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Improving the measurement of QALYs in Dementia: Developing patient- and carer-reported health state classification systems using Rasch analysis

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Abstract

Objectives: Cost-utility analysis is increasingly used to inform resource allocation. This requires a means of valuing health states before and after intervention. Although generic measures are typically used to generate values, these do not perform well with people with dementia. We report the development of a health state classification system amenable to valuation for use in studies of dementia, derived from the DEMQOL system, a measure of health-related quality of life in dementia by patient self-report (DEMQOL) and carer proxy-report (DEMQOL-Proxy).

Methods: Factor analysis was used to determine the dimensional structure of DEMQOL and DEMQOL-Proxy. Rasch analysis was subsequently used to investigate item performance across factors in terms of item-level ordering, functioning across subgroups, model fit and severity-range coverage. This enabled the selection of one item from each factor for the classification system. A sample of people with a diagnosis of mild/moderate dementia (n=644) and a sample of carers of those with mild/moderate dementia (n=683) were used.

Results: Factor analysis found different 5-factor solutions for DEMQOL and DEMQOL-Proxy. Following item reduction and selection using Rasch analysis, a 5-dimension classification for DEMQOL and a 4-dimension classification for DEMQOL-Proxy were developed. Each item contained 4 health state levels.

Conclusion: Combining Rasch and classical psychometric analysis is a valid method of selecting items for dementia health state classifications from both the patient and carer perspectives. The next stage is to obtain preference weights so that the measure can be used in the economic evaluation of treatment, care and support arrangements for dementia.

Introduction:

In the economic evaluation of emerging health technologies or interventions, it is common to employ cost-utility analysis using the cost per Quality-Adjusted Life Year (QALY) gained to inform the allocation of resources. QALYs are used to measure the impact of an intervention on both quality and quantity of life. Quality of life is measured using health state values which are scored using preference information gained either from a representative general population or relevant patient sample.

Generic preference-based measures (PBM) of health such as the EQ-5D [1, 2], SF-6D [3] and HUI3 [4] are widely used as a means of generating health state values for use in the calculation of QALYs [5]. PBMs include dimensions of health and related response levels that enable respondents to indicate the severity of the problem they may be experiencing. For example the EQ-5D includes a 5 dimension health state classification system (mobility, self-care, usual activities, pain/discomfort, anxiety/depression), each with three health state levels. Therefore the EQ-5D generates 243 health states, a selection of which have been valued to generate the preference weights used to calculate QALYs [2].

'Dementia' is a syndrome which may be caused by a number of illnesses in which there is progressive decline in multiple areas of function, including memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as agitation, aggression, wandering, shouting, repeated questioning, sleep disturbance, depression, and psychosis. Dementia not only has a major impact on those with the disorder, but also has profound, negative effects on family members who provide the majority of care. Family carers are often elderly and frail themselves and have high levels of carer burden, depression and physical illness, and decreased quality of life [6-8].

Dementia is a common disorder in later life with prevalence rates increasing rapidly with age; for example, the rate is less than 1% for those aged under 69, but rises to 30% for those over 90. According to the World Alzheimer Report [9], there are currently 36 million people with dementia worldwide; this number is projected to exceed 60 million by 2032, and 115 million by 2050. Among the consequences is a projected rapid rise in the costs of care, support and treatment. If expected trends in prevalence, staff costs and (unpaid) carer availability are overlaid onto England's current care system, total health and social care expenditure will more than treble over a 30-year period from £17 billion [10] to over £50 billion [11]. This highlights the strategic importance of dementia care, and also the need for valid PBMs enabling the assessment of treatment and services that are developed to target this enormous health and social care challenge.

There is debate around the extent to which generic PBMs fully capture aspects of quality of life associated with some medical conditions [12] and the validity of using generic PBMs in dementia is uncertain. It has been suggested that the EQ-5D does not sufficiently cover the impact of changes in cognitive functioning on quality of life [13, 14]. Although the cognitive challenges of dementia- including deficits in memory, insight, language and interpretation- would be expected to impact on an instrument's performance, there has been little validation of these generic instruments for this condition. A cognitive dimension has been developed for the EQ-5D, but utility values for the EQ-5D incorporating this component are not available [15]. Differences in response have also been found between people with dementia and family carers, with patients reporting higher utility scores than carer proxies' report [16, 17].

To increase the accuracy and validity of assessment there has been interest in developing PBMs from condition-specific measures in order to target medical conditions more effectively in terms of health-related quality of life (HRQL)[18]. This is because non preference based condition-specific measures are widely used in trials but cannot be used for cost-effectiveness analysis. The first stage of this is the development of a health state classification system amenable to valuation from an

existing condition-specific measure. This has recently been carried out for a range of conditions including overactive bladder syndrome [19], urinary incontinence [20], flushing symptoms [21], asthma [22] mental health problems [23]. The second stage is to value a set of the health states generated using a standardised preference elicitation technique. [24]

In response to the debate about the economic evaluation of dementia, we describe the first stage of the development of condition-specific PBMs for self-report by people with dementia and for proxy-report by carers. The first stage is to apply classical psychometric and Rasch analysis [25] to develop reduced health state classification systems from the self-report DEMQOL and the carer-report DEMQOL-Proxy [26, 27] that are amenable to valuation using a standard preference elicitation technique. Using Rasch alongside classical psychometric techniques is an accepted method of developing HRQL instruments [28]. Reduced classification systems are used as in their original form the DEMQOL and DEMQOL-Proxy contain too many items to carry out valuation. The analyses applied here to determine the dimensional structure of each instrument and subsequently to select one item for each dimension have been reported elsewhere [19, 22]. However, this study is the first to use this process to develop a classification system for dementia and also the first for a proxy-reported quality of life instrument.

