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ORIGINAL RESEARCH

Important aspects of health not captured by EQ-5D: Views of the UK general public

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Abstract

Introduction: The EQ-5D is a standardized instrument designed for use as a generic measure of health outcome. It was (and is) intended to provide information about a "common core" of dimensions known to be relevant across a range of conditions, and valued highly by people. However, the five dimensions may not fully capture the health-related impacts of certain conditions. This study analyses the views of a sample of the UK general public about important aspects of health that they consider to be missing from the five EQ-5D dimensions. **Methods**: Survey respondents were asked whether there are any aspects of health they consider to be important but are not captured by the five EQ-5D dimensions; and if so, what these aspects of health are. The responses (text comments) were analyzed using a conventional content analysis framework with analyst triangulation. Data were collected from a broadly representative sample of the UK general public via a paper questionnaire administered as part of face-to-face interviews. **Results**: Data are available for 436 respondents. One-hundred and seventy-nine respondents (41.1%) provided suggestions of aspects of health they considered important but not captured by the five EQ-5D dimensions. These were organized into 22 themes by the study team. Sensory deprivation (particularly vision and hearing) and mental health (referred to either in general terms or with reference to a specific condition) were the aspects of health most commonly mentioned by respondents. **Conclusions**: To some extent, the findings of this study support the choice of areas in which exploratory "bolt-on" work has been conducted to date. The study can provide the basis for more detailed qualitative and quantitative research to inform further review of the EQ-5D descriptive system.

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Introduction

The term "health" is defined by the World Health Organization (WHO) as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" [1]. The WHO's definition has not been amended since 1948, and has been criticised for being too absolute and for failing to capture recent changes in demographics and the nature of disease [2]. It has been suggested that any attempt to define health may be futile [3]. However, it is important to understand what health entails in order to determine what aspects of health need to be measured, as measurement is needed in order to evaluate policies and interventions.

The EuroQol Group's EQ-5D is a standardised instrument designed for use as a measure of health outcome. It was designed as a generic instrument capable of providing simple descriptive profiles across a wide range of conditions and treatments, and of identifying differences between populations and population groups [4]. It was intended to provide information about a "common core" of dimensions known to be relevant across a range of conditions, and valued highly by people. It was not originally intended to be a comprehensive, standalone instrument for capturing all aspects of health for all purposes, but rather, a brief and convenient measure to be used in conjunction with other, more detailed generic and condition-specific measures [5]; though increasingly it is used as a standalone measure [6]. It should be noted that while early studies of EQ-5D referred to it as a measure of health-related quality of life, we follow the suggestion by Karimi and Brazier [7] that it is more appropriate to think of such instruments as measures of "self-perceived health status".

The five EQ-5D dimensions (mobility, self-care, usual activities, pain/discomfort, anxiety/depression) were chosen to capture physical, mental and social functioning [8]. Candidate dimensions were identified by a review of existing generic measures and a survey of lay concepts of health [9], and selected based on a largely conceptual process. The original descriptive system had separate dimensions for "main activity" and "social relationships" (ability to pursue family and leisure activities), while an additional energy dimension was considered but not incorporated due to evidence that its inclusion had no significant effects either on self-reported health or on the valuation of health states [4].

There is evidence that the dimensions currently included in the EQ-5D descriptive system are able to assess health status validly across a range of physical and mental health conditions including diabetes [10,11], arthritis [12] and many cancers [13,14]. In other areas of health, however, the five dimensions may not fully capture the health-related impacts of certain conditions. Such areas include vision and hearing [14,15], cognition [16], sexual function, incontinence [17] and severe mental health conditions such as

schizophrenia [18]. The EQ-5D may not be psychometrically valid and sensitive to the impacts of a particular condition if changes in health are not reflected in the descriptive system.

