

## **Title: THE ADOLESCENT PERSPECTIVE OF THE IMPACT OF WEIGHT STATUS ON QUALITY OF LIFE**

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## Abstract

**BACKGROUND:** Obesity, particularly in the younger population, is a major public health concern as the proportion of young people classified as overweight or obese has been rising over the past decade. Economic evaluations are used to inform resource allocation decision making in the health care context. Generic preference based measures such as the EQ-5D have been shown to have limited sensitivity to changes in body mass index (BMI), therefore a valid and reliable health state classification system to a) Measure weight specific quality of life (QoL) and b) Assign preference values to different aspects of weight specific QoL is necessary; in order to carry out fully informed Cost Utility Analysis (CUA) of weight management interventions aimed at adolescents.

**AIMS:** To create a new weight specific questionnaire appropriate for adolescents aged 11-18 years and ultimately for the elicitation of preference values.

**METHODS:** A sample of weight management treatment seekers and a general school sample of adolescents (aged 11 to 18) were interviewed. Semi-structured interviews probed adolescents' perceptions of the impact of weight statuses on QoL. Interviews were analysed using the Framework method (a type of thematic analysis). Transcripts were coded by the first author. The generation and coding of themes was closely guided by supervisors and advisors experienced in the field of qualitative analysis.

**RESULTS:** Sixteen one-to-one interviews with adolescents from weight management services and one focus group with a school sample of adolescents was conducted. Data saturation (where further interviews with adolescents generated no new information) was reached at interview number 13 and this was confirmed with the use of a saturation matrix. Three additional one-to-one interviews were carried out as well as a school focus group interview in order to confirm sample saturation. A new weight specific questionnaire containing 29 items (questions) was generated covering six domains of QoL, including: 1. Symptoms, 2. Physical function, 3. Psychological wellbeing / Personal constructs, 4. Cognitive functioning, 5. Social wellbeing and 6. Role activities.

**CONCLUSIONS:** The views of adolescents are critical to the development of a new weight specific QoL instrument. The content of the instrument was informed by adolescents living in the UK. This new measure will be more suited than generic preference based instruments, in capturing changes that matter to this age group.

## Introduction

### *Obesity*

Obesity, particularly in the younger population, is a major public health concern. In adults, obesity is defined by a Body Mass Index (BMI) of 30 or more (morbidly obese is defined as a BMI of 40+). BMI is obtained by dividing a person's weight in kilograms by the square of their height in metres (National-Obesity-Observatory-(NOO), June 2009). Overweight individuals have a BMI between 25 and 30. It is more difficult to categorise their weight status BMI of children and adolescents, as their BMI changes with respect to age and sex (National-Obesity-Observatory-(NOO)). This makes. As a result of this, "growth reference charts" are used to define the weight status of individuals under the age of 19 (National-Obesity-Observatory-(NOO), June 2009). The British 1990 growth reference is the most commonly used reference in the UK (Cole et al., 1995). In England, 23.6% of men and 24.4% of women over the age of 15 are obese and a further 41.4% and 32.0% overweight (Health-Survey-for-England, 2008). In addition 20% of boys and 16.5% of girls (average 18.3%) aged 10-11 years are classified as obese (The-health-and-social-care-information-centre, December 2009).

Childhood obesity is known to increase the risk of a wide range of physical and psychological illnesses, impaired educational attainment, low earnings and poverty (Lobstein et al., 2004). Due to the long term health risks of childhood obesity (such as respiratory diseases and type 2 diabetes) and the emotional and psychological effects of being obese, public health initiatives and specialised weight management interventions have been developed specifically for the adolescent population (National-Institute-for-Clinical-Excellence-(NICE), December 2006).

Obesity and its associated co-morbidities have significant cost implications for the NHS. At present the cost to the UK economy of overweight and obesity was estimated at £15.8 billion per year in 2007, including £4.2 billion in costs to the NHS (National-Obesity-Observatory-(NOO)). The UK Government Office for Science's Foresight project 'Tackling Obesities: Future choices' estimates this will more than double by 2050 (Butland et al., 2007). In terms of lost productivity, the Foresight report estimates that obesity already costs the wider economy around £16 billion, and that this will rise to £50 billion per year by 2050 if left unchecked (Butland et al., 2007). Given the significance of the financial demands of obesity on the UK NHS, and the limited health care budget, there is a need for economic evaluation to aid informed decision making in the NHS.

### *Economic Evaluation*

Economic evaluations are used to inform resource allocation decision making within the NHS (National-Institute-for-Clinical-Excellence-(NICE), June 2008). Economic evaluations typically assess the incremental costs and benefits associated with a new intervention, compared with standard practice. They inform decision making when faced with the aim of maximising the outputs from the expenditure of a fixed budget. Within England and Wales the National Institute for Health and Clinical Excellence (NICE) methodology guidelines are used for the appraisal of new and existing technologies (National-Institute-for-Clinical-Excellence-(NICE), June 2008). The guidance states that the quality-adjusted-life-year (QALYs), which combines both length and quality of life (consisting of anchor points at zero (the 'dead' state) and one (full health)) into a single summary measure, should be used for the assessment of benefits. QALYs are generated from preference based instruments, which use preference-based methods to elicit values to health states.

Preference based measures have been developed from economics and decision theory in order to provide an estimate of individuals' preferences for different health states ((Drummond et al., 1996); (Bakker and van-der-Linden, 1995)). This form of instrument uses preference-based methods to value health states. These states can be defined with the use of a descriptive system. Descriptive systems are made up of domains, items within domains and response categories for each item. Health states are valued by individuals using preference elicitation techniques to derive preference values (or utility weights) for each health state. For a more detailed description of elicitation

techniques available for valuation of health states; and the individuals who can be asked to value health states see Brazier et al. (Brazier et al., 2007). In the context of this study, a health state refers to the description of individuals' QoL or health related QoL (HRQoL).