Methods

The DEMQOL system:

The DEMQOL system was developed to generate a measure of HRQL for people with dementia using patient self-report and carer proxy-report [26, 27]. The system was designed to be used across different types of dementias, care arrangements, and levels of severity. The psychometric properties of the DEMQOL system have shown it to be both reliable and valid, and as such it provides a solid evidence basis for the development of a health state classification system for people with dementia by self- and proxy-report.

DEMQOL

DEMQOL was developed from a conceptual framework that includes health and well-being, cognitive functioning, social relationships, daily activities and self concept [29]. The instrument consists of 28 items answered on a 4-point Likert scale (a lot/quite a bit/a little/not at all) and administered by an interviewer using response cards. All items refer to the last week. Items are scored 1 to 4, generating a total score between 28 and 112, with higher scores indicative of better HRQL. Factor analyses during the development phase of the instrument were limited and not conclusive. However, a 4-factor solution was defined (daily activities, memory, positive emotion and negative emotion). The results of psychometric testing to date indicate that DEMQOL is acceptable for use for patients with mild or moderate dementia (defined by a Mini Mental State Examination (MMSE) [30] score ≥ 10 alongside a definite diagnosis of dementia).

DEMQOL-Proxy

DEMQOL-Proxy was developed from the same five dimension conceptual framework, with items worded for carers. It contains 31 items again scored 1 to 4 (score range 31 to 124) and is interviewer administered using response cards. All items refer to the last week. The proxy measure has been

validated across the full range of dementia severity. Factor analysis in the development phase was again limited but suggested a two-factor solution (functioning and emotion).

Dataset

The data used in this study is a large, clinically representative sample that has been aggregated from two sources: a sample of patients and carers attending a memory service in South London [31], and a sample of patients and carers from other community services in South London. Patients and carers completed the DEMQOL and DEMQOL-Proxy when they presented at the service as part of the diagnosis process. After excluding those in the memory service sample without a definite International Classification of Diseases (ICD-10) diagnosis of dementia (N=445), those with severe dementia (N=74), and those completing less than half the patient (N=151) and carer (N=112) measures, the sample sizes used for the Psychometric and Rasch analyses were N=644 for DEMQOL and N=683 for DEMQOL-Proxy. Among the people with mild or moderate dementia included in the analyses, 61% were female, 76% were White-British and the mean age was 78.8 (range 44 to 97) years. The mean age of the carer sample (who were carers of those with mild or moderate dementia) was 59.9 (range 27 to 88), 29% were the spouse of the person with dementia and 33% were their son or daughter. The gender of the carers is only available for those in the community service sample, and of this group 75% were female. The study was approved by the University of Sheffield ethics committee.

Analysis

The objective of the analysis was to derive from DEMQOL and DEMQOL-Proxy, respectively, multidimensional patient-reported and proxy-reported health state classifications. Our aim was to reduce the number of items included in the classification to one per dimension whilst retaining as

many of the dementia-related HRQL concepts included in the original measures as possible. This involves the analyses described in the following sections alongside input from the project team that includes clinicians, dementia experts and the original instrument developers. The item text and response options of the items selected for the classification system were then converted into health state levels to allow valuation. At this stage it is important to alter the text of the original item as little as possible so that responses can be clearly mapped onto the preference index. Factor analysis was carried out using SPSS version 16 [32] and Rasch analysis using Rasch Unidimensional Measurement Models (RUMM2020) [33].

Factor analysis:

Exploratory factor analysis was used to investigate the factor structure of both DEMQOL and DEMQOL-Proxy following the methods used in the original development of the DEMQOL instruments [26, 27]. This was done to further investigate the factor structure of the instruments on a larger sample than was used in the original validation study. A range of factor structures (from 2 to 10 factors) was investigated using principal axis factoring with varimax rotation. The analysis was also carried out with a view to reducing the number of items at this stage, as both non- and cross-loading items were removed from the factor structure. Factor loading is an indication of the strength of the correlation between the item and the factor, and items were defined as non-loaders if they did not load on any factor at a level of 0.4 or above. Cross-loaders were defined as items that loaded above 0.4 on more than one factor, with a difference of less than 0.2 between the two loadings [34].

Rasch analysis:

Rasch analysis [25] is a logit modelling technique that can be used to inform the selection of items from an existing condition-specific measure to generate a health state classification [19, 22]. Rasch analysis converts item responses into a continuous latent scale covering the full severity range, and

positions individual responses on the scale. Item responses are assumed to be a function of the location of both the person and the item on the logit scale. As the technique also assumes unidimensionality, Rasch was applied separately to each of the dimensions established by factor analysis. The following steps and criteria guided the selection of items for each domain.

