

***Title***

Views of the UK general public on important aspects of health not captured by EQ-5D

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## **Abstract**

**Introduction:** The EQ-5D is a standardised 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. However, the five dimensions may not fully capture the health-related impacts of certain conditions. This study analyses the views of the UK general public about important aspects of health considered to be missing from the instrument.

**Methods:** Survey respondents were asked whether there are any aspects of health they consider to be important but are not captured by the EQ-5D, and if so, what these aspects of health are. The responses (text comments) were analysed using content analysis with analyst triangulation. Data were collected from a broadly representative sample of the general public via a paper questionnaire administered as part of face-to-face interviews.

**Results:** Data are available for 436 respondents, 179 of whom suggested aspects of health they considered important but not captured by the five EQ-5D dimensions. These were organised into 22 themes. Sensory deprivation and mental health were the aspects of health most commonly mentioned by respondents.

**Conclusions:** Respondents identified several important aspects of health that are not covered by the EQ-5D descriptive system. The study can provide the basis for more detailed qualitative and quantitative research – in particular, to examine the views of different patient groups – to inform further review of the EQ-5D descriptive system. The results also have implications for the sensitivity of other generic measures.

### **Key points for decision makers**

Views were sought from the UK general public about important aspects of health considered to be missing from the EQ-5D health outcome measure.

Twenty-two themes emerged from the responses, reflecting the brief nature of the EQ-5D.

Sensory deprivation and mental health were the aspects of health most commonly mentioned by respondents.

## **1. 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 patients, populations and population groups [4]. According to Williams [5], the EQ-5D was intended to provide information about a "common core" of dimensions that are known to be relevant across a range of conditions, and that represent people's salient concerns about health. 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" (for example, work, study, housework) 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 on affected patients. 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 (that is, a state describing "no problems" on any of the five EQ-5D dimensions; see task 1 in supplementary appendix I) and "full health". The primary results of that study are reported elsewhere [24].

## **2. Methods**

### **2.1. 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. The interviewers' role was to provide instruction and guidance as the respondents completed the tasks. Details of the sample recruitment process are reported elsewhere [24]. The survey was approved by the Ethics Committee of the University of Sheffield's School of Health and Related Research (approval reference: 0711KW).

### **2.2. Survey instrument**

Respondents first completed a valuation questionnaire. The purpose of the valuation questionnaire was to obtain numeric "values" reflecting the strength of respondents' preferences for different EQ-5D-5L health states, as necessary to facilitate the use of EQ-5D-5L data in economic evaluation. 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), in which respondents gave a rating to each description using a 0-to-100 scale where 0 represented "worst imaginable health state" and 100 represented "best imaginable health state";
3. ranking task in which respondents were asked to rank six health state descriptions (full health, perfect health, no health problems, best imaginable health, 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 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 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 online supplementary appendix I. In this paper, we analyse the responses to task 4. Responses to the other tasks are briefly summarised in online supplementary appendix II.

### **2.3. Methods of analysis**

Responses to task 4 (text comments) were analysed using a 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.

## **3. 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; and more likely than average to be married and/or retired.

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 about here>

When asked whether there were aspects of health they considered important but were not covered by the five EQ-5D dimensions, 177 respondents (40.6%) answered "Yes" and the remaining 259 (59.4%) answered "No". In response to the open-ended question that followed, text responses were provided by 179 respondents (41.1%; all of the 177 respondents who initially answered "Yes" and two of the respondents who initially answered "No"). The two groups were very similar in terms of observable background characteristics, though respondents who provided text responses in task 4 were more likely to be have a degree than respondents who did not (Table 1).

After familiarising themselves with the data, the study team sought to identify common themes. LL initially proposed 21 themes. Following group discussion and deliberation, some themes were split (for example, an initial theme of "dexterity/balance" was split into two separate themes) and others were combined; though most of LL's proposed themes were kept unchanged. This process resulted in 22 themes (see Table 2, which includes examples of the responses provided). The study team then 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. The theme labelled "Other" was used to capture responses that were unintelligible or did not fit into the other themes, and did not contain enough information to allow meaningful categorisation.

<Table 2 about here>

## **4. Discussion**

This study used a survey to obtain the views of a UK general public sample about aspects of health they consider to be important but are not captured by the five EQ-5D dimensions. Twenty-two themes were identified in the response data, with aspects relating to sensory deprivation and mental health mentioned most frequently.

