how their appearance bothered them because of their health, for example because of having to wear glasses, or when they had visible health symptoms or had to take medication for example they were embarrassed when other people saw their eczema.

Child: but because of my figure, but, because of my figure, because my bones are quite heavy so, I'm quite big so sometimes I get a bit teased about that

(A20, female, 11, very good health)

Child: cos everyone sees you in the class and you feel a bit embarrassed.

(B108, female, 10, very good health)

Child: sometimes I forget to cream my legs and I get a bit embarrassed in P.E.

(B82, female, 10, good health)

## **11. Feeling jealous**

This arose in the younger children and was similar in some ways to the embarrassed dimension that arose in the older group, however it was not as strong. Some of the issues children raised were hinting at being embarrassed. Children felt jealous of others as they didn't want to have their health problem and wanted to be like others who didn't have any problems. They also felt jealous when they couldn't join in activities that others could because of their health.

Child: because like I think other peoples legs and arms are not like that  
I wish mine weren't like that and things like that.

Interviewer: How does it make you feel?

Child: Umm a bit jealous because like, people, um other people don't  
have it on their body, I wish I was the same as them because  
I'm like the only person who has eczema on my body in my  
family and be like thinking like well how come she's got it.  
(B33, female, 8, fair health)

Child: sometimes I feel I wish I didn't wear them, sometimes yeah  
(A15, female, 9, good health)

One overall theme that arose was the idea of being normal, or children thinking of what a usual role would be for a child of their age and then thinking



how they differed from this, for example, saying they couldn't do what they would normally do when they were well, or couldn't do what other children their age do. They also sometimes expressed a desire to be like other children who didn't have the health problems they had or to be what they described as normal, meaning free of the health problem.

## **Discussion**

This qualitative study has generated a wide range of dimensions of HRQoL. There were many reasons why the dimensions emerged, as different health problems could result in the same impact on HRQoL. For example, if a child's hearing was affected, it sometimes meant they found lessons difficult as they couldn't hear the teacher and it also meant they had some pain in their ear. Other children had an allergy which affected their lessons because their concentration was affected and they were scratching which also gave rise to pain. Also, breathlessness led to children feeling worried and frustrated.

Most dimensions arose from children across the range of levels of health and through both acute and chronic health problems. However, feeling scared or worried seemed to arise mainly in children who had chronic health problems such as asthma or eczema who worried about when their symptoms came back and what would happen to them. Embarrassment arose mainly through health problems which gave rise to visible symptoms such as rashes, or came about through children who felt they were overweight.

Quite often, the way in which children thought about these dimensions was in terms of the overall theme of a departure from normal, meaning children were thinking of what a usual role would be for a child of their age and then thinking how they differed from this.

Although the dimensions are intended to be mutually exclusive, there are relationships between them, for example, not being able to join in activities may make a child feel sad, or being in pain may mean that a child may not be able to sleep. This is perfectly acceptable for a HRQoL measure as it is often the case that people have problems on several dimensions at once. Although the dimensions may be related through these problems, they are still different dimensions of HRQoL and reflect the differing impact of problems on children's lives.

This work has some evidence that there is a similar HRQoL framework for 7-11 years old children as the same dimensions (except one) arose from each group. Even though the language and terminology used by the age groups sometimes differed, they were describing the same concepts. This gives confidence that one measure can be developed, however more work is required on the appropriate wording to use, to make sure it is suitable for all ages.

The interviews worked best in a one to one setting as sometimes children would be discussing sensitive information. The format of the interview worked well in that children first became comfortable with providing descriptive

information about their health and then went on to talk about how it affected them in their lives. This research has demonstrated that it is feasible to interview children about their health and that they are able to understand and describe how health affects their lives.

The dimensions identified include many of the areas of HRQoL covered in widely used adult PBMs, such as the SF-6D (Brazier et al 2002) and the EQ-5D (Dolan 1997), such as physical, emotional and social aspects. For example, the EQ-5D contains a pain dimension and an anxiety/depression dimension. Whilst not described in the same terms, the worrying and sad/unhappy dimensions in this work are similar in concept to the latter.