Step 1: Item level ordering

First, the response ordering of individual items is investigated. Items are ordered if the observed response at any given point along the logit (i.e. severity) scale is in line with the expected response. If items are disordered it indicates that respondents cannot distinguish between response choices. If this is the case then adjacent response levels are collapsed and the item is no longer considered for inclusion in the health state classification.

Step 2: Examination of Differential Item Function (DIF)

The second stage is to check the items for the presence of DIF. This investigates whether item responses differ across patient characteristics when equal amounts of the underlying characteristic are present. There are two types of DIF, uniform and non-uniform. Uniform DIF occurs when groups consistently display a difference in response in the same direction across the full range of the construct being measured. Non-uniform DIF occurs when responses between groups systematically diverge depending on the level of the attribute present. The patient characteristics investigated for the DEMQOL instruments are gender and age (split into two groups, below 65 and 65 or above). Items where DIF occurs are split into component factors (for example a male and female sub group) and the Rasch model is refitted. Items displaying DIF are not considered for the health state classification.

Step 3: Goodness of fit to the Rasch model

The third stage is to investigate the goodness of fit of items to the Rasch model. This is done by assessing fit residuals and item trait interactions. Fit residuals estimate the amount of divergence between the expected and observed responses and are investigated for both respondents and items. Divergence residuals > l2.5l are considered high, so respondents outside of these levels are removed from the analysis. When all of the respondents fit the model, items are checked in the same way and items with residuals outside of the acceptable level are excluded from selection to the health state classification. The overall mean fit residual for both items and respondents should be approximately 0 and the standard deviation around 1. The item trait interaction measures overall differences between observed and expected responses for subgroups of responders (dependent on where responders lie on the logit scale). This implies that they are subgroups with similar severity levels of the construct being measured. Item trait interactions are measured using the $\chi 2$ test statistic which is > 0.01 for a well fitting model (i.e. non significant). Items with the highest overall difference are removed one by one until only well fitting items remain. This means that the overall goodness of fit statistic is non significant.

Step 4: Item selection

When all of the remaining items in each dimension are ordered, do not display DIF and fit the Rasch model, the Rasch results, along with classical psychometric techniques, are used to select an item for the health state classification. Item range on the logit scale and spread at logit 0 are used as the main criterion. A large range indicates that an item covers a fuller range of severity of the underlying construct being measured. It is also aimed at selecting an item that incorporates values both above and below 0 as this indicates that it covers both more severe and less severe cases respectively. Spread at logit 0 relates to the spread of response at the average item severity and

again a higher spread indicates better item coverage across the latent space. Item goodness of fit statistics are also used to guide selection, and classical psychometric analyses such as missing data, floor and ceiling effects are also considered.

Results

Factor analysis

Separate 5-factor structures for both the DEMQOL and DEMQOL-Proxy measures were established and these are displayed in Tables 1 and 2 below. The 5-factor structure for DEMQOL explained 45.5% of the variance in the model, with factors defined as: cognition, positive emotion, negative emotion, social relationships and loneliness. Four items did not load on any factor. The 5-factor structure for DEMQOL-Proxy explained 49.3%, with factors defined as: cognition, positive emotion, negative emotion, daily activities and appearance. Two items did not load on any factor and 6 items cross-loaded on 2 factors and so were removed. There are similarities across both factor structures in terms of cognition and positive and negative emotion but also key differences.

Rasch analysis and item selection

The item selection process for each factor of the DEMQOL and DEMQOL-Proxy is described below. Table 3 displays the overall goodness of fit to the Rasch model by dimension and Tables 4 and 5 display the item-by-item breakdown of the psychometric and Rasch analysis results for each dimension of DEMQOL and DEMQOL-Proxy respectively.

DEMQOL:

Cognition factor:

Of the six items included in this factor, all were ordered on the logit scale. None of the six items displayed DIF by gender or age group. After fitting the items to the Rasch model, only one item (17, "worry about thoughts being muddled") exhibited poor fit and was removed. This left five items available for selection. Items 15 ("worry about forgetting who people are"), 16 ("worry about forgetting what day it is") and 18 ("worry about difficulty making decisions") fitted the model well in terms of fit residuals and chi p-values. However, they also displayed the lowest range and spread at logit 0, so were not considered further. Of the remaining two items, item 14 ("worry about forgetting things that happened recently") was selected for the health state classification as it displays the largest range and spread and lowest ceiling effect of all the available items. It is also measuring a key characteristic of dementia, and is therefore a conceptually strong item to use in the classification system.

Negative emotion factor:

The response categories for all five items were ordered on the logit scale. Item 11 ("felt irritable") displayed uniform DIF by gender, with females scoring consistently higher across all points of the logit scale. Following this, it was split into male and female component factors and was no longer considered for the health state classification. No items displayed DIF by age group, and the four remaining items fitted the Rasch model. As the question stem for many of the items included in DEMQOL ask about how worried respondents have been about, for example, cognitive functioning and social relationships, item 2 which investigates general feelings of worry was excluded from further consideration to avoid double counting. The remaining items -- 4 ("felt frustrated"), 7 ("felt sad") and 12 ("felt fed up") -- display good range and spread at logit 0. Item 4 was selected as it has a relatively large $\chi 2$ p value, spread, performs better using the classical psychometric criteria and clinically it was felt to be the most valid in relation to dementia.