In addition, ceiling effects (where patients rate themselves at the best level on all dimensions) have been observed with the EQ-5D, and this may impair the ability of the descriptive system to measure small changes in health at the less severe end of the scale. To a large extent, the presence of ceiling effects is likely to be a function of the number and labels of response levels for each dimension; however, it may also be due to the relevance of the dimensions themselves with respect to "milder" health problems. An objective in the development of the EQ-5D-5L (the new, five-level version of the EQ-5D) was to address the presence of ceiling effects [19]. Evidence to date suggests that EQ-5D-5L is associated with a substantial reduction in ceiling effects compared to the EQ-5D(-3L), though a significant proportion of patients still report no problems on all five dimensions [20,21].

Further attempts to improve the sensitivity of the descriptive system include the development of "bolt-on" dimensions for the EQ-5D in a number of physical and mental health areas including cognition [16], psoriasis [22], vision, hearing and tiredness [23]. However, it is currently unclear which conditions and associated aspects of health should be considered for further bolt-on research.

The primary aim of this paper is to report the views of the UK general public about aspects of health that they consider to be important but do not perceive as being captured by the five EQ-5D dimensions. For this purpose, we analyse responses to follow-up tasks included in a wider study assessing differences in time trade-off valuations using two different comparator health states: EQ-5D-5L health state 11111 and "full health". The primary results of that study are reported elsewhere [24].

Methods

Administration of survey

Data were collected from a broadly representative sample of the UK general public via face-to-face interviews undertaken by three experienced interviewers working for Sheffield Hallam University. All interviews were carried out in a one-to-one setting in the homes of respondents. Details of the sample recruitment process are reported by Shah et al. [24]. The survey was approved by the Ethics Committee of the University of Sheffield's School of Health and Related Research.

Survey instrument

Respondents first completed a valuation questionnaire. This comprised a series of time trade-off and discrete choice experiment tasks (following an adapted version of the EuroQol Group protocol for valuing EQ-5D-5L health states [25]). A computer-based tool was used to administer the valuation tasks and to capture the response data. The methods and results of the valuation questionnaire are reported elsewhere [24] and are not discussed in this paper.

Immediately after completing the valuation questionnaire, respondents were asked to complete a short pen-and-paper follow-up questionnaire, which comprised the following tasks (in order):

1. paired comparison task in which respondents were asked to indicate whether they considered 11111 and full health to be "the same as each other", and if not, to explain (open-ended comment) what makes them different from each other;
2. visual analogue scale rating of 11111 and full health (plus two impaired EQ-5D-5L health states);
3. ranking task in which respondents were asked to rank six health state descriptions (full health, perfect health, no health problems, 11111, healthy) in order of how much they would want to live in them;
4. initial question asking respondents whether there are any aspects of *health* they consider to be important but are not captured by the five EQ-5D dimensions, followed by (for respondents who answered "Yes" to the initial question) an open-ended text box to indicate what these aspects of health are;
5. initial question asking respondents whether there are any aspects of *quality of life* they consider to be important but are not captured by the five EQ-5D dimensions, followed by (for respondents who answered "Yes" to the initial question) an open-ended text box to indicate what these aspects of quality of life are.

No definition of the term "health" was presented to respondents.

The follow-up questionnaire is reproduced in full in Appendix I. In this paper, we analyse the responses to task 4. Responses to the other tasks are briefly summarised in Appendix II.

Methods of analysis

Responses to task 4 (text comments) were analysed using a conventional content analysis framework [26] with analyst triangulation [27], adopting the following five-step approach:

1. All members of the study team familiarised themselves with the data, reading each response individually and making notes of first impressions, with a view to identifying general themes in the responses.
2. Themes were proposed by one member of the study team (LL) and modified following discussion with the rest of the team.
3. Responses were coded according to their themes by two team members independently (MFJ and LL).
4. Disagreements were resolved through discussion by the relevant team members.
5. Any remaining disagreements were resolved by a third team member (KS).

A similar approach was used to analyse responses to task 1. Responses to tasks 2 and 3 were examined using basic descriptive analyses such as the calculation of mean ratings and rankings. Differences across respondent subgroups were assessed using the chi-squared test. A simple overview of common themes emerging from responses to task 5 was also undertaken. See Appendix II for a summary of responses to tasks 1, 2, 3 and 5.