The results 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 investigation 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. However, it is worth noting that further work is required to investigate the valuation of bolt-on dimensions, as the addition of a bolt-on may affect a given respondent's preferences for the existing EQ-5D dimensions. It is therefore unclear how a disutility for a bolt-on dimension should be incorporated into existing value sets to facilitate the use of this information in economic evaluation. 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].

The results also have implications for the scope and use of other generic preference-based measures such as the Short-Form 6-Dimension (SF-6D) [35,36] and the Health Utility Index Mark 3 (HUI-3) [37]. The SF-6D is derived from the SF-36, which is based on the WHO definition of health and includes dimensions measuring physical functioning, role functioning, social functioning, pain, mental health and vitality. There is clear overlap between the SF-6D and the EQ-5D, and many of the concepts raised by respondents as missing from the EQ-5D are also not covered explicitly by the SF-6D (a notable exception being vitality). By contrast, the HUI-3 was developed following a "within-the-skin" approach [38] and includes dimensions measuring vision, hearing, speech, ambulation, dexterity, emotion, cognition and pain. The HUI-3 has less overlap with the EQ-5D than the SF-6D, and a number of the aspects suggested by respondents in this study, such as sensory issues, are included in the HUI-3 descriptive system. On the other hand, dimensions measuring social functioning, which were also found to be important to respondents, are not included in the HUI-3. Differences in which dimensions are included and how included dimensions are described may influence the choice of

measure to be used in a given research study. The HUI-3 may be useful in a condition where sensory issues are important, perhaps alongside the EQ-5D to allow for a more holistic measurement of the impacts of the condition. The SF-6D may be useful for some mental disorders because of the ways in which it differs from EQ-5D in terms of how it measures mental health problems.

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. It would be useful to understand which specific health impacts people think of as important when they refer to broadly defined disease areas, such as cancer. Many of these may be captured by condition-specific measures that are able to provide a more detailed profile of the 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. For practical reasons, 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). Hence, while the majority of respondents did not nominate any important aspects of health beyond those covered by the EQ-5D dimensions, it is acknowledged that the findings might have differed had the respondents been asked to consider the dimensions 'cold' (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). The fact that the follow-up tasks appeared at the end of an interview involving many different cognitively demanding exercises meant some respondents may have experienced fatigue, which may have reduced their inclination to engage in the later tasks with the same level of attention that they had given the earlier tasks. Respondents wishing to complete the interview as quickly as possible may have answered "No" to the initial question in task 4 in order to avoid having to answer the second question. This would have led to an underestimation of the number of important aspects of health that are not captured by the EQ-5D.

Potential avenues for future research could be to ask people for their views about the EQ-5D dimensions without familiarising them with the EQ-5D instrument in preceding tasks; or to ask people to nominate important aspects of health without presenting the

EQ-5D dimensions as a starting point (to see whether they suggest similar aspects of health unprompted).

## **5. 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 – in particular, to examine the views of different patient groups – to inform further review of the EQ-5D descriptive system.