Positive emotion factor:

Rasch analysis of this factor shows that all of the items are ordered and none display either uniform or non-uniform DIF by gender or age group. Items 3 ("felt that you are enjoying life"), 6 ("felt full of energy") and 10 ("felt lively") cover a high range of the logit scale and have high spread at logit 0. However, these items were excluded as items 1 ("felt cheerful") and 5 ("felt confident") both displayed better range and spread and were felt to be clearer constructs that would provide a better overall classification for positive emotion. Of these items, both perform similarly using all criteria and there is little to choose between them. Item 1 was selected for the health state classification due to a concern that item 5 may pick up confidence as a personality trait rather than as a component of positive emotion.

Social relationships factor:

The item responses of three items: (21 ("worry about how you get on with people"), 22 ("worry about getting affection") and 25 ("worry about getting help") were disordered on the logit scale. Each was reordered in turn and the Rasch model refitted. However, these items are no longer under consideration for the health state classification. Item 26 ("worry about getting to the toilet on time") does not fit the model (p value < 0.01) so was also excluded. This left items 23 ("worry about people not listening to you") and 24 ("worry about making yourself understood") as potential items for inclusion. Neither item covers a large range or spread. Overall, however, item 24 covers more of the severe end of the logit scale, displays a better fit residual statistic and chi square value and so was selected for the health state classification.

Loneliness factor:

The response categories for both item 8 ("felt lonely") and 20 ("worry about not having enough company") are ordered and neither item displays DIF by gender or age group. Item 20 has higher spread at logit 0 but item 8 covers more of the severe end of the scale and also asks directly about loneliness rather than worry about an aspect of loneliness. For these reasons item 8 was selected for the health state classification.

DEMQOL-Proxy:

Cognition:

Of the nine items included in this factor, item 20 ("worry about making self understood") was disordered between 'quite a bit' and 'a lot', and was therefore not considered further. Item 12 ("worry about memory in general") displayed uniform DIF by age, with those below 65 consistently scoring lower than those aged 65 or above. The item was split into its component factors and not considered further. No items displayed DIF by gender. Items 14 ("worry about forgetting things that happened recently"), 15 ("worry about forgetting people's names"), 18 ("worry about thoughts being muddled") and 19 ("worry about difficulty making decisions") were excluded as they do not fit the Rasch model. Of the remaining items, 13 ("worry about forgetting things long ago") was thought to be investigating a problem that occurs late in the course of dementia so was excluded. Item 17 ("worry about forgetting what day it is") was felt to be more representative of the issues around memory and cognition in terms of proxy reporting than item 26 ("worry about things taking longer than they used to") and was therefore selected for the health state classification.

Negative emotion:

All five items are ordered on the logit scale and none display DIF by age group or gender. Item 9 ("felt irritable") did not fit the model, and so was excluded from further consideration. Item 2 ("felt worried") was also excluded due to the reasons mentioned earlier regarding the question stem of other worry items included on the proxy measure. Items 5 ("felt sad") and 10 ("felt fed up") were also excluded due to the possible focus on aspects of co-morbid depression which is prevalent in those with dementia [35, 36]. Of the remaining items, item 7 ("felt distressed") has poor spread, low item fit (p = 0.014), does not cover the more severe end of the scale and has large ceiling effects. Therefore item 3 ("felt frustrated") was selected. This is because it displays strong fit statistics and good range and spread. It is also repeated across both health state classifications (i.e. both DEMQOL and DEMQOL-Proxy).

Daily activities:

Item 23 ("worry about getting what he/she wants from the shops") displays disordering between quite a bit and a lot. Items 24 ("worry about using money") and 25 ("worry about looking after his/her finances") have poor fit to the model so no items remain for selection. It was therefore decided to omit this factor from the proxy health state classification.

Positive emotion:

All three items are ordered and none display DIF by age group or gender. However, item 11 ("felt that there are things to look forward to") does not fit the model. Of the remaining items -- Q4 ("felt full of energy") and Q8 ("felt lively") -- item 8 displays considerably higher range and spread and also better fit to the model so was selected for the health state classification.

Appearance:

The fit of item 21 ("worry about keeping self clean") is approaching significance (p = 0.044) and the item also displays lower range and spread than item 22 ("worry about keeping self looking nice"). Therefore as it performs better on all indicators, item 22 was selected.

Final health state classification systems:

The final health state classification systems that have been developed for DEMQOL and DEMQOL-Proxy following the item selection process are displayed in table 6. The DEMQOL descriptive system includes 5 dimensions. Each dimension has 4 health state levels that correspond to the response options used on the original instrument, and therefore means that the DEMQOL classification system generates a possible 1024 (i.e. 4^5) health states. The final DEMQOL-Proxy classification system contains 4 dimensions each with 4 health state levels and this allows a possible 256 (i.e. 4^4) health states to be generated.