NICE identifies the EQ-5D as the appropriate source for obtaining the utility weights for the QALYs (National-Institute-for-Clinical-Excellence-(NICE), June 2008). The applicability of the EQ-5D is however limited in the assessment of weight management interventions as it may not fully reflect the affect of weight status or changes in weight status on QoL. For example important domains influenced by weight status such as 'public distress' and 'sexual life' are not fully captured in the EQ-5D, whilst "condition specific" instruments may be more applicable for the assessment of weight status and changes in weight status on QoL. However, the majority of existing weight specific QoL measures lack preference weights and thus cannot be used to calculate QALYs.

Adolescent specific QoL / HRQoL generic instruments allow for assessment of HRQoL for the young population. However they have been found to perform poorly in discriminating between different body-mass index (BMI) subgroups on physical, psychological and emotional dimensions of functioning relative to weight-related measures (Kolotkin et al., 2006). The value in using weight specific QoL measures to assess interventions for overweight & obese adolescents is therefore strengthened.

A valid and reliable tool to a). Measure weight specific QoL and b). Assign preference values to different aspects of weight specific QoL is necessary to carry out fully informed CUA of weight management interventions aimed at the adolescent population

### *Existing Measures*

A recent review of preference based weight specific measures carried out by the authors identified only one instrument: the Impact of weight on Quality of Life (IWQoL-Lite, (Brazier et al., 2004)). Preference values were derived for the IWQOL-Lite instrument (Kolotkin et al., 2001) by mapping values from the SF-6D, another generic preference based measure, onto it.

There are a number of drawbacks of using this measure in CUA of weight management interventions aimed at the younger population. Firstly, the IWQOL-Lite was developed for use with the adult population. The use of adult measures for a younger population is discouraged as HRQoL perceptions differ between these populations (Eiser and Morse, 2001). The applicability of the IWQOL-Lite is limited to the adolescent population given its target adult population.

In addition to this, there are limitations in the method with which preference values were mapped from the generic instrument to the weight specific instrument. A major weakness in the mapping study, which is noted in Brazier et al. (Brazier et al., 2004), was that there may be aspects of the condition that have not been properly reflected in the SF-6D index. For example, the authors identify that the SF-36 might not fully reflect the importance of the impact of weight status on 'public distress' and 'sexual life' domains of QoL, present in the IWQoL-Lite. These domains did not enter as significant variables in the econometric models estimated in the study, which might lead to an underestimation of the importance of the impact of weight status on these domains of QoL.

An important observation proposed by the authors, is that the mapping approach is only as strong as the degree of overlap between the two descriptive systems where mapping is being undertaken. Also that the preference based descriptive system needs to provide a valid description of the condition and its treatment for the mapping approach to generate a valid prediction of preference values (Brazier et al., 2004). The authors conclude 'such a mapping exercise is always a second best exercise compared to either the direct use of the SF-6D or a valuation of the condition-specific instrument' Brazier et al. ((Brazier et al., 2004), pp. 459).

The existence of three non preference based self reported weight specific instruments targeting 11 to 18 year old, was also identified in the literature search. As the three instruments lack preference

values they are not suitable for CUA ((Kolotkin et al., 2006); (Zeller and Modi, 2009); (Morales et al., 2011)). The most widely used preference based generic descriptive systems contain a range of 5 to 9 items (Brazier et al., 2007). This is a practical constraint on the number of items within a descriptive system as it is unlikely that respondents would be able to handle a larger number when undertaking valuation exercises. Non preference based instruments of HRQoL/QoL do not have to operate within this constraint and hence can have much larger descriptive systems (Brazier et al., 1999).

### ***The proposed research***

The overall aim of this research is to develop a new preference based weight specific instrument that can be utilised in the calculation of QALYs for CUA. Specifically, the new measure will be used for the assessment of weight management interventions aimed at the adolescent population. The focus of this paper is on the development of the content of the new weight specific questionnaire. The structure of the paper is as follows: The methods used in creating the new weight specific measure are reported, the qualitative analysis is then described, and this is followed by the results section. The paper ends with discussion around the findings and the conclusions.

## Methods

### ***The use of adolescents' views to inform the content of the questionnaire***

The views of adolescents were used to inform the content of the new weight specific questionnaire. Frequently, descriptive systems for condition specific measures have been developed from interviews with patients, their carers, doctors and experts. It is believed that these individuals are the most appropriate to provide information on the domains of QoL that are important (McColl, 2005) as they are most informed of the impact of morbidity on different aspects of QoL. Other potentially relevant populations that could provide information on the content of this new measure are: parents/guardians, paediatric health care professionals, the general population, health care decision makers and a general sample of young people.

Parents have often been asked about the HRQoL of their children as proxy respondents, but there is evidence that parents' views are affected by their own health status, knowledge, experience and expectations (Petrou, 2003). There is mixed evidence in the literature about whether parent and child reports of health related QoL (HRQoL) agree. There may also be areas or contexts of the child's life that are unknown or less well known to parents such as school life (Matza et al., 2004). For this reason, parents may not be the most appropriate single source.

In a similar manner to parents, paediatric health care professionals will have indirect views. Although health care professionals may be informed about how health affects young people, it is possible that their views too are likely to be affected by their own health status, knowledge, experience and expectations.

It could be argued that the general adult population may have an informed and a relevant view on the impact of weight status on QoL, as everyone was once a child and many will be parents. There is also an argument that they are representative of society and this measure is being developed for resource allocation decisions in society and therefore the general adult population would be an appropriate population to consult.

Although all the populations outlined above might provide information on what they feel are the appropriate and relevant aspects of QoL for decision making, it can be argued that the most relevant and appropriate population is the adolescents themselves as they have firsthand experience of how weight status impacts upon their QoL. Including the views of adolescents could be seen as most relevant as they are the population the measure is to be completed by. Content validity would be increased (Stevens, 2009) and the language and terminology would be more appropriate than using the views of others. Therefore the content of measure is developed primarily with the users (adolescents) rather than other potentially relevant populations. In order to identify the impact of weight status on adolescents' QoL, interviews were undertaken with adolescents aged 11 – 18.