Results

The interviews were conducted between May and October 2014. The valuation questionnaire was completed in full by 456 respondents. Responses to the follow-up questions are available for 436 respondents. These data are unavailable for the remaining respondents due to a recording error. The respondents with missing data did not differ greatly from the rest of the sample in terms of key observable characteristics (age, gender, self-reported health). The remainder of this paper reports the responses of the 436 respondents for whom data are available.

The background characteristics of the sample are summarised in Table 1. Older (36.0% of the sample are aged 60 and over) and female (58.0%) individuals are overrepresented in comparison to the general population [28]. The sample is also relatively well-educated, with 44.5% of respondents educated to university degree level or equivalent.

When asked about their own level of health today (i.e. on the day of the interview), 221 respondents (50.7%) self-reported as being in health state 11111. Of these 221 respondents, 184 (83.3%) self-reported an EQ-VAS score of less than 100, indicating that despite having no problems with the five dimensions covered by EQ-5D, they considered their level of health to fall short of the EQ-VAS upper anchor of "best imaginable health". The mean EQ-VAS score for respondents self-reporting as being in 11111 was 89.5 (median: 90; inter-quartile range: 85-96; full range: 46-100).

Table 1. Sample background characteristics

	Sample (N=436) N (%) [i]	General population [ii] %
Age		
18-29	75 (17.2%)	20.7%
30-44	95 (21.8%)	26.3%
45-59	109 (25.0%)	24.7%
60-74	126 (28.9%)	18.5%
75+	31 (7.1%)	9.9%
Gender		
Female	253 (58.0%)	49.2%
Male	183 (42.0%)	50.8%
Economic activity		
Employed or self-employed	212 (49.2%)	59.4%
Retired	140 (32.5%)	13.1%
Student	28 (6.5%)	8.8%
Looking after home or family	21 (4.9%)	4.2%
Other / none of the above	33 (7.7%)	14.5%
Marital status		
Single / never Married	64 (14.8%)	34.6%
Married or same-sex civil partnership	305 (70.8%)	46.8%
Separated or divorced [iii]	35 (8.1%)	11.7%
Widowed [iv]	27 (6.3%)	6.9%
Education		
Degree	193 (44.5%)	
No degree	241 (55.5%)	
Responsibility for children		
Yes	153 (35.3%)	
No	241 (55.5%)	
Experience of serious illness		
In self	144 (33.0%)	
In family	282 (64.7%)	
In caring for others	166 (38.1%)	
Self-reported health using EQ-5D-5L		
11111	221 (50.7%)	
Any other health state	215 (49.3%)	
Self-reported health using EQ-VAS		
<80	125 (28.7%)	
80-89	96 (22.0%)	
90-99	174 (39.9%)	
100	41 (9.4%)	

[i] Percentages exclude small number of missing values
[ii] General population data based on UK Census results (Office for National Statistics, 2011), where available
[iii] Comprises individuals who are separated but in a same-sex civil partnership and who were formerly in a same-sex civil partnership which is now legally dissolved
[iv] Includes individuals who are the surviving partner from a same-sex civil partnership

One-hundred and seventy-nine respondents (41.1%) provided text responses when asked whether there were aspects of health they considered important but were not covered by the five EQ-5D dimensions. After familiarising themselves with the data, the study team identified 22 themes (see Table 2, which includes examples of the responses provided) and set out to assign each response to one or more of those themes.

MFJ and LL first coded the responses independently of each other (assigning each response into one or more of the 22 themes and providing a short written justification). For 126 of the 179 responses (70.4%), both authors were in agreement about all of the

themes that the responses should be assigned to. For 156 of the 179 responses (87.2%), both authors were in agreement about at least one of the themes.