Discussion:

This study reports the generation of condition-specific health state classification systems for dementia for patient self-report and carer proxy-report from two non-preference-based-measures, DEMQOL and DEMQOL-Proxy. It builds on methodology used by Brazier et al [20] and Young et al [19, 21, 22], and applies factor analysis and classical psychometric techniques alongside Rasch analyses to develop dementia-specific health state classification systems that are amenable to valuation. This is the first stage in developing a condition specific PBM that will be used to generate QALYs following the preference valuation of a selection of the health states generated by the classification systems.

Our re-analysis of the factor structure of DEMQOL and DEMQOL-Proxy, using large, clinically representative samples, suggests that both measures have interpretable domains that are amenable to the generation of health states. This is in contrast to the original validation study that found only minimal support for subscales [26, 27]. The difference may be due to the much larger sample used for this study. Although Mavranezouli et al [23] have used Rasch to generate health states from the CORE-OM measure of mental health, this is the first attempt to develop a classification system for an instrument measuring HRQL for a specific mental disorder.

This work is also the first attempt to derive a health state classification for proxy-report. The two classification systems are complementary but there are key differences which reflect some of the divergence in focus between patients and carers in terms of evaluating HRQL in dementia. For example, the inclusion of an appearance dimension on the proxy measure may reflect a carer's ability to observe the person with dementia or concerns about the patient's cleanliness, and this may not be shared by the patient. However, the inclusion across both measures of cognition and positive and negative emotion factors reflects the importance of cognitive functioning and mood both for the person with dementia and those involved in their care. At the item level, the proxy classification system dimensions are concepts that are clearly observable by carers, and may be

more observable than those selected for the patient measure with the exception of frustration which is included in both classification systems. Patients generally report higher or better HRQL than proxies [37], and some evidence suggests that agreement between patient and proxy report is higher for more observable aspects of HRQL such as physical mobility, but lower for more subjective domains such as emotional wellbeing [38]. The development of a proxy-specific health state classification where all of the dimensions and associated health state levels are meaningful to carers in terms of their everyday experiences may address some of the concerns about using generic measures as a means of proxy report in dementia and the differences that are found [16].

Previous research [19, 21] has demonstrated that using a combination of classical psychometric techniques and Rasch analysis is a feasible way of generating health states that are amenable to valuation and this has again been demonstrated here. Rasch analysis adapting the guidelines developed in this earlier work has facilitated the selection of items by quantifying their performance and therefore complements the classical psychometric analyses by adding a further level of complexity and rigor to the selection process. It has been demonstrated that it is possible to derive classification systems for specific mental disorders using the methodology described here. Further work may apply the methods to other mental health specific measures to subsequently enable the economic evaluation of new interventions for mental health using condition specific tools.

A limitation of this study is that the Rasch results have not been validated on a separate sample as has been done in previous studies using Rasch to generate health states [22]. Validation was not possible in this study as the sample size was not sufficient to randomly allocate responses to two subgroups. The optimum number required for Rasch analysis is 500 [39]. There are also concerns around the use of condition specific PBMs including the extent to which they capture co morbidities [40]. This issue may be addressed by investigating the performance of both the EQ-5D and the condition specific PBMs as part of the secondary analysis of dementia intervention trials.

Rasch analysis is only one of the advanced item response theory (IRT) techniques that may be used to select items for a health state classification. It may be possible for future work to investigate the health state classification systems generated using different IRT techniques, with a view to establishing whether different methods select different items and if so which are most representative of the condition-specific HRQL issues. Non-Rasch-based IRT methods have been used in the development of HRQL and clinical measures [41, 42], and have also informed the selection of items from existing instruments for a composite measure of global functioning in dementia [43]. However, the methods have not been used in the development of health state classification systems. It is also possible that Rasch selects items with the best statistics that may not be the most representative of quality of life for that dimension for either patient self-report or carer proxy-report. Clinical input during the selection process maximises face validity. Items with the strongest Rasch statistics may also not be valid for the health state classification. In this study the negative emotion item 'felt worried' displayed the best Rasch statistics for both instruments but could not be used as the wording used for other items meant that the classification system would have generated nonsensical health states.

The patient and carer health state classification systems should be reliable and valid for use with the relevant populations. This is because the data used for the development are representative of the population in which the instrument will be used as they were collected in memory and community services where many of the clients have mild to moderate dementia. Proxy-report by carers is an essential component of the evaluation of people with dementia [44], and administering measures in an interview setting with response cards (as done with the DEMQOL system) can also increase accuracy. The data also included demographic information that enabled us to investigate DIF characteristics and this helped to strengthen the item selection process [19].

Both the patient and carer measures cover a broad range of HRQL issues in dementia. The absence of activity limitation as a factor here is perhaps surprising. However the lack of association between

HRQL in dementia and activity limitation has been repeatedly reported [45]. Here the Rasch analysis found that the original daily activities items did not meet the minimum threshold for inclusion. In future research it may be possible to investigate additional dimensions that cover further areas of quality of life such as those related to daily activities. Another important limitation is that it has not been possible to consider responsiveness for DEMQOL and DEMQOL-Proxy in the consideration of the item selection for the health state classification. The ability to detect health state change over time is of central importance and so responsiveness needs to be addressed in future research that includes DEMQOL and DEMQOL-Proxy as outcome measures at multiple time points. Two large independent trials are underway (MRC-DOMINO [46] and HTA-SADD) which will enable these analyses to be completed.