The focus of this paper is on the consultation with adolescents. However, in order to ensure that all relevant aspects of QoL affected by weight status were identified, further consultations with individuals who have expertise and experience in the field of adolescent obesity, were sought in creating the new questionnaire. This additional aspect of the research will be given elsewhere.

## ***Sampling***

### **Stage 1**

One-to-one interviews were conducted with adolescents enrolled in two Leeds based weight management programmes. Adolescents and their families access the services by way of GP referrals. Both programmes offer a multifaceted weight management intervention addressing both health and lifestyle behaviours. Both have a mixture of adolescents in terms of gender and age. The percentage of ethnic minorities compared to white British adolescents, however, is low in both services.

Staff from both services identified families that could be approached to take part in the research. A pack containing the following was given to all families that were identified by staff members when they attended their training session: a). An information sheet and consent form for the adolescent (both documents utilised wording and language that was appropriate for the younger population and were run through readability software). b). An information sheet and opt out form for carers of adolescents. Carers were given the opportunity to opt the young person out of taking part in the study. Participants who were not opted out of taking part in the study provided a signed consent form if they agreed to take part.

Adolescents were split into two groups; the younger adolescent group (11-14 year olds), and the older adolescent group (15 – 18 year olds). Adolescents were sampled purposively using the primary sampling criteria. This included gender and age, in order to try to make sure that the views of the full range of the obese and overweight adolescent population were covered. It was understood that all adolescents enrolled into either of the programs would have to have been clinically obese or overweight for their age and gender. Thus it was assumed that all adolescents recruited from weight management services had a current or previous BMI above the normal range.

### **Stage 2**

In addition to obtaining the views of adolescents enrolled in weight management services, the views of a general sample of adolescents regarding the impact of weight on QoL was also sought. This was carried out in order to make sure that all aspects of QoL that might be affected by weight status are captured. It was thought to be important to include the views of this population in informing the content of the descriptive system, as, although these individuals are not current consumers of weight management services, their views count, as these individuals could be future consumers of services. Also they could have strong opinions about weight status and how it affects their life that could add to the content identified in Stage 1.

It was decided that adolescents in Stage 2 should be interviewed in a focus group (FG) setting. This would provide a forum for participants to draw upon their differing attitudes, feelings, beliefs, experiences and reactions in a way in which would not be feasible using one-to-one interviewing. Compared to individual interviews, which aim to obtain individual attitudes, beliefs and feelings, focus groups elicit a multiplicity of views within a group context, potentially allowing access to a larger amount of information within the FG interview (Ritchie et al., 2003).

As with Stage 1 participants from the school setting were identified by school staff. The school was based in West Yorkshire and selected because of its willingness to participate in the research. A similar pack as in Stage 1 was taken home by adolescents in the school. Signed consent forms were obtained from both parents/carers and adolescents in order for adolescents to take part in the research. Weight related discussions taking place in the school setting, could potentially stigmatise some adolescents. This may result in a higher potential risk of distress to adolescents in the school context compared to adolescents recruited from the weight management setting and hence, why consent was sought from both parents/carers and adolescents in the school context.

The sampling criteria adopted in Stage 1 was utilised in Stage 2. Adolescents' BMI was not measured, as the aim of this part of the study was to obtain the views of a general sample of adolescents regardless of their weight status.

## **Interviews**

### **Stage 1**

Interviews were offered in the most convenient setting for adolescents enrolled in weight management services (e.g. before or after a training session at the weight management venue, at home or at the University).

A semi structured interview was carried out with adolescents, using a topic guide in order to identify the impact of weight status on their own lives. The interview consisted of three parts. Part A contained an introduction of the researcher and the research, followed by questions about general background information (i.e. age, family circumstances and current area of residence). Part A concluded with questions about perceived weight status of the adolescent as well as family members. This was in order to start adolescents thinking about their weight and prepare them for Part B. In Part B adolescents were asked about the different things that they do in their own lives (both when they are in school and in evenings, weekends and holidays). Probing was used to identify how different activities were affected by weight status. Part C of the interview was informed by the literature; specifically by three existing non preference based self reported weight specific instruments that were identified in the literature. Although these instruments are not suitable for the calculation of QALYs, they provide a good foundation for informing the content of a preference based QoL instrument. Using themes identified by these measures, adolescents were asked about their views on the impact of weight status on these themes (which included physical activity, socialising and self-esteem). This was undertaken in order to confirm that all potential aspects of QoL affected by weight status had been covered during the interview process (interview topic guide available on request).

### **Stage 2**

The school setting was used to conduct the general population based FG interviews in Stage 2. As with Stage 1 a semi structured interview was carried out using a similar topic guide. Key differences in this Stage were as follows: In Part A after the introduction, adolescents were shown an example of different body sizes for boys and girls using silhouettes of weight status. The silhouettes contained 4 body shapes for boys and girls 1=thin, 2=normal, 3=overweight and 4=obese. The different silhouettes were presented to adolescents only by number without any word labels in order to not influence responses. Adolescents were asked to *'Imagine you know someone that is the size in example (4) – it could be a friend at school or at home, or it could be a relative'*. They were then asked: a). *'How do you think they would be affected by their size, b). Why do you think this would be affected, c). How do you think this person would feel'*. As per the previous stage (stage 1 Part C) the literature was used to inform Part B. Themes identified in the literature but NOT brought up in Part A of the FG discussions were examined in terms of how adolescents viewed weight status impacting upon these particular aspects of QoL.

Interviews in stages 1 and 2 were designed in order to understand and explore all of the consequences of weight status and its impact on different aspects of adolescents QoL. For example, the impact of having difficulty keeping up with others when running could lead to the consequence of being short of breath as well as feelings of frustration or unhappiness. The use of closed questions were avoided where possible. Open questions were posed to obtain the most depth and explanation in respondents answers. For example questions such as 'did that affect you' were

avoided instead questions like ‘how did that affect you’ or ‘how did that make you feel’ were used instead.

