

# Generation of preference-based indices from DEMQOL and DEMQOL-PROXY for use in economic evaluation

<https://neurodegenerationresearch.eu/survey/title-of-pigeneration-of-preference-based-indices-from-demqol-and-demqol-proxy-for-use-in-economic-evaluation/>

## Title of project or programme

Title of PI      Generation of preference-based indices from DEMQOL and DEMQOL-PROXY for use in economic evaluation

## Principal Investigators of project/programme grant

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- United Kingdom

## Source of funding information

Department of Health (DH)

## Total sum awarded (Euro)

584802

## Start date of award

01-01-2009

## Total duration of award in months

26

## The project/programme is most relevant to

- Alzheimer's disease and other dementias

## Keywords

Dementia, Health Status Indicators, Quality-Adjusted Life Years, Quality of Life, Models, Economic.

## Research abstract in English

Background: Recently, instruments have been developed that can measure quality of life in dementia. This means we can find out if treatments improve or impair the overall life quality of those to whom they are given. However these instruments are too long to be used in economic evaluations and we have little information on how people value states of health in dementia. The ways that have been developed for the population as a whole do not work well in dementia. This is due to the inherent impairments in dementia of recall, time perception, insight and expressive and receptive communication. Taken together this means there is a need to develop a new method to enable the effective economic analysis of drug and non-drug interventions for dementia. In practical terms, the unsatisfactory nature of the current evidence base has been clearly illustrated by the major difficulties presented to the National Institute for Health and Clinical Excellence (NICE) in their recent (TAG111).

Design: We propose a five stage methodology. 1. Derivation of the health state classification – The first stage is to fashion a health state classification (like the EQ-5D in structure) by sampling items from the original instruments using conventional and advanced psychometric methods. We will use existing datasets in which DEMQOL and DEMQOL-Proxy have been used. These will be used to generate health states for valuation consisting of existing items from DEMQOL and DEMQOL-Proxy respectively, so they can be derived from any study using DEMQOL and DEMQOL-Proxy instruments. They will be known as DEMQOL-nD and DEMQOL-Proxy-nD (where n is the number of items in the shortened measure). 2. Main population valuation survey – this will be conducted with a general population sample and will use a time trade-off technique, where respondents are asked how many years they would be willing to sacrifice in order to be in full health. In addition we propose to use two ordinal methods for valuation, ranking and a discrete choice experiment. 3. Patient/carer valuation survey – while the main valuation survey is a representative sample of the general public to conform to the requirements of NICE and other reimbursement authorities. However there are active issues in whether this is the right group given the nature of the disorder and the state of public attitudes and understandings of dementia. We will therefore complete a supplementary valuation survey of people with dementia and their carers in order to explore the size and direction of any deviation from the general public's values. In preparing this proposal the Alzheimer's Society is clear that they would wish the values of people with dementia and their family carers to be directly investigated. 4. Modelling – Data will be modelled to estimate preference-based scoring algorithms that can be applied to existing and future DEMQOL and DEMQOL-Proxy data. 5. Application to trial data – The final phase of the study will be to apply these algorithms to two trial datasets that are underway (HTA-SADD, a placebo-controlled RCT of the treatment of depression in dementia; and MRC-DOMINO, a placebo-controlled RCT of donepezil and memantine alone and in combination for the treatment of those where treatment response is questioned) to estimate QALYs directly. We will also test the psychometric properties of the indices; and compare the results of using the two DEMQOL indices, the EQ-5D, and population and patient/carer valuations.

Setting & target population: The community and people with dementia and their family carers in contact with services.

Health technologies being assessed: Development of preference-based single indices for DEMQOL and DEMQOL-Proxy for use in economic evaluation using general population and patient/carer values. They will be known as DEMQOL-nD and DEMQOL-Proxy-nD (where n is the number of items in the shortened measure).

Measurement of cost and outcome: fixed within the HTA-SADD and MRC-DOMINO protocols.

Project timetable: 22 month project. 1m set up; 1-8m phase 1; 9-14m phase 2; 9-19m phase 3; 9-19m phase 4; 15-22m

phase 5; 20-22 report preparation.

### **Lay summary**

Recently, instruments have been developed that can measure quality of life in dementia. This means we can find out if treatments improve or impair the overall life quality of those to whom they are given. However these instruments are too long to be used in economic evaluations and we have little information on how people value states of health in dementia. The ways that have been developed for the population as a whole do not work well in dementia. This is due to the inherent impairments in dementia of recall, time perception, insight and expressive and receptive communication. Taken together this means there is a need to develop a new method to enable the effective economic analysis of drug and non-drug interventions for dementia. In practical terms, the unsatisfactory nature of the current evidence base has been clearly illustrated by the major difficulties presented to the National Institute for Health and Clinical Excellence (NICE) in generating their recent Technology Appraisal Guidance (TAG111).

We propose to generate from our existing long quality of life measures (DEMQOL and DEMQOL-Proxy) two new brief measures to be known as DEMQOL-nD and DEMQOL-Proxy-nD (where n is the number of items in the shortened measure). We will then generate values for different health states from the general population and patient/carer viewpoints. Finally we will test these using data from treatment trials that are underway. The work will be divided between analysis of existing datasets and new interviews with a general population sample drawn from Sheffield and a patient/carer sample from south London. The patient/carer sample will be drawn from clinical contacts by researchers very skilled in such interviews. Full written informed consent will be obtained from all participants, no people with dementia without capacity will be included since they would not be able to complete the interview needed to generate the values. The research costs are made up of: the time of skilled economist, psychometrician and statistician time for the design and analytic elements; the costs of the population survey; and the needs for skilled trained research workers to engage with people with dementia and their carers in the interview phase.

### **In which category does this research fall?**

- Health and social care research