In summary, we have developed two health state classifications amenable to valuation to measure dementia-specific HRQL by patient self- and carer proxy-report from a condition-specific instrument. Using well validated measures such as DEMQOL and DEMQOL-Proxy along with a representative sample of patients and carers suggests that the classification system should provide an appropriate representation of HRQL in dementia. The next stage is to obtain preference weights so that the measure can be used in the economic evaluation of treatments and care arrangements for dementia. Both people with dementia and a representative sample of the general population will value a selection of the health states generated from the DEMQOL and DEMQOL-Proxy classification systems using the Time Trade Off (TTO) [47] method of generating preference weights. Reliable and valid condition-specific PBMs for people with dementia and their carers should go some way towards addressing the concerns around using generic PBMs in dementia.

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Table 1: DEMQOL - Factor analysis revalidation

Factor	Item	Loading
Cognition	Q17. How worried have you been about your thoughts being muddled?	0.682
	Q19. How worried have you been about poor concentration?	0.627
	Q16. How worried have you been about forgetting what day it is?	0.612
	Q14. How worried have you been about forgetting things that happened recently?	0.605
	Q15. How worried have you been about forgetting who people are?	0.539
	Q18. How worried have you been about difficulty making decisions?	0.504
Negative emotion	Q4. Have you felt frustrated?	0.634
	Q12. Have you felt fed up?	0.609
	Q11. Have you felt irritable?	0.536
	Q7. Have you felt sad?	0.458
	Q2. Have you felt worried?	0.418
Positive emotion	Q10. Have you felt lively?	0.787
	Q6. Have you felt full of energy?	0.751
	Q3. Have you felt that you are enjoying life?	0.579
	Q5. Have you felt confident?	0.568
	Q1. Have you felt cheerful?	0.449
Social relationships	Q23. How worried have you been about people not listening to you?	0.664
	Q22. How worried have you been about getting the affection that you want?	0.637
	Q21. How worried have you been about how you get on with people close to you?	0.567
	Q25. How worried have you been about getting help when you need it?	0.527
	Q24. How worried have you been about making yourself understood?	0.487
	Q26. How worried have you been about getting to the toilet on time?	0.450
Loneliness	Q8. Have you felt lonely?	0.739
	Q20. How worried have you been about not having enough company?	0.656
Non/cross loading	Q9. Felt distressed	non
	Q13. Felt that there are things that you wanted to do but couldn't	non
	Q27. How worried have you been about how you feel in yourself?	non
	Q28. How worried have you been about your health overall?	non

Table 2: DEMQOL-Proxy - Factor analysis revalidation

Factor	Item	Load
Cognition	Q14. How worried would you say [*patient*] has been about forgetting things that happened recently?	0.755
	Q18. How worried would you say [*patient*] has been about his/her thoughts being muddled?	0.695
	Q12. How worried would you say [*patient*] has been about his/her memory in general?	0.661
	Q19. How worried would you say [*patient*] has been about difficulty making decisions?	0.651
	Q15. How worried would you say [*patient*] has been about forgetting people's names?	0.604
	Q17. How worried would you say [*patient*] has been about forgetting what day it is?	0.575
	Q20. How worried would you say [*patient*] has been about making him/herself understood?	0.471
	Q13. How worried would you say [*patient*] has been about forgetting things that happened a long time ago?	0.457
	Q26. How worried would you say [*patient*] has been about things taking longer than they used to?	0.430
Negative emotion	Q5. Would you say that [*patient*] has felt sad?	0.687
	Q7. Would you say that [*patient*] has felt distressed?	0.681
	Q10. Would you say that [*patient*] has felt fed up?	0.666
	Q2. Would you say that [*patient*] has felt worried?	0.632
	Q3. Would you say that [*patient*] has felt frustrated?	0.618
	Q9. Would you say that [*patient*] has felt irritable?	0.531
Daily activities	Q24. How worried would you say [*patient*] has been about using money?	0.810
	Q25. How worried would you say [*patient*] has been about looking after his/her finances?	0.655
	Q23. How worried would you say [*patient*] has been about getting what he/she wants from the shops?	0.518
Positive emotion	Q8. Would you say that [*patient*] has felt lively?	0.833
	Q4. Would you say that [*patient*] has felt full of energy?	0.810
	Q11. Would you say that [*patient*] has felt that there are things to look forward to?	0.454
Appearance	Q21. How worried would you say [*patient*] has been about keeping him/herself clean?	0.772
	Q22. How worried would you say [*patient*] has been about keeping him/herself looking nice?	0.720
Non and cross loaders	Q1. Would you say that [*patient*] has felt cheerful?	non
	Q6. Would you say that [*patient*] has felt content?	non
	Q16. How worried would you say [*patient*] has been about forgetting where he/she is?	cross
	Q27. How worried would you say [*patient*] has been about getting in touch with people?	cross
	Q28. How worried would you say [*patient*] has been about not having enough company?	cross
	Q29. How worried would you say [*patient*] has been about not being able to help other people?	cross
	Q30. How worried would you say [*patient*] has been about not playing a useful part in things?	cross
	Q31. How worried would you say [*patient*] has been about his/her physical health?	cross