Following discussion between MFJ and LL and examination of each other's justifications, full agreement was reached about 163 of the 179 responses (91.1%). The views of a third author, KS, were sought regarding the remaining 16 responses. KS was able to make a decision about all 16 responses. In all cases, KS chose a theme that had initially been proposed by either MFJ or LL. Some responses were assigned to multiple themes – for example, one respondent's response was "Sight. Smell. Hearing. Speaking." This response was assigned to themes 4 (communication) and 18 (sensory).

Minor amendments to the definitions of the themes were made at various points during the data analysis. These were all discussed and agreed by the relevant members of the study team.

Sensory deprivation (particularly vision and hearing) and mental health (referred to either in general terms or with reference to a specific condition such as dementia) were the aspects of health most commonly mentioned by respondents. Other frequently mentioned aspects included the ability to communicate and the ability to form and engage in relationships. There were 10 mentions of non-health outcomes that may result from ill health, such as one's financial situation.

Table 2. Themes used for coding of open-ended responses to task 4 and number of responses assigned to each theme (with examples)

No.	Theme name	Theme description	No. responses assigned to theme	Examples
1	Absence of illness or unspecified other illnesses	General references absence or presence of other illness, or needing medical attention	21	"Chronic illness" "Disease"
2	Balance	Reference to balance issues	1	"Having bad balance"
3	Cancer	Reference to cancer	10	"Cancer"
4	Communication	Reference to communication	15	"Ability to communicate" "Speech"
5	Cardiovascular disease	Reference to CVD-related conditions	4	"Stroke"
6	Dexterity	Reference to dexterity issues	1	"Dexterity – ability to pick up and handle"
7	Epilepsy	Reference to epilepsy or fits	2	"Epilepsy"
8	Gastroenterological and urological	Reference to gastro or urological conditions	4	"Incontinence"
9	Immune	Reference to immune system	1	"Immune systems"
10	Independence	Reference to health-related independence	5	"Everyone wants to be able to look after themselves"
11	Infertility	Reference to (in)fertility	1	"Infertility"
12	Lifestyle and fitness	Reference to lifestyle and fitness issues e.g. smoking, being overweight	13	"Weight and fitness" "Diet. Exercise. Smoking."
13	Mental health	Reference to:		
13a	a) General / unspecified	a) mental health generally	29	"Mental health"
13b	b) Happiness, wellbeing and emotional health	b) happiness, wellbeing and/or emotional health	15	"Emotional wellbeing" "Self-esteem"
13c	c) Specific mental health conditions	c) specific mental health conditions and/or disorders that affect mental or cognitive functioning	28	"Dementia" "Stress" "Autism"
14	Non-health outcomes	Reference to non-health outcomes e.g. ability to work, financial security	10	"Work – employment" "Financial stability"
15	Other	Unintelligible responses or responses that do not fit into the other categories	11	"Having a very high pain threshold" "Quality of each aspect"
16	Relationships	Reference to relationships, loneliness and sociability	15	"Personal relationships, family and friends" "Feeling part of society"
17	Respiratory illness	Reference to respiratory health and asthma	6	"Asthma"
18	Sensory	Reference to sensory deprivation	50	"Vision, hearing" "Loss of any senses"
19	Sexual function	Reference to sex	1	"Sex"
20	Skin	Reference to skin	1	"Dermatological problems"
21	Spirituality	Reference to spiritual health	6	"Spiritual health"
22	Tiredness	Reference to tiredness, vitality or sleep	4	"Energy levels"

Discussion

The results of this study can be compared to those of Devlin et al. [29], who asked similar questions to respondents in New Zealand as part of a postal questionnaire. In that study, 29% of respondents suggested aspects of health not covered by EQ-5D that they considered to be important. Common responses (aside from miscellaneous concerns and specific health conditions) included: "fitness", "happiness", "spiritual and emotional health" and "mental health and cognition". The authors report notably fewer responses related to communication and sensory capacities than in the present study, but in many other respects the results of the studies were quite similar. Devlin et al. noted that in their data a "holistic view of health emerges quite strongly – the idea that health is more than the absence of problems, consistent with the WHO definition of health" (p.1275) – this is reflected in some of the responses to task 1 in the present study (Appendix II). Regarding mental health, Connell et al. carried out interviews with people with mental health conditions and found that the dimensions included on generic measures, including EQ-5D, did not cover the domain space well given the wide-ranging impacts of the conditions [30].