All interviews were carried out by the primary researcher (YO) and recorded and transcribed verbatim. Data saturation (the point at which the collection of new data does not shed any further light on the issue under investigation (Ritchie et al., 2003) was assessed with the aid of a saturation matrix (Brod et al., 2009). For the current study, this was the point at which no new aspects of QoL are identified as being affected by weight status, by carrying out more interviews with adolescents. Information collected from the interviews was summarised using the saturation matrix. The rows of the matrix consist of each individual interviewed (in chronological order) whilst the columns represented general aspects or ‘themes’ of QoL. Cells in the matrix were highlighted if a particular respondent had identified a particular aspect of QoL being affected by their weight status. Where the theme was not highlighted by a particular respondent, then the corresponding cell was greyed out. When each cell in the matrix was highlighted at least once and no new information was identified regarding a particular theme then data saturation would have been reached.

Transcription of audio files was outsourced and participant’s names were anonymised. All participants were given study names by the primary researcher (YO).

### ***Ethics***

Ethical approval for this study was granted from the University of Leeds Research Ethics Committee – Faculty of Medicine & Health review panel.

## Analysis

The aim of carrying out the interviews was to identify the aspects of QoL affected by weight status and data analysis was guided by this aim.

Thematic analysis was applied to interview data in order to identify aspects of QoL affected by weight status as reported by participants (Ritchie et al., 2003). Data were sorted and managed using the Framework approach. The Framework method was developed by the National Centre for Social Research (Ritchie et al., 2003). The approach has been successfully utilised in a similar study (Stevens, 2009), and provides a systematic thematic way of summarizing and classifying data. For the current study, the aim of the analysis was to produce a theme and case based chart that summarised all the data into one matrix. A matrix consisting of cases (represented by each row) and themes (represented by each column) would be produced once all the data was charted. The matrix summarizes and synthesises the data generated from the interviews whilst retaining the terminology and language used by participants. A short summary of the steps involved for the Framework approach is provided below (the guide by Ritchie and Lewis, 2003, provides a more detailed account):

- **Step 1:** In order to be re-familiarised with the issues identified in the interviews, review all of the data generated from the interviews by re-reading transcripts and re-listening to audio recordings;
- **Step 2:** Identify recurring themes & ideas from carrying out Step 1;
- **Step 3:** Devise a thematic framework from the information generated in Step 2. Group together themes and ideas identified in Step 2 into 'Main themes' and 'Sub-themes'; and
- **Step 4:** Go through each interview transcript and code using the main themes and sub-themes identified in Step 3.

The process of coding can be carried out using qualitative software or other non qualitative software packages. In the current study both types of packages were used ((QSR-International, 2011) and (Microsoft, 2011)). The qualitative analysis was carried out in two phases. In the initial phase of analysis, data focusing on adolescents own experiences were assessed. This related to data generated from Parts A and B in stage 1, one-to-one interviews, and Part A in stage 2 focus group interviews. In the second phase the data generated from the interviews that was informed by the literature was analysed. The analysis was carried out in two phases in order to maintain a neutral stand point on the first phase analysis of the interviews. This meant that the findings from the literature were put to one side and the 'pure' data from adolescents themselves drove the themes and sub-themes.

For the phase 1 analysis, the different themes and sub-themes were coded in Word 2010 (Microsoft, 2011) where different themes and sub-themes were highlighted in different colours. All of the information that was highlighted was then charted by producing a matrix in Excel. A case (representing each row in the matrix which was either a one-to-one or FG interview) and theme (representing each column in the matrix) based chart was produced across all themes and subthemes. Each theme was then evaluated individually.

The data generated in the phase 2 analysis were informed by the literature, and thus the transcripts were structured according to pre-identified themes. This made it easier to produce the case and theme based charts using the Nvivo9 qualitative software (QSR-International, 2011). Transcripts were formatted and read into the programme to aid efficient analysis.

The matrices were used to develop wording for the new weight specific questionnaire. The draft questions aimed to maintain the language and terminology used by participants. Once the full list of draft questions was created to reflect different aspects of adolescents' lives that were affected by weight status, consultations with individuals who have expertise and experience in the field of

adolescent obesity was carried out. An amended list of questions was then created. A mapping process was then undertaken to map questions to overall domains of QoL. This mapping process was carried out in order to create a reduced questionnaire making it more applicable for the elicitation of preference values. The mapping process was informed by the findings of the Fitzpatrick et al. (1998) review (Fitzpatrick et al., 1998), which summarized the range of domains/dimensions assessed by patient reported outcome measures used in clinical trials.

### ***Validation of qualitative analysis***

A subset of the transcripts were checked for accuracy. The data analysis was closely guided by input from supervisors and advisors experienced in the field of qualitative analysis. The coding of themes and sub-themes was an iterative process that was closely overseen by the primary supervisor. The final list of themes and sub-themes and the coding of transcripts was also reviewed by the same supervisor.

## Results

### ***Participants in the one-to-one interviews***

Participants were recruited mainly from weight management Service A as there was a limited number of adolescents that fit the age range that was required for the study from weight management Service B. A total of 20 families from weight management Service A (19 current users and one on the waiting list) were approached to take part in the study, of these, interviews were carried out with 15 adolescents.

Two families were approached from weight management Service B. One adolescent agreed to take part in the study. In total 16 one-to-one interviews with adolescents were conducted. Table 1 summarises the background information of participants taking part in the one-to-one interviews.

### ***Participants in the focus group interviews***

School staff approached six adolescents (staff selected adolescents that they thought would suited to FG discussions, i.e. vocal and not shy of putting their point across) to take part in the FG interviews. One FG interview was arranged with the younger adolescent age group (11-14yrs). One parent from the younger adolescent age group opted their child out of taking part in the study. Unfortunately the timing of interviewing meant that there was a clash with summer examinations, and thus a FG could not be arranged with the older adolescent age group (15 – 18yrs). Background information on the five FG participants is given in Table 1.