Table 3: Goodness of fit to the Rasch model for each domain

Dimension	X2 (DF)	P-value	Item fit (SD)	Person fit (SD)	PSI
DEMQOL					
Cognition	29.54 (30)	0.49	-0.35 (0.36)	-0.30 (0.88)	0.78
Positive emotion	75.44 (51)	0.01	-0.01 (1.01)	-0.23 (0.81)	0.75
Negative emotion	49.85 (45)	0.29	-0.14 (1.17)	-0.45 (1.15)	0.79
Relationships	34.10 (25)	0.11	-0.07 (0.99)	-0.19 (0.77)	0.73
Loneliness	10.74 (7)	0.15	0.72 (0.61)	-0.33 (0.71)	0.73
DEMQOL-Proxy					
Cognition	43.79 (39)	0.28	-0.40 (0.64)	-0.27 (0.75)	0.64
Negative emotion	56.11 (40)	0.05	0.10 (1.27)	-0.28 (0.90)	0.81
Positive emotion	9.66 (9)	0.38	0.43 (0.29)	0.76 (1.14)	0.78
Appearance	10.56 (8)	0.23	0.61 (0.42)	-0.50 (0.98)	0.72

Table 4: DEMQOL - Psychometric and Rasch analyses

		Classical			Rasch							
Factor	Item	Factor loading	% floor	% ceiling	Missing	Disordered	Item range	Fit resid	Chi p value	Spread at logit	DIF	Poor fit (chi<0.01)
Cognition												
	14. Worry about forgetting things that happened recently	0.605	5.7	38.5	0.2		-0.769 to 2.037	-0.158	0.740	0.12 to 0.68		
	15. Worry about forgetting who people are	0.539	1.6	68.9	0		-2.019 to 0.236	-0.551	0.385	0.44 to 0.88		
	16. Worry about forgetting what day it is	0.612	4.2	51.7	1		-0.780 to 1.287	-0.112	0.477	0.22 to 0.69		
	17. Worry about your thoughts being muddled	0.682	3.0	59.9	0.6							Yes
	18. Worry about difficulty making decisions	0.504	2.3	60.6	0.4		-1.196 to 0.800	-0.559	0.354	0.31 to 0.77		
	19. Worry about poor concentration	0.627	5.1	42.5	0.8		-0.641 to 1.905	-0.673	0.279	0.13 to 0.65		
Negative emotion												
	Q2. Felt worried	0.418	3.7	42.2	0.6		-1.262 to 1.564	1.164	0.030	0.17 to 0.78		
	Q4. Felt frustrated	0.634	6.1	44.9	0.6		-0.753 to 1.348	-0.626	0.155	0.21 to 0.68		
	Q7. Felt sad	0.458	3.3	54.0	0.8		-0.916 to 0.980	0.877	0.866	0.27 to 0.71		
	Q11. Felt irritable	0.536	1.9	55.3	0.2						Yes (gender)	
	Q12. Felt fed up	0.609	4.8	45.8	0.6		-0.979 to 1.400	-1.558	0.031	0.20 to 0.73		
Positive emotion												
	Q1. Felt cheerful	0.449	5.0	12.4	0.2		-3.104 to 2.427	1.208	0.165	0.08 to 0.96		

Factor	Item	Factor loading	% floor	% ceiling	Missing	Disordered	Item range	Fit resid	Chi p value	Spread at logit	DIF	Poor fit (chi<0.01)
	Q3. Felt that you are enjoying life	0.579	7.8	14.9	1.4		-2.757 to 2.104	-0.267	0.348	0.11 to 0.94		
	Q5. Felt confident	0.668	9.3	8.1	1.4		-2.747 to 2.843	0.839	0.915	0.06 to 0.94		
	Q6. Felt full of energy	0.751	22.8	9.5	1.0		-1.387 to 2.474	-0.907	0.326	0.08 to 0.80		
	Q10. Felt lively	0.785	22.8	6.8	1.0		-1.421 to 2.962	-1.575	0.181	0.05 to 0.81		
Social relationships												
	Q21. Worry about how you get on with people close to you	0.567	2.5	75.3	0.8	Yes (quite a bit/a lot)						
	Q22. Worry about getting the affection that you want	0.637	2.2	77.2	1.2	Yes (quite a bit/a lot)						
	Q23. Worry about people not listening to you	0.664	1.4	73.9	1.2		-0.681 to 1.025	-1.754	0.027	0.26 to 0.66		
	Q24. Worry about making yourself understood	0.487	2.0	69.9	1.6		-0.205 to 1.280	-0.087	0.472	0.22 to 0.55		
	Q25. Worry about getting help when you need it	0.527	2.2	77.2	1.8	Yes (quite a bit/a lot)						
	Q26. Worry about getting to the toilet on time	0.450	1.9	79.7	1.6							Yes
Loneliness												
	Q8. Felt lonely	0.739	3.4	62.8	1.7		-1.044 to 2.309	0.293	0.256	0.09 to 0.74		
	Q20. Worry about not having enough company	0.656	1.6	68.8	0.6		-2.228 to 1.624	1.154	0.153	0.16 to 0.90		