Similarly the SF-6D contains dimensions on pain, mental health, vitality, social functioning, physical functioning and role limitations. Some of the dimensions developed in this work, such as feeling tired or weak and joining in activities, seem similar in concept to vitality and social and physical functioning. The dimensions also conform to the World Health Organization (WHO) classification of health. (WHO, 1948)

Table 4 lists the dimensions of the most frequently used generic paediatric instruments in the literature, the PEDSQOL, the Child Health Questionnaire (CHQ) and the HUI2 along with those of the new measure. It shows some similarity in coverage but also some important differences. The HUI 2 (Torrance, Feeny, Furlong, Barr, Zhang & Wang 1996) is the only existing paediatric generic PBM. It takes a functioning “within skin” approach. For example, sensation is derived from questions asking about vision, hearing

and speech. The dimensions developed in this study go beyond this, in that the consequences of hearing and vision problems were looked at, for example in joining in activities or being able to manage their school work. Whilst there are some similarities to the dimensions developed here, for example pain and daily routine, there are many differences, for example the HUI2 does not include sleep, jealous, embarrassed and tired/weak.

The PEDSQoL (Varni, Seid & Rode 1999) goes beyond how health affects children in that it includes areas such as physician/nurse communication. The CHQ (Eiser & Morse 2001) includes more than HRQoL with dimensions related to the family, for example family activities and family cohesion and includes a behaviour dimension. There are also some similarities with the dimensions developed here, for example pain and emotions.

The qualitative approach taken here of directly looking for dimensions and the explanations behind them is similar to that taken by Grewal (Grewal, Lewis, Flynn, Brown, Bond & Coast 2006) in their development of a generic QoL measure for older people. In this work, they conceptually grouped data into mutually exclusive attributes of QoL. It is in contrast to the more common approach taken in the instrument development literature, where large lists of items are generated and then a technique such as factor analysis is used to develop dimensions (Drotar Schwartz, Palermo & Burant 2006), (Riley, Forrest, Rebok, Starfield, Green, Robertson et al 2004). The qualitative approach is more useful in developing a PBM since this requires one item per

dimension and levels within these in order to construct a health state classification.

There was breadth of coverage in terms of acute and chronic health problems in the sample, although it is acknowledged that there are gaps at the lower end, in that there were comparatively fewer interviews carried out on children whose health was rated as fair or poor. This is not surprising given that the population was recruited through schools and so tended to exclude those children who are in hospital or not in mainstream education.

There was a notable difference in response rates between the schools. There could be many reasons for this, including the fact that school A has 67% of pupils with a first language other than English and in many cases, the parents do not speak English, and therefore may not have read/understood the letter and information leaflet asking for consent to approach their child.

It is acknowledged that the population interviewed in this research all come from Sheffield and it is not certain that the results of this will apply nationally. However the breadth of socio economic diversity reached in the sampling should ensure that the measure is likely to be applicable more widely than Sheffield and this is something that can be tested in future research.

Involving children in developing the content of the descriptive system helps ensure content and face validity as it should be comprehensive in its coverage and be appropriate for the population. This work is also in line with the Food

and Drug Administration guidelines on patient-reported outcome measures, which recommend that development of paediatric instruments should consider age-related vocabulary and language comprehension, and fairly narrow age groupings should be used to account for developmental differences. (Food and Drug Administration 2006)

These dimensions are intended to form a generic measure and need to be suitable for a wide range of conditions and health problems found in the general paediatric population. It may be that the measure does not perform so well in more serious paediatric health conditions, as the measure has been developed on a relatively healthy sample. Future work testing the measure on clinical populations will help to determine how well the measure performs in different patient groups.

The next stage of this research is to produce a health state classification system based on these dimensions which is amenable to valuation.

## **Conclusion**

This work has identified the ways in which children age 7-11 years say health affects their lives. A range of dimensions of HRQoL emerged, covering physical, social and emotional aspects. The dimensions have been developed directly from the relevant population, increasing the content and face validity. There was also no influence from any other source, such as parents, teachers, medical professionals or the literature as bottom up methods were used. This work has also demonstrated that children of this age are able to

provide information on HRQoL and gives some evidence of a stable framework across age. Further work is needed to develop a health state classification system that is amenable to valuation and to test it in different paediatric patient populations.