**Table 1: Background information on participants interviewed**

	Participant ID	Duration of interview (mins)	BMI baseline	Most recent BMI
<b>Stage 1: 1-to-1 interviews (n=16)</b>	<b>Girls aged 11-14 years old</b>			
	GL_Y_1	16.22	27.16	27
	GL_Y_2	20.37	27.1	27.1
	GL_Y_3	25.37	30.04	29.6
	GL_Y_5	33.34	25.2	25.15
	GL_Y_6	35.06	42.2	41.3
	GL_Y_7	40.55	30.72	29.9
	<b>Girls aged 15-18 years old</b>			
	GL_O_8	16.29	35.11	35.44
	GL_O_9	36.45	37.7	36.79
	GL_O_10	53.02	30.8	28.7
	GL_Y_4	25.5	NA (on waiting list)	NA (on waiting list)
	<b>Boys 11-14 years old</b>			
	BO_Y_1	16.51	27.57	27.12
	BO_Y_2	31.34	30.6	26.9
	BO_Y_3	34.05	29.76	24.26
BO_Y_4	60.1	20.77	20.59	
<b>Boys 15-18 years old</b>				
BO_O_5	17.27	33.48	33.03	
BO_O_6	42.29	40.81	38.07	
<b>Stage 2: FG interviews (n=1)</b>	<b>Focus group (2 girls &amp; 3 boys aged 11-14 years)</b>			
	BO_Y_FG	47.49	NA (perceived to be normal weight for age and gender)	NA (perceived to be normal weight for age and gender)

## **Interviews**

It was felt that all adolescents who took part in the interviews understood what the research was about and took the interviews seriously. None of the adolescents asked to stop the interview early. For two interviews with the younger participants, parents sat in on the interview. Two interviews took place in the University premises at the request of participants; otherwise all other interviews took place at participant's homes, or in school or weight management service premises. Interviews varied in length from 17 to 70 minutes.

Saturation was reached when all cells in the saturation matrix were highlighted at least once and when no new themes or issues emerged from carrying out more interviews. On completion of one-to-one interview number 13, all of the themes that emerged from the interviews had been discussed at least once. Three further one-to-one interviews were carried out but no new information emerged from conducting these interviews. In the FG interview, the majority of issues and themes previously discussed in the preceding one-to-one interviews were identified in the first part of the interview. The only thing that was not mentioned was the effect of weight status on the relationships with family members. Overall the findings from carrying out the FG interview confirmed that no new themes or issues would emerge and saturation had been reached.

## **Analysis**

The Framework analysis generated an initial list of 50 draft questions covering the impact of weight status on the QoL of adolescents. After the consultation process with the experts a refined list of 46 questions was identified. The mapping of questions to domains of QoL generated six domains covering 14 sub-domains covering a further reduced set of 29 questions. Table 2 provides the list of 46 questions and the mapping of these onto the 6 domains of QoL. Once mapped onto domains of QoL, it was felt that the 46 questions could be further reduced to 29 questions, and would still adequately capture the full range of domains of QoL. A constraint in designing a descriptive system for economic evaluation is that the health states defined by the system should be amenable to valuation (i.e. between 5 to 9 items, see Brazier et al. (Brazier et al., 2007)).

## **Domains of QoL identified**

Descriptions of the domains and sub-domains identified from the mapping process explained above are given below; illustrated with examples of some of the data that was generated from the interviews with adolescents.

## **Symptoms**

The symptoms domain related to the consequences of adolescents performing physically demanding tasks such as running or playing sports (e.g. basketball, cycling or football). When performing these types of activities adolescents reported having body pain or ache, being short of breath or getting tired quickly.

### **Example 1**

**Young person:**

***“The odd times like my legs ache a little bit but that’s only if like we’ve been walking quite fast, if we’re going to be late for school we walk quite fast....”***  
(GL\_Y\_2, Girl aged 11-14 yrs, Baseline BMI 27.1)

### **Example 2**

**Interviewer:**

***“When you walk to the bus stop do you ever think that your weight affects you when you’re walking to the bus stop?”***

**Young person:**

***“It’s like I get tired”***  
(GL\_Y\_4, Girl aged 11-14 yrs, Baseline BMI NA)

**Table 2: Mapping draft questions to domains of QoL**

No.	Framework analysis theme (s): Barriers to physical activity	Sub-Domain	Domain
1.	I avoid being active e.g. when walking long distances or going up stairs	Daily routine	Physical function
2.	I have low energy in the morning I don't have energy when I get up in the morning		
3.	Reaching down is hard for me		
4.	It's hard for me to wash or dress myself		
5.	I avoid taking part in activities e.g. when playing games or sports or running	Physical activity	Physical function
6.	I feel that other people are better than me when I take part in activities e.g. when playing games or sports or running		
7.	It's hard for me to keep up with the others when I take part in activities e.g. when playing games or sports or running		
8.	I get out of breath easily if I am active e.g. when walking about or going up stairs	Out of breath	Symptoms
9.	I get out of breath easily if I take part in activities e.g. when playing games or sports or running		
10.	I get tired easily if I am active e.g. when walking about or going up stairs	Tired; Weak	Symptoms
11.	I get tired easily if I take part in activities e.g. when playing games or sports or running		
12.	I have pain if I am active e.g. when walking about or going up stairs	Pain; hurt; ache	Symptoms
13.	I have pain if I take part in activities e.g. when playing games or sports or running		
<b>No.</b>	<b>Framework analysis theme(s): School &amp; social</b>		
14.	I get picked on because of my weight	Socialising	Social wellbeing
15.	I feel like people avoid me because of my weight		
16.	My school work is affected when I get picked on because of my weight	School/ college work	Cognitive functioning
<b>No.</b>	<b>Framework analysis theme(s): Future</b>		
17.	I feel that my weight will get in the way of my future	Future prospects	Role activities
	I feel that my weight will stop me from doing what I want in the future		
18.	I worry about my health in the future		
<b>No.</b>	<b>Framework analysis theme(s): Body esteem</b>		
19.	I can't fit into clothes most people my age fit into	Embarrassed, uncomfortable	Psychological wellbeing / Personal constructs
20.	I avoid getting changed in front of others		
21.	I don't like the way I look		
<b>No.</b>	<b>Framework analysis theme(s): Eating / food</b>		
22.	I find it hard to eat food that is healthy	Self control	Psychological wellbeing / Personal constructs
23.	I find it hard to not eat too much food		
24.	How I feel inside affects my eating		