Generic measures, such as EQ-5D, have an important role to play and are well established in the measurement of health status. They facilitate comparisons between treatments and disease areas for the purpose of economic evaluation, and are increasingly used to measure population health and health gain in patients undergoing routine operations. The findings of this study provide valuable insights into the EQ-5D descriptive system by highlighting those areas where further evaluation would be beneficial.

To some extent, the findings of this study support the choice of areas in which exploratory bolt-on work has been conducted to date, namely sensory deprivation [23] and mental health/cognition [16,31]. The other aspects of health mentioned by respondents may inform the agenda for future bolt-on research. Some of the aspects also reflect areas of health where condition-specific preference-based measures have been developed as an alternative to generic instruments. Examples include EORTC-8D for cancer [32], DEMQOL-U for dementia [33] and CORE-6D for general mental health [34].

This research has identified common areas that general public respondents perceive as missing from the EQ-5D classification system. Many respondents cited specific medical conditions rather than generic health dimensions in their responses. This is consistent with the findings of van Dalen et al., who found that the biomedical dimension of health was considered important by people, regardless of whether they were considering health

in themselves or in others, or good or poor health [9]. The design of our study did not allow for probing or detailed questioning of the rationales behind respondents' responses (for example, to understand whose health they were thinking about).

Further qualitative research is required to establish the potential impacts on health that people associate with specific conditions. For example, "cancer" (mentioned on 10 occasions in the task 4 responses) has a variety of potential impacts including (treatment-related) fatigue and the effects on emotional health of a terminal diagnosis. Condition-specific measures are able to provide a more detailed profile of these impacts. Both condition-specific and generic instruments can be used alongside each other to provide a detailed profile of an individual's health whilst allowing for comparability across conditions.

Further quantitative research is also required to establish how important the identified themes are relative to the EQ-5D dimensions (which themselves differ in importance across different health areas); and whether and what people would be willing to trade for improvements in the dimensions not currently included in the EQ-5D. Exploratory work has tested the impact of adding a bolt-on dimension, and on how it interacts with existing dimensions [14]. It is likely that this would differ depending on the dimension added.

The methods used by the study team to organise and code the responses into different themes appear to be feasible for analysing these kinds of qualitative data. The level of agreement between team members was high, with the majority of responses (74.1% of task 1 responses; 70.4% of task 4 responses) assigned to the same themes by two team members independently at step III. Agreement about the coding of all responses was reached by step V.

Some limitations of the study should be mentioned. Although steps were taken to minimise bias (such as having different team members code the responses independently in the first instance), our approach necessarily involved subjective judgement. Different researchers might have interpreted the responses differently. For example, we assigned mentions of dementia to the "Specific mental health conditions" theme on the grounds that it is characterised by mental and cognitive impairment. An alternative approach would be to include a separate theme to cover dementia. The subjective judgement involved in these kinds of decisions means that any attempt to judge a theme that appears more often as being "more important" should be treated with a degree of caution.

The study sought only views of the general public, many of whom were in good health (as indicated by the distribution of self-reported EQ-VAS ratings) and claimed to have no

experience of serious illness in themselves. Other potentially relevant groups, such as clinicians and patients, were not involved. Since the EQ-5D is intended to include dimensions that are "relevant to patients across the spectrum of conditions, as well as to the general population" [4], it would be informative to undertake a similar study with a sample comprising patients with high-prevalence conditions.

The results may have been influenced by a type of ordering effect. The tasks described in this paper were completed by respondents *after* they had completed a series of health state valuation tasks (in which they became familiar with the EQ-5D dimensions and encountered the concepts of "full health" and/or 11111). The findings of this study might have differed had the respondents been asked to consider the dimensions 'cold' – and indeed, the results of the valuation tasks might also have differed had the follow-up tasks instead been included as warm-up or 'priming' tasks.