Table 5: DEMQOL-Proxy - Psychometric and Rasch analyses

		Classical				Rasch					
Factor	Item	Factor loading	% floor	% ceiling	Missing	Disordered	Item range	Fit resid	Chi p value	Spread at logit 0	DIF	Poor fit (chi<0.01)
Cognition												
	Q12. Worry about his/her memory in general	0.660	14.1	24.3	2.4						Yes (Age)	
	Q13. Worry about forgetting things that happened a long time ago	0.456	1.6	68.7	2.4		-2.203 to -0.904	-0.967	0.175	0.71 to 0.90		
	Q14. Worry about forgetting things that happened recently	0.754	14.1	23.9	2.5							Yes
	Q15. Worry about forgetting people's names	0.603	5.9	48.5	2.6							Yes
	Q17. Worry about forgetting what day it is	0.575	6.9	44.1	2.9		-0.947 to 0.324	-0.628	0.211	0.42 to 0.72		
	Q18. Worry about his/her thoughts being muddled	0.695	6.7	43.0	3.5							Yes
	Q19. Worry about difficulty making decisions	0.650	6.7	49.5	2.8							Yes
	Q20. Worry about making him/herself understood	0.469	2.9	66.2	2.5	Yes (quite a bit/a lot)						
	Q26. Worry about things taking longer than they used to	0.428	3.2	51.1	3.5		-1.75 to 0.52	0.555	0.393	0.52 to 0.85		
Negative emotion												
	Q2. Felt worried	0.632	9.5	23.4	2.8		-1.287 to 2.284	0.823	0.976	0.10-0.79		
	Q3. Felt frustrated	0.616	10.5	26.8	3.6		-1.007 to 1.923	1.126	0.695	0.15-0.76		
	Q5. Felt sad	0.687	4.4	38.7	3.8		-2.005 to 1.411	-0.902	0.091	0.22-0.84		
	Q7. Felt distressed	0.681	4.5	50.448.5	3.8		-2.081 to 0.655	-1.614	0.014	0.34 to 0.89		
	Q9. Felt irritable	0.530	4.4	35.9	3.2							Yes
	Q10. Felt fed up	0.663	8.5	26.9	4.1		-1.243 to 2.047	0.624	0.606	0.11 to 0.78		
Daily activities												

Factor	Item	Factor loading	% floor	% ceiling	Missing	Disordered	Item range	Fit resid	Chi p value	Spread at logit	DIF	Poor fit (chi<0.01)
	Q23. Worry about getting what he/she wants from the shops	0.504	1.8	74.1	5.9	Yes (quite a bit/a lot)						
	Q24. Worry about using money	0.798	2.2	72.8	5.8							Yes
	Q25. Worry about looking after his/her finances	0.665	4.0	65.6	7.8							Yes
Positive emotion												
	Q4. Felt full of energy	0.809	40.1	4.2	3.5		-2.694 to 2.545	0.221	0.142	0.07-0.94		
	Q8. Felt lively	0.833	34.7	3.1	3.7		-3.243 to 3.276	0.629	0.735	0.04-0.96		
	Q11. Felt that there are things to look forward to	0.453	26.5	5.1	3.6							Yes
Appearance												
	Q21. Worry about keeping self clean	0.772	2.3	80.8	2.8		-0.782 to 0.703	0.310	0.044	0.33 to 0.69		
	Q22. Worry about keeping self looking nice	0.720	1.5	76.4	2.6		-1.630 to 1.452	0.903	0.938	0.19 to 0.84		

Table 6: Health state classification systems - DEMQOL and DEMQOL-Proxy

DEMQOL	**DEMQOL-Proxy**
COGNITION	COGNITION
1. I do not worry at all about forgetting things that happened recently	1. I do not worry at all about forgetting what day it is
2. I worry a little about forgetting things that happened recently	2. I worry a little about forgetting what day it is
3. I worry quite a bit about forgetting things that happened recently	3. I worry quite a bit about forgetting what day it is
4. I worry a lot about forgetting things that happened recently	4. I worry a lot about forgetting what day it is
NEGATIVE EMOTION	NEGATIVE EMOTION
1. I do not feel frustrated at all	1. I do not feel frustrated at all
2. I feel frustrated a little	2. I feel frustrated a little
3. I feel frustrated quite a bit	3. I feel frustrated quite a bit
4. I feel frustrated a lot	4. I feel frustrated a lot
POSITIVE EMOTION	POSITIVE EMOTION
1. I feel cheerful a lot	1. I feel lively a lot
2. I feel cheerful quite a bit	2. I feel lively quite a bit
3. I feel cheerful a little	3. I feel lively a little
4. I do not feel cheerful at all	4. I do not feel lively at all
RELATIONSHIPS	APPEARANCE
1. I do not worry at all about making myself understood	1. I do not worry at all about keeping myself looking nice
2. I worry a little about making myself understood	2. I worry a little about keeping myself looking nice
3. I worry quite a bit about making myself understood	3. I worry quite a bit about keeping myself looking nice
4. I worry a lot about making myself understood	4. I worry a lot about keeping myself looking nice
LONELINESS	
1. I do not feel lonely at all	
2. I feel lonely a little	
3. I feel lonely quite a bit	
4. I feel lonely a lot	