**Table 2 cont: Mapping draft questions to domains of QoL**

No.	EMOTION	Sub-domain*	Domain
<b>Emotions - PHYSICAL</b>			
25.	I get <b>frustrated</b> being slower than others I get <b>annoyed</b> being slower than others e.g. when playing games or sports or running	Angry or Annoyed	Psychological wellbeing / Personal constructs
	I feel <b>upset</b> because others are faster than me (YONGER ADOLECENTS) e.g. when playing games or sports or running	Frustrated	
26.	I feel <b>disappointed</b> with myself being slower than others e.g. when playing games or sports or running	Disappointed	Psychological wellbeing / Personal constructs
	I feel <b>upset</b> because others are faster than me (YONGER ADOLECENTS) e.g. when playing games or sports or running	Unhappy	
27.	I feel <b>frustrated</b> because walking about or going up stairs is hard for me I feel <b>annoyed</b> because walking about or going up stairs is hard for me	Angry or Annoyed	Psychological wellbeing / Personal constructs
	I feel <b>upset</b> because walking about or going upstairs is hard for me (YONGER ADOLECENTS)	Frustrated	
28.	I feel <b>frustrated</b> because I get tired easily I feel <b>annoyed</b> because I get tired easily	Angry or Annoyed	Psychological wellbeing / Personal constructs
	I feel <b>upset</b> because I get tired easily (YONGER ADOLECENTS)	Frustrated	
<b>Emotion - CLOTHES &amp; BODY ESTEEM</b>			
29.	I feel <b>upset</b> when the clothes I want aren't made in my size	Unhappy	Psychological wellbeing / Personal constructs
	I feel <b>disappointed</b> when the clothes I want aren't made in my size	Disappointed	
30.	I feel <b>self-conscious</b> in shops when I go looking for new clothes to buy	Uncomfortable or Embarrassed	Psychological wellbeing / Personal constructs
31.	I feel <b>uncomfortable</b> when I get changed in front of others	Uncomfortable or Embarrassed	Psychological wellbeing / Personal constructs
32.	I am <b>not happy</b> that I have to get bigger sized clothes than most people my age	Unhappy	Psychological wellbeing / Personal constructs
33.	I am <b>not happy</b> about telling people my size in clothes	Unhappy	Psychological wellbeing / Personal constructs
34.	I feel <b>left out</b> when I go clothes shopping with my friends	Socialising	Social wellbeing
35.	I am <b>unhappy</b> that I can't swap clothes with my friends	Socialising	Social wellbeing
<b>Emotion - FOOD</b>			
36.	I feel <b>unhappy</b> when I can't eat what I want	Unhappy	Psychological wellbeing / Personal constructs
37.	I feel <b>guilty</b> when I eat unhealthy food	Self control	Psychological wellbeing / Personal constructs
38.	I feel <b>guilty</b> when I eat too much		
39.	I feel <b>self-conscious</b> when I eat in front of others	Uncomfortable or Embarrassed	Psychological wellbeing / Personal constructs
40.	I feel <b>embarrassed</b> if I eat more than other people		
<b>Emotion - SCHOOL</b>			
41.	When I am at school I feel <b>unwanted</b>	Socialising	Social wellbeing
	I feel <b>different</b> because of my size when I am at school		
42.	I feel <b>upset</b> when I get picked on at school because of my size	Socialising	Social wellbeing
<b>Emotion - SOCIAL</b>			
43.	My size makes me feel <b>less confident</b> around people I don't know well	Uncomfortable or Embarrassed	Psychological wellbeing / Personal constructs
44.	I am not able to <b>enjoy</b> myself when I go out	Uncomfortable or Embarrassed	Psychological wellbeing / Personal constructs
45.	I feel <b>self-conscious</b> when I go out	Uncomfortable or Embarrassed	Psychological wellbeing / Personal constructs
46.	I <b>stick out</b> from other people my age	Uncomfortable or Embarrassed	Psychological wellbeing / Personal constructs
	I feel <b>different</b> to other people my age (YOUNGER ADOLECENTS)		

## Physical function

Discussions around physical activity could be split into two categories: daily routine and physical activity. Some adolescents spoke about having difficulty keeping up with others when walking around or when bending over. Others identified having problems keeping up with others when performing physical activity.

### Example 1

*Interviewer:* “Do you ever think that your weight affects you when you’re in games lessons?”

*Young person:* “Yeah cause I can’t do things as well as I can with others”

*Interviewer:* “What types of things can’t you do as well as others?”

*Young person:* “Run as fast as others, as long as others, and stuff like that”

(BO\_Y\_2, Boy, aged 11-14 yrs, Baseline BMI 30.6)

### Example 2

*Interviewer:* “So thinking beyond school, when you think about your weekends or your normal kind of holidays, what are the types of things that you can think of that are affected by your weight?”

*Young person:* “Oh every time I bend down, I feel like that (pointing at belly) gets in the way.....and I’m like, and I’ll bash it backwards and then when I’m reaching it’ll come out and my back’ll go and I’m like aargh”

(BO\_Y\_4, Boy, aged 11-14 yrs, Baseline BMI 20.77)

## Psychological wellbeing / Personal constructs

There were many issues raised by adolescents around the way they felt about the way they look as well as the way they felt inside. Numerous variants of the same emotion was given such as for example feeling bad, sad, unhappy or upset.

### Example 1

*Young person:* “I sometimes feel upset, and feel like sometimes I feel upset that I can’t do stuff like with my friends, school friends do”

(GL\_Y\_2, Girl, aged 11-14 yrs, Baseline BMI 27.1)

### Example 2

*Interviewer:* “So thinking through all the activities that you’ve mentioned on a typical school day, is there anything that you can think of that we’ve not talked about that you think is affected by your weight?”