Conclusions

Respondents in our survey identified several aspects of health that they considered to be important but not covered by the EQ-5D descriptive system, with those related to sensory deprivation and mental health mentioned most often. We hope that this study can provide a basis for more detailed qualitative and quantitative research to inform further review of the EQ-5D descriptive system.

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Appendix I: Follow-up questionnaire

Task 1

Please look at the following two health descriptions.

No problems in walking about
No problems washing or dressing yourself
No problems doing your usual activities
No pain or discomfort
Not anxious or depressed

Full Health

Do you consider these descriptions to be the same as each other?

☐ Yes   ☐ No

If no:

Please explain what you think makes them different from each other
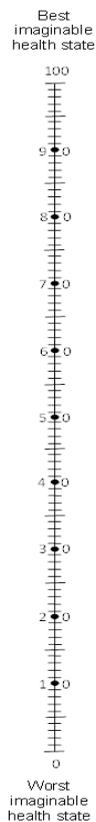
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Task 2

Please look at the following health descriptions and rank them on the scale below in order from best to worst (where 0 is the worst health imaginable and 100 is best health imaginable).

To do this, please write the letter in the right hand corner of the health description on the scale below next to the number that you want to give to that description

Health states can be ranked the same.

No problems in walking about **No** problems washing or dressing yourself **No** problems doing your usual activities **No** pain or discomfort **Not** anxious or depressed **A**

Full Health   **B**

No problems in walking about **No** problems washing or dressing yourself **Slight** problems doing your usual activities **No** pain or discomfort **Not** anxious or depressed **C**

Moderate problems in walking about **Severe** problems washing or dressing yourself **No** problems doing your usual activities **Extreme** pain or discomfort **Extremely** anxious or depressed **D**

Best
imaginable
health state

100

9 0

8 0

7 0

6 0

5 0

4 0

3 0

2 0

1 0

0

Worst
imaginable
health state

Task 3

Please look at the following health descriptions.

Health description	Rank
Full health	
Perfect health	
No health problems	
Best imaginable health	
No problems in walking about **No** problems washing or dressing yourself **No** problems doing your usual activities **No** pain or discomfort **Not** anxious or depressed	
Healthy	

- Which of the above would you most want to live in? Please write a number 1 in the appropriate box.

- Which of the above would you least like to live in? Please write a number 6 in the appropriate box.

- Please rank the other descriptions in the order that you would want to live in them (from 2 to 5).

Task 4

Consider the following dimensions:

> **Mobility** – Ability to walk about
>
> **Self-care** – Ability to wash or dress yourself
>
> **Usual Activities** – Ability to do usual activities
>
> **Pain or discomfort** – Level of pain or discomfort
>
> **Anxiety or depression** – Level of anxiety or depression

Are there aspects of **health** that are not included above that you consider to be important? If yes, what are they?

☐ Yes   ☐ No

_____

_____

_____

_____

_____

Task 5

Are there aspects of **quality of life** that are not included above that you consider to be important? What are they?

☐ Yes   ☐ No

_____

_____

_____

_____

_____

Appendix II: Responses to tasks 1, 2, 3 and 5

Task 1: Are 11111 and full health "the same as each other"

When asked whether they considered 11111 and full health to be the same as each other, 305 respondents (70.0%) answered "Yes".

The 131 respondents who answered "No" were then asked to explain what makes 11111 and full health different from each other. One-hundred and thirty-nine responses were provided, with a small number of respondents providing explanations that could be separated into multiple distinct responses. After familiarising themselves with the data, the study team identified six themes (Table 2) and set out to assign each response to one or more of those themes.