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Table 1: Characteristics of the Schools

	<b>Gender</b>	<b>NCY**3-6 (age 7-11 years)</b>
<b>Sheffield LEA<sup>+</sup></b>	% boys	51.13%
	% girls	48.87%
<b>School A<sup>+</sup></b>	% boys	54.58%
	% girls	45.42%
<b>School B<sup>+</sup></b>	% boys	46.34%
	% girls	53.66%
<b>National<sup>+</sup></b>	% boys	51.22%
	% girls	48.78%

	<b>Eligible for Free School Meals (%)</b>	<b>Total SEN* (%)</b>	<b>Ethnic Minority (NCY** 1 to 6) (%)</b>	<b>First Language other than English (NCY** 1-6) (%)</b>
<b>LEA<sup>+</sup></b>	19.1%	21.0%	21.4%	13.5%
<b>School A<sup>+</sup></b>	25.00%	27.00%	83.10%	68.90%
<b>School B<sup>+</sup></b>	9.50%	16.00%	36.00%	18.20%
<b>Median for Sheffield<sup>+</sup></b>	13.64%	21.18%	11.25%	2.33%
<b>National**</b>	16.98%	17.28%	20.6%	12.5%

<sup>+</sup>Source: Pupil Level Annual School Census (PLASC) as of January 2006. PLASC is a census of all children in the school system.

<sup>++</sup>Source: <http://www.dfes.gov.uk/rsgateway/DB/SFR/s000682/index.shtml>

Accessed 20/12/2007

[http://www.dfes.gov.uk/rsgateway/DB/SFR/s000744/UPDATEDSFR30\\_2007.pdf](http://www.dfes.gov.uk/rsgateway/DB/SFR/s000744/UPDATEDSFR30_2007.pdf)

Accessed 20/12/2007

\*SEN (special educational needs)

\*\*NCY (National Curriculum Year)

**Table 2: Characteristics of the Samples**

Characteristic	n (7-9 years)	n (9-11 years)
Total sample	41	33
Male	19	15
Female	22	18
Y3	22	-
Y4	19	-
Y5	-	18
Y6	-	15
Excellent health	13	11
Very good health	14	13
Good health	10	8
Fair health	2	1
Poor health	2	0
White	8	16
Mixed/dual heritage	2	7
Asian or Asian British	5	6
Black or Black British	1	2
Chinese	0	0

**Table 3: Dimensions of HRQoL**

Dimension	7-9 Years	9-11 Years
1	Worried Scared	Worried
2	Sad Upset	Sad Upset Unhappy Miserable
3	Annoyed Frustrated	Annoyed Frustrated Angry
4	Hurt Pain	Hurt Pain
5	School work	Learning
6	Daily Routine	Daily Routine
7	Tired Weak  Drowsy	Tired Weak Energy Weary
8	Joining in activities that want to	Joining in activities that want to
9	Sleep	Sleep
10		Embarrassed
11	Jealous	

**Table 4 Comparison of dimensions with three existing paediatric generic instruments**

New measure	HUI2	PEDSQoL	CHQ (CF87)
Worried/Scared	Emotion	Worry**	Mental health
Sad/Upset/Unhappy/Miserable		Psychological* functioning	Role/social functioning (emotional)
Annoyed/Frustrated/Angry			Self-esteem
Jealous			
Embarrassed			
Tired/Weak/Drowsy/Energy/ Weary			
Hurt/Pain	Pain	Pain**	Bodily pain Discomfort
Sleep			
Daily Routine	Self Care		
School work/Learning	Cognition	Cognitive problems**	
Joining in activities that want to	Mobility	Social functioning*	Physical functioning
		Physical functioning*	Role/social functioning (physical)
	Sensation		
		Physician/nurse communication**	
		Perceived physical appearance**	
		Nausea**	
		Treatment anxiety**	
		Procedural anxiety**	
			Parental impact (emotional)
			Parental impact (time)
			Family activities
			Family cohesion
			Global item: change in health
			General health perceptions
			General behaviour

\*Core measure

\*\*Symptom/treatment related module