*Young Person:* “Getting dressed, could be one, but we’ve already covered that, cause I could have to get bigger clothes”

*Interviewer:* “Okay, so tell me a bit more about that”

*Young Person:* “Well once I got this shirt that wasn’t big enough so I had to take it back and get another one”

*Interviewer:* “How does that make you feel?”

*Young person:* “Upset because the one didn’t fit me and I wanted that one”

*Interviewer:* “And how do you find shopping in general for clothes?”

*Young Person:* “(Feel) self conscious...about what other people will think”

(BO\_Y\_2, Boy, aged 11-14 yrs, Baseline BMI 30.6)

## Cognitive functioning

The impact of weight status on concentration or being able to complete school work was mentioned by adolescents, though the majority of adolescents did not feel that their weight affected their participation in school classes. Adolescents pointed out that the main aspect of their school life that was affected by their weight was when they had to take part in physical activities.

### Example 1

*Interviewer:* “Do you think your weight affects you at all, joining in at school?”

*Young person:* **“Sometimes, but not that much..... affects me in PE”**  
(GL\_Y\_3, Girl, aged 11-14 yrs, Baseline BMI 30.04)

### Example 2

*Interviewer:* “I want you to imagine that you had a friend or a relative that has this body shape, and I want you to tell me how you think that body shape would affect them in school”

*Young person (girl):* **“Struggling like in PE and things like that”**

*Young person (boy):* **“They might be focused too much on erm the bullies.....like their grades and everything, so they might slip down”**  
(FG)

## Social wellbeing

The impact of weight status on socialising took many forms. These manifested themselves in the way adolescents were treated by others in school or outside of school, whether or not they wanted to socialise because of the way they looked and also in terms of their relationships with friends and family.

### Example 1

*Young person:* **“...if like, I’m sitting next to, someone who I don’t know as well, and we just start talking, I don’t, I’m not as confident cos I don’t feel confident, so I’m not gonna act it with them”**

*Interviewer:* “Do you think that your weight ever affects your ability to make new friends then?”

*Young person:* **“Yeah, I kind of erm, stop myself sometimes”**

(GL\_O\_10, Girl, aged 16-18, Baseline BMI 30.8)

## Role activities

Finally some adolescents were very aware that their weight could have an impact on their future prospects. Others however saw their weight as something that they were doing something about now – and thus would change in the immediate future.

### Example 1

*Young Person:* **“I agree with that because some people think, I think that some people won’t accept you in jobs because of your size”**

(BO\_Y\_2, Boy, aged 11-14, Baseline BMI 30.6)

### Example 2

*Young person:* **“When I think, when I grow up and want to be this want to be that, then I think well what’s going to happen to my weight and everything, yeah”**

(GL\_Y\_3, Girl, aged 11-14, Baseline BMI 30.04)

### Example 3

*Young person:* **“No because you could like lose it and then it, you’d look back and you’d think oh I said it’d affect my future but it really hasn’t.”**

(GL\_O\_8, Girl, aged 15-18, Baseline BMI 35.11)

Table 3 provides a summary of the final list of domains, sub-domains and questions generated from the analysis. It shows the different aspects of QoL adolescents identified as being affected by their

weight status mapped to domains of QoL. Weight status seems to affect a broad range of domains in adolescents' lives including: social, psychological, cognitive and physical functioning domains.

A comparison of the domains identified by the new measure and the three existing weight specific QoL measures is provided in Table 4. These three measures are all aimed at the adolescent population and include the following instruments: Impact of weight on QoL – Kids (IWQOL – Kids, (Kolotkin et al., 2006)); Sizing Me Up, (Zeller and Modi, 2009); and Youth Quality of Life Instrument – Weight Module (YQOL-W, (Morales et al., 2011)).

**Table 3: Identification of domains & sub domains\***

Domain	Sub-Domain	Item wording informed by adolescents own words (29 items in total)
<b>Symptoms</b>	<b>Pain</b>	I have body pain / ache
	<b>Tired</b>	I get tired
		I get low energy
<b>Out of breath</b>	I get out of breath	
<b>Physical function</b>	<b>Daily routine</b>	I struggle to keep up when I am walking around with others
		I struggle when I am going up stairs
		I struggle to reach or bend down
	<b>Physical activity</b>	I struggle to keep up with others when doing physical activity
		I struggle to keep up with others when I play sports
		I avoid doing things like running, cycling, swimming or playing sports
<b>Psychological wellbeing / Personal constructs</b>	<b>Angry or Annoyed</b>	I feel angry or annoyed because I am unable to do the same things as others
	<b>Frustrated</b>	I feel frustrated because I am unable to do the same things as others
	<b>Uncomfortable or Embarrassed</b>	I feel uncomfortable or embarrassed getting changed in front of others
		I feel uncomfortable or embarrassed shopping for clothes
		I feel uncomfortable or embarrassed meeting new people
		I feel uncomfortable or embarrassed eating in front of others
	<b>Unhappy</b>	I feel unhappy because I can't eat what I want
		I feel unhappy about the way I look
		I feel unhappy because I am unable to do the same things as others
	<b>Disappointment</b>	I feel disappointed because clothes aren't made in the size I need
<b>Self control</b>	I struggle to keep in control of what I eat	
<b>Cognitive functioning</b>	<b>School / college work</b>	I struggle to do as well as others at school
		I struggle to concentrate on school / college work
<b>Social wellbeing</b>	<b>Socialising</b>	I get treated differently at school, such as being teased or picked-on or left out
		I get treated differently at home, such as being teased or picked-on or left out
		People treat me differently when I go out
		I avoid playing / hanging out or socialising with others
<b>Role activities</b>	<b>Future prospects</b>	I worry about my health in the future
		I worry about the type of job/career I will be able to have

\*Informed by the Fitzpatrick et al. review ((Fitzpatrick et al., 1998) pp. 7)

**Table 4: Comparison of domains identified in the new measure with the three existing weight specific QoL measured aimed at the younger population**