BM and LL first coded the responses independently of each other (assigning each response into one of the six themes and providing a short written justification). One-hundred and nine of the 139 responses (74.1%) were assigned to the same theme by both authors. Following discussion between BM and LL and examination of each other's justifications, agreement was reached about 132 of the 139 responses (95.0%). The views of a third author, KS, were sought regarding the remaining seven responses. KS was able to make a decision about all seven responses. In all cases, KS chose a theme that had initially been proposed by either BM or LL.

Comments suggesting that the five EQ-5D dimensions are not exhaustive of all conditions and health problems were made most frequently, accounting for 50 of the 139 responses (Table 2). Another common theme comprised comments that suggested that people with medical conditions with mild or no apparent symptoms could nevertheless be considered to be in a state of less than full health.

Table 2. Themes used for coding of open-ended responses to task 1 (what makes 11111 and full health different)

No.	Theme name	No. responses assigned to theme	Theme description	Examples
1	Asymptomatic or mild disease	31	People with an illness may have no/few symptoms or may not be in need of health care. This could be due to the mildness of their condition or the absence of symptoms.	"Could have a tumour without having symptoms" "You can have a condition that can affect your life but not in a bad way, but you are not in full health."
2	Five dimensions not exhaustive of all conditions	50	Some conditions affect health dimensions not covered by the five EQ-5D dimensions. This could be stated either in general terms or in reference to specific conditions/dimensions not covered (e.g. vision problems).	"The left-hand side does not mention all faculties, e.g. sight, hearing, mental." "You can have respiratory problems and still be able to do the above."

No.	Theme name	No. responses assigned to theme	Theme description	Examples
3	Physicality and Fitness	10	People in state 11111 may not be ill but could be fitter or more physically active, and so are not necessarily in "full health".	"Full health implies no illness and fully fit rather than just 'no problems'." "You may be able to walk next to a person but when running together there may be a difference in distance and speed."
4	Wellbeing	27	The five dimensions do not capture wellbeing, quality of life, spirituality or lifestyle aspects.	"Health isn't just the absence of illness or injury, it is a state of wellbeing." "Full health is a collection of factors - physical, psychological and social wellbeing. Someone can have everything on the left-hand side of the list and still not be in full health because of loneliness."
5	Same	3	Full health and 11111 are the same as each other.	"They are similar."
6	Other	18	Responses that are unintelligible, do not fit into the other categories, or do not contain enough information to allow categorisation.	"Because it doesn't ask about or mention any past problems."

Task 2: Visual analogue scale rating of 11111 and full health

374 respondents (85.8%) gave full health a rating of 100 (mean rating: 98.6; standard deviation: 4.3). By contrast, 253 respondents (58.2%) gave 11111 a rating of 100 (mean rating: 95.1; standard deviation: 7.8). Respondents who had previously stated that they considered 11111 and full health to be the same as each other were statistically significantly more likely to have given the same rating to both descriptors (chi-squared test; $p<0.01$).

Task 3: Ranking of six health state descriptions

Of the six health state descriptions included in the ranking task, "perfect health" was most often ranked as the state that respondents most wanted to live in (ranked best or joint-best by 60.5% of respondents). Full health and 11111 were ranked best or joint-best by 42.7% and 20.9% of respondents, respectively.

Table 3 shows how many times each health state was ranked best or joint-best.

Table 3. Summary of responses to task 3 (ranking of six health states according to how much respondents would want to live in them)

Health state description	N (%) ranking health state as best or joint-best	Mean rank
Perfect health	264 (60.6%)	1.64
Full health	186 (42.7%)	2.00
Best imaginable health	151 (34.6%)	2.88
No health problems	108 (24.8%)	3.02
11111	91 (20.9%)	4.15
Healthy	85 (19.5%)	3.77

Task 5: Important aspects of quality of life not captured by the five EQ-5D dimensions

Two-hundred and four respondents (46.8%) provided text responses when asked whether there were aspects of quality of life they considered important but were not covered by the five EQ-5D dimensions. The majority of those respondents (67.6%) had also provided text responses in task 4. Commonly mentioned aspects of quality of life included relationships, loneliness, happiness and living conditions.