## REFERENCES

1. Grad FP. The Preamble of the Constitution of the World Health Organization. *Bulletin of the World Health Organization* 2002;80(12):982.
2. Huber M, Knottnerus JA, Green L, van der Horst H, Jadad AR, Kromhout D, Leonard B, Lorig K, Loureiro MI, van der Meer JW, Schnabel P. How should we define health? *BMJ* 2011;26:343.
3. Jadad AR, O'Grady L. How should health be defined? *BMJ* 2008;337:a2900.
4. Gudex C. The descriptive system of the EuroQol Instrument. In: Kind P, Brooks R, Rabin R., eds., *EQ-5D concepts and methods: a developmental history*. Dordrecht: Springer; 2005.
5. Williams A. The EuroQol Instrument. In: Kind P, Brooks R, Rabin R. (eds) *EQ-5D concepts and methods: a developmental history*. Dordrecht: Springer; 2005.
6. Janssen MF, Birnie E, Haagsma JA, Bonsel GJ. Comparing the standard EQ-5D three-level system with a five-level version. *Value in Health* 2008;11:275-84.
7. Karimi M, Brazier J. Health, health-related quality of life, and quality of life: what is the difference? *Pharmacoeconomics* 2016;34:645-649.
8. Brooks R. *Health status measurement: a perspective on change*. Hampshire: Macmillan Press Ltd, 1995.
9. van Dalen H, Williams A, Gudex C. Lay people's evaluations of health: are there variations between different subgroups? *Journal of Epidemiology and Community Health* 1994;48:248-53.
10. Janssen MF, Lubetkin EI, Sekhobo JP, Pickard AS. The use of the EQ-5D preference-based health status measure in adults with Type 2 diabetes mellitus. *Diabetic Medicine* 2011;28(4):395-413.
11. Mulhern B, Meadows K. The construct validity and responsiveness of the EQ-5D, SF-6D and Diabetes Health Profile-18 in Type 2 diabetes. *Health and Quality of Life Outcomes* 2014;12(42).
12. Marra CA, Woolcott JC, Kopec JA, Shojania K, Offer R, Brazier JE, Esdaile JM, Anis AH. A comparison of generic, indirect utility measures (the HUI2, HUI3, SF-6D, and the EQ-5D) and disease-specific instruments (the RAQoL and the HAQ) in rheumatoid arthritis. *Social Science and Medicine* 2005;60:1571-82.
13. Pickard AS, Wilke CT, Lin HW, Lloyd A. Health utilities using the EQ-5D in studies of cancer. *Pharmacoeconomics* 2007;25(5):365-84.
14. Longworth L, Yang Y, Young T, Mulhern B, Hernandez-Alava M, Mukuria C, Rowen D, Tosh J, Tsuchiya A, Evans P. Use of generic and condition specific measures of health related quality of life in NICE decision making: systematic review, statistical modelling and survey. *Health Technology Assessment* 2014;18(9).

15. Espallargues M, Czoski-Murray CJ, Bansback NJ, Carlton J, Lewis GM, Hughes LA, Brand CS, Brazier JE. The impact of age-related macular degeneration on health status utility values. *Investigative Ophthalmology & Visual Science* 2005;46(11):4016-23
16. Krabbe PFM, Stouthard ME, Essink-Bot ML, Bonsel G. The effect of adding a cognitive dimension to the EuroQol multiattribute health-status classification system. *Journal of Clinical Epidemiology* 1999;52(4):293-301.
17. Kaarlola A, Pettilä V, Kekki P. Performance of two measures of general health-related quality of life, the EQ-5D and the RAND-36 among critically ill patients. *Intensive Care Medicine* 2014;30(12):2245-52.
18. Mulhern B, Mukuria C, Barkham M, Knapp M, Byford S, Soeteman D, Brazier J. Using preference based measures in mental health conditions: the psychometric validity of the EQ-5D and SF-6D. *British Journal of Psychiatry* 2014;205(3):236-243.
19. Herdman M, Gudex C, Lloyd A, Janssen MF, Kind P, Parkin D, Bonsel G, Badia X. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Quality of Life Research* 2011;20(10):1727-36.
20. Janssen MF, Pickard AS, Golicki D, Gudex C, Niewada M, Scalone L, Swinburn P, Busschbach J. Measurement properties of the EQ-5D-5L compared to the EQ-5D-3L across eight patient groups: a multi-country study. *Quality of Life Research* 2013;22(7):1717-27.
21. Agborsangaya CB, Lahtinen M, Cooke T, Johnson JA. Comparing the EQ-5D 3L and 5L: measurement properties and association with chronic conditions and multimorbidity in the general population. *Health and Quality of Life Outcomes* 2014;12(74).
22. Swinburn P, Lloyd A, Boye KS, Edson-Heredia E, Bowman L, Janssen B. Development of a disease-specific version of the EQ-5D-5L for use in patients suffering from psoriasis: lessons learned from a feasibility study in the UK. *Value in Health* 2013;16(8):1156-62.
23. Yang Y, Rowen D, Brazier J, Tsuchiya A, Young T, Longworth L. An exploratory study to test the impact on three "bolt-on" items to the EQ-5D. *Value in Health* 2015;18(1):52-60.
24. Shah K, Mulhern B, Longworth L, Janssen MF. An empirical study of two alternative comparators for use in time trade-off studies. *Value in Health* 2016;19:53-9.
25. Oppe M, Devlin NJ, van Hout B, Krabbe PF, de Charro F. A program of methodological research to arrive at the new international EQ-5D-5L valuation protocol. *Value in Health* 2014;17:445-53.

26. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qualitative Health Research* 2005;15(9):1277-88.
27. Patton MQ. Enhancing the quality and credibility of qualitative analysis. *Health Services Research* 1999;34(5 Part 2):1189-208.
28. Office for National Statistics. Census: Digitised Boundary Data (England and Wales) [computer file]. UK Data Service Census Support; 2011. Available from: <http://edina.ac.uk/ukborders> [Accessed October 23, 2014]
29. Devlin NJ, Hansen P, Selai C. Understanding health state valuations: a qualitative analysis of respondents' comments. *Quality of Life Research* 2004;13(7):1265-77.
30. Connell J, O'Cathain A, Brazier J. Measuring quality of life in mental health: Are we asking the right questions? *Social Science and Medicine* 2014;120:12-20.
31. Janssen MF, Krabbe PFM, Lamers L, Oppe M, Stolk E, Vermeulen K, van Hout B. The Cognition dimension revisited: a detailed study on its added value and interactions with EQ-5D core dimensions. Paper presented at the EuroQol Plenary Meeting, Montreal; 2013.
32. Rowen D, Brazier J, Young T, Gaugris S, King M, Craig B, Velikova G. Deriving a preference based measure for cancer using the EORTC QLQ-C30. *Value in Health* 2011;14(5):721-31.
33. Mulhern B, Rowen D, Brazier J, Smith S, Tait R, Watchurst C, Chua KC, Loftus V, Young TA, Lamping D, Knapp M, Howard RJ, Banerjee S. Development of DEMQOL-U and DEMQOL-Proxy-U: Generation of preference based indices from DEMQOL and DEMQOL-Proxy for use in economic evaluation. *Health Technology Assessment* 2013;17(5).
34. Mavranezouli I, Brazier JE, Rowen D, Barkham M. Estimating a preference-based index from the Clinical Outcomes in Routine Evaluation-Outcome Measure (CORE-OM): valuation of CORE-6D. *Medical Decision Making* 2013;33(3):381-95.
35. Brazier J, Roberts J, Deverill M. The estimation of a preference-based measure of health from the SF-36. *Journal of Health Economics* 2002;21:271-92.
36. Brazier JE, Roberts J. Estimating a preference-based index from the SF-12. *Medical Care*. 2004;42(9):851-59.
37. Horsman J, Furlong W, Feeny D, Torrance G. The Health Utilities Index (HUI®): concepts, measurement properties and applications. *Health and Quality of Life Outcomes* 2003;1:54.
38. Ware JE, Brook RH, Davies AR, Lohr KN. Choosing measures of health status for individuals in general populations. *American Journal of Public Health* 1981; 71(6):620-625.