IWQOL-Kids (27 items)	Sizing Me Up (22 items)	YQOL-W (21 items)	NEW MEASURE (29 draft items)
PHYSICAL COMFORT	PHYSICAL FUNCTIONING	ENVIRONMENT (Challenge of physical activity)	SYMPTOMS
			PHYSICAL FUNCTION
BODY ESTEEM	EMOTIONAL FUNCTIONING	ENVIRONMENT (Finding clothes that fit, Feeling comfortable in school/public)	PSYCHOLOGICAL WELLBEING / PERSONAL CONSTRUCTS
	SOCIAL AVOIDANCE	SELF (Psychosocial impact, Body dissatisfaction, Coping strategies)	ROLL ACTIVITIES (future prospects)
SOCIAL LIFE	TEASING/MARGIANALISATION	SOCIAL (Fitting in, Avoiding participation, Feeling attractive, Social acceptance)	SOCIAL WELLBEING
FAMILY RELATIONSHIPS			
	POSITIVE SOCIAL ATTRIBUTES		
			COGNATIVE FUNCTION

## Discussion

This study has generated a new weight specific questionnaire that is based on the views of adolescents aged 11-18 living in the UK. A range of aspects of QoL that is affected by weight status was identified through consultation with adolescents. These aspects were then mapped onto commonly known domains of QoL, which were identified in the context of outcome measures used in clinical trials (Fitzpatrick et al., 1998). A single aspect of QoL an adolescent acknowledged as being affected by their weight status, could affect more than one domain of QoL. For example, an adolescent who finds it hard to keep up with their peers when doing physical activity, could experience breathlessness and feelings of frustration. In this case, weight status impacted upon the adolescent's physical ability, which affected both the symptom and emotion domains of QoL.

The 'bottom up' approach obtains the views of the population of interest to inform the content of a new QoL measure. This approach was taken in constructing a new weight specific questionnaire, and is similar to that taken by Grewal et al. (Grewal et al., 2006) and Stevens (Stevens, 2009). Both studies directly identified domains of QoL through the narratives given by interview participants, in the development of a generic QoL measure for older and paediatric populations, respectively. The studies give further support to the qualitative approach in informing the content of a new QoL measure. Furthermore, the involvement of adolescents in the development of the new measure is in line with the Food and Drug Administration guidelines (Food-and-Drug-Administration, February 2006) on patient reported outcome measures, as it will warrant the content and face validity of the new measure. Carrying out interviews with the younger age group also ensures that the age-related vocabulary and language comprehension is appropriate for the age group under study (Stevens, 2009).

There are four key limitations regarding the sample of participants interviewed in the study that need to be acknowledged. Firstly, the population of adolescents interviewed were based in Leeds, and it is not certain that the views of these individuals will reflect the views of adolescents throughout the UK. Leeds, however, is unique in providing a rich source potential study participants, due to its long history of offering weight management programmes to the younger population. Some of the providers are recognised service and training providers by the Department of Health under the Framework Agreement for Child Weight Management (Cross-Government-Obesity-Unit, March 2009 ). Primary care trusts (PCTs) throughout the UK utilise the services offered in Leeds. As such, it is unlikely that the recruitment of adolescents in other areas of the UK could offer such a rich source of potential participants. In addition to interviews with adolescents, consultation with individuals involved with the delivery of these services was carried out, in order to ensure that any issues omitted from the interviews would have been flagged up.

The majority of adolescents were recruited from the community based weight management services. These services offer guidance, support and education on both health and lifestyle behaviours. Weight management interventions also include hospital based interventions such as surgery. Pharmaceutical interventions are also available for weight management. The views of adolescents undertaking these other forms of weight management interventions have not been included in the study. This population of adolescents may differ from those utilising community based service with respect to the severity of their weight status. The applicability of the new measure in the 'non-community based treatment seeking' population of adolescents is something that can be tested in future research.

Of the individuals interviewed from the weight management services, the majority fell within the 11-14 year old age group. Related to this, the FG carried out in the school sample included adolescents in the younger age group, but none in the 15-18 year old age group. This might result in some key aspects of QoL affected by weight status in the older age group of adolescents being omitted. Again, this is something that will need to be addressed in future research.

An assessment of the comparison between the new measure and the existing measures in Table 4 shows a similarity in the content of the new measure with respect to the existing measures. Important differences however exist. Firstly, although physical functioning / comfort are addressed in existing measures, the *consequences* of weight status on physical activity, in terms of symptoms are not clearly defined. For example in the YQOL-W, one of the items relating to this domain asks 'Because of my weight exercising is hard for me'. However, it is not possible to identify 'what' exercising impacts upon i.e. breathing or low energy levels etc. The new measure allows respondents to identify limitations of performing different activities (in the physical function domain) and the consequences resulting from performing these activities (in the symptoms domain).

Another key difference is that the impact of weight status on future work or health is only partially identified in one of the existing measures. The YQOL-W includes the item 'I worry that my weight will prevent me from getting a good job'. In the new instrument, current concern over the impact of weight status on future health is also incorporated.

In terms of the impact of weight status on family relationships, the new measure takes a more general standpoint – for example the IWQOL-Kids has six items about negative treatment by family members. The new measure includes one item that should cover this range of issues 'I get treated differently at home, such as being teased or picked-on or left out'.

The Sizing Me Up instrument contains a 'Positive social attributes' domain. The new measure does not contain any items that fit this domain. Perhaps this is because the interviews were designed to probe the limitations associated with weight status. It must however be noted that during each of the interviews with adolescents that was carried out in the current study, positive feelings about weight were investigated, but none of the adolescents interviewed identified with this notion. Finally, one domain that was identified in the new measure, but not in any of the existing instruments was the impact of weight status on cognitive function. The existing instruments discuss the social impact of weight status in school – but none of the items thus far have specifically addressed issues regarding academic work.

## Conclusions

The views of adolescents have driven the content of a new 29 item weight specific QoL measure. For the measure to be applicable for the calculation of QALYs, preference values need to be elicited for health states as described by the new measure. The next step will be to reduce the number of items so that the new measure is appropriate for the elicitation of preference values.

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