**Table 1. Sample background characteristics**

	<b>Respondents who suggested aspects of health in task 4 (N=179)</b>	<b>Respondents who did not suggest aspects of health in task 4 (N=257)</b>	<b>Total sample (N=436)</b>	<b>General population <sup>a</sup></b>
Age				
18-29	29 (16.2%)	46 (17.9%)	75 (17.2%)	20.7%
30-44	40 (22.4%)	55 (21.4%)	95 (21.8%)	26.3%
45-59	50 (27.9%)	59 (23.0%)	109 (25.0%)	24.7%
60-74	45 (25.1%)	81 (31.5%)	126 (28.9%)	18.5%
75+	15 (8.4%)	16 (6.2%)	31 (7.1%)	9.9%
Gender				
Female	102 (57.0%)	151 (58.8%)	253 (58.0%)	49.2%
Male	77 (43.0%)	106 (41.3%)	183 (42.0%)	50.8%
Economic activity				
Employed or self-employed	86 (48.0%)	126 (49.0%)	212 (48.6%)	59.4%
Retired	55 (30.7%)	85 (33.1%)	140 (32.1%)	13.1%
Student	10 (5.6%)	11 (4.3%)	21 (4.8%)	8.8%
Looking after home or family	13 (7.3%)	15 (5.8%)	28 (6.4%)	4.2%
Other / none of the above	13 (7.3%)	20 (7.8%)	33 (7.6%)	14.5%
Missing	2 (1.1%)	0 (0.0%)	2 (0.5%)	
Marital status				
Single / never Married	27 (15.1%)	37 (14.4%)	64 (14.7%)	34.6%
Married or same-sex civil partnership	128 (71.5%)	177 (68.9%)	305 (70.0%)	46.8%
Separated or divorced <sup>b</sup>	13 (7.3%)	22 (8.6%)	35 (8.0%)	11.7%
Widowed <sup>c</sup>	7 (3.9%)	20 (7.8%)	27 (6.2%)	6.9%
Missing	4 (2.2%)	1 (0.4%)	5 (1.2%)	
Education				
Degree	96 (53.6%)	97 (37.7%)	193 (44.3%)	
No degree	81 (45.3%)	160 (62.3%)	241 (55.3%)	
Missing	2 (1.1%)	0 (0.0%)	2 (0.5%)	
Responsibility for children				
Yes	68 (38.0%)	85 (33.1%)	153 (35.1%)	
No	109 (60.9%)	172 (66.9%)	281 (64.5%)	
Missing	2 (1.1%)	0 (0.0%)	2 (0.5%)	
Experience of serious illness				
In self	62 (34.6%)	82 (31.9%)	144 (33.0%)	
In family	124 (69.3%)	158 (61.5%)	282 (64.7%)	
In caring for others	71 (40.0%)	95 (37.0%)	166 (38.1%)	
Self-reported health using EQ-5D-5L				
11111	93 (52.0%)	128 (49.8%)	221 (50.7%)	
Any other health state	86 (48.0%)	129 (50.2%)	215 (49.3%)	
Self-reported health using EQ-VAS				
<80	49 (27.4%)	76 (29.6%)	125 (28.7%)	
80-89	43 (24.0%)	53 (20.6%)	96 (22.0%)	



90-99	78 (43.6%)	96 (37.4%)	174 (39.9%)
100	9 (5.0%)	32 (12.5%)	41 (9.4%)

39. <sup>a</sup> General population data based on UK Census results (Office for National Statistics, 2011), where available

40. <sup>b</sup> 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

41. <sup>c</sup> Includes individuals who are the surviving partner from a same-sex civil partnership

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

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"

# 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.

<p><b>No</b> problems in walking about <b>No</b> problems washing or dressing yourself <b>No</b> problems doing your usual activities <b>No</b> pain or discomfort <b>Not</b> anxious or depressed</p> <p style="text-align: right;"><b>A</b></p>
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<p style="text-align: center;"><b>Full Health</b></p> <p style="text-align: right;"><b>B</b></p>
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<p><b>No</b> problems in walking about <b>No</b> problems washing or dressing yourself <b>Slight</b> problems doing your usual activities <b>No</b> pain or discomfort <b>Not</b> anxious or depressed</p> <p style="text-align: right;"><b>C</b></p>
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<p><b>Moderate</b> problems in walking about <b>Severe</b> problems washing or dressing yourself <b>No</b> problems doing your usual activities <b>Extreme</b> pain or discomfort <b>Extremely</b> anxious or depressed</p> <p style="text-align: right;"><b>D</b></p>
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Best  
imaginable  
health state



Worst  
imaginable  
health state

### Task 3

Please look at the following health descriptions.

Health description	Rank
<b>Full health</b>	<input type="text"/>
<b>Perfect health</b>	<input type="text"/>
<b>No health problems</b>	<input type="text"/>
<b>Best imaginable health</b>	<input type="text"/>
<b>No</b> problems in walking about <b>No</b> problems washing or dressing yourself <b>No</b> problems doing your usual activities <b>No</b> pain or discomfort <b>Not</b> anxious or depressed	<input type="text"/>
<b>Healthy</b>	<input type="text"/>

- 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:

<p><b>Mobility</b> – Ability to walk about</p> <p><b>Self-care</b> – Ability to wash or dress yourself</p> <p><b>Usual Activities</b> – Ability to do usual activities</p> <p><b>Pain or discomfort</b> – Level of pain or discomfort</p> <p><b>Anxiety or depression</b> – Level of anxiety or depression</p>
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Are there aspects of **health** that are not included above that you consider to be important? If yes, what are they?

Yes       No

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## 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

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## 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
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### **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.