

This is a **Sample** version of the
Dementia Quality of Life (DEMQOL)

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The full complete version includes –

- Overview information
- Review report
- Scoring & Interviewer Manual
- Complete DEMQOL (interview) Questionnaire/Test
- Complete DEMQOL (Proxy) Questionnaire/Test

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Dementia Quality of Life (DEMQOL)

Background: Dementia is one of the most common and serious disorders in later life. It causes irreversible decline in global intellectual and physical functioning, and has a significant personal, social, health and economic impact on people with dementia, their family carers, and health and social services. Although measures of cognitive, functional and behavioural outcomes are widely used to evaluate interventions for dementia, the challenge of measuring broader outcomes such as health-related quality of life (HRQoL) has only recently begun to be addressed. This presents challenges about how to assess the subjective perceptions and experiences of the person with dementia in a reliable and valid way.

Objectives: To develop and validate a psychometrically rigorous measure of health-related quality of life (HRQoL) for people with dementia: DEMQOL.

Data sources: Literature review. Expert opinion. Interviews and questionnaires.

Review methods: Gold standard psychometric techniques were used to develop DEMQOL and DEMQOL-Proxy. A conceptual framework was generated from a review of the literature, qualitative interviews with people with dementia and their carers, expert opinion and team discussion. Items for each component of the conceptual framework were drafted and piloted to produce questionnaires for the person with dementia (DEMQOL) and carer (DEMQOL-Proxy). An extensive two-stage field-testing was then undertaken of both measures in large samples of people with dementia ($n = 130$) and their carers ($n = 126$) representing a range of severity and care arrangements. In the first field test, items with poor psychometric performance were eliminated separately for DEMQOL and DEMQOL-Proxy to produce two shorter, more scientifically robust instruments. In the second field test, the item-reduced questionnaires were evaluated along with other validating measures ($n = 101$ people with dementia, $n = 99$ carers) to assess acceptability, reliability and validity.

Results: Rigorous evaluation in two-stage field testing with 241 people with dementia and 225 carers demonstrated that in psychometric terms: (1) DEMQOL is comparable to the best available dementia-specific HRQoL measures in mild to moderate dementia, but is not appropriate for use in severe dementia [Mini Mental State Examination (MMSE) <10]; and (2) DEMQOL-Proxy is comparable to the best available proxy measure in mild to moderate dementia, and shows promise in severe dementia. In addition, the DEMQOL system has been validated in the UK in a large sample of people with dementia and their carers, and it provides separate measures for self-report and proxy report, which allows outcomes assessment across a wide range of severity in dementia.

Conclusions: The 28-item DEMQOL and 31-item DEMQOL-Proxy provide a method for evaluating HRQoL in dementia. The new measures show comparable psychometric properties to the best available dementia-specific measures, provide both self- and proxy-

report versions for people with dementia and their carers, are appropriate for use in mild/moderate dementia (MMSE \geq 10) and are suitable for use in the UK. DEMQOL-Proxy also shows promise in severe dementia. As DEMQOL and DEMQOL-Proxy give different but complementary perspectives on quality of life in dementia, the use of both measures together is recommended. In severe dementia, only DEMQOL-Proxy should be used.

Use of DEMQOL-Proxy in severe dementia: People with severe dementia have been largely overlooked in research studies, despite the fact that there are considerable numbers who present a major challenge to health and social services. The greatest detrimental impact on the person with dementia, family carers and society is concentrated in those with severe dementia, who constitute between 17 and 28% of the population of people with dementia over 65.¹⁸ Interventions need to be developed and tested to address their multiple complex needs. Such work requires the development of a quality of life measure for use in severe dementia. There is preliminary evidence that DEMQOL-Proxy has the characteristics of a good measure in this group, but this requires further evaluation.

Scoring: The overall quality of life question is not included in the score for either DEMQOL or DEMQOL-Proxy. All other items are scored 1 (a lot) to 4 (not at all), except for the positive items indicated by asterisks (*) The positive items should be reverse scored. Scored items are summed to produce a total score. A higher score indicates better health-related quality of life (HRQoL).

References: S Banerjee (Professor of Mental Health and Ageing), D Lamping (Reader in Psychology) and M Prince (Professor of Epidemiology). S Smith (Lecturer), S Banerjee, D Lamping, J Murray (Senior Lecturer in Social Research), M Prince, R Harwood (Consultant Physician), E Levin (Senior Research Fellow), A Mann (Professor of Epidemiological Psychiatry) and M Knapp (Professor of Health Economics)

DEMQOL and DEMQOL-Proxy - Interviewer Manual

Instructions for administration:

You will need a copy of the DEMQOL questionnaire for each interviewee and a separate card with the response scales printed large scale.

1. Introducing the questionnaire:

1.1 Ensure that the person with dementia/carer is comfortable and happy to participate

1.2 If the carer is also present during the interview with the person with dementia, explain that it is the *person with dementia's* feelings and understandings that you are interested in. Reiterate that there are no right or wrong answers.

1.3 Explain that you are interested in how people feel about things that happen everyday. Explain that you will ask some questions, for example about the activities that people do during a day, how they feel, their relationships.

1.4 Show the person with dementia/carer the response card and encourage the patient to hold it if appropriate.

1.5 Read verbatim the instructions on the front of the questionnaire.

1.6 Read aloud the practice question. Point to each response option on the response card as it is said. Ask the person with dementia/carer to either say or point to the response he or she has chosen. Probe the response using the suggested probe questions to check whether the respondent has understood the question. If the practise question is successfully completed then continue with the rest of the questionnaire. If the person with dementia/carer cannot complete the practise question, then attempt the first five questions. If the person with dementia/carer is still struggling, suggest that you take a break for 10 minutes. When the interview is resumed start at the top of the next section. If the person with dementia/carer is still struggling after 5 questions then stop the interview.

1.7 If the person with dementia/carer successfully completes the practise question, but cannot do the questions in the first section of the questionnaire then, attempt the first five questions. If the person with dementia/carer is still struggling, suggest that you take a break for 10 minutes. When the interview is resumed start at the top of the next section. If the person with dementia/carer is still struggling after 5 questions then stop the interview.

2. Administering the questionnaire items:

2.1 Read each question exactly as it is written. If there is an example in the question, this must always be read too. Read aloud each response option, pointing to each response as you say it.

2.2 When the person with dementia/carer has indicated his or her response, mark it on the questionnaire. Mark only one response for each question. If the patient does not or cannot answer an item (for any reason), record the response as missing.

2.3 Try not to prompt with the phrase "*so that doesn't worry you at all?*" as this encourages a yes/no answer. Instead use the phrase "*how much does that worry you?*" and repeat the four response options.

2.4 For each question read both the stem and the item content. If the person has difficulty with an item

repeat both the stem and the item verbatim. If they still have difficulty then repeat second part of the stem (ie “..are you worried about”) and the item content.

2.5 At the end of the interview go back to any missed items and if appropriate ask the person with dementia/carer to complete them.

This is the end of the Sample View of the DEMQoL interviewer manual. The full complete version comes with 5 sections of interviewer guideline criteria

Study ID

DEMQOL (version 4)

Instructions: Read each of the following questions (in bold) verbatim and show the respondent the response card.

I would like to ask you about your life. There are no right or wrong answers. Just give the answer that best describes how you have felt in the last week. Don't worry if some questions appear not to apply to you. We have to ask the same questions of everybody.

Before we start we'll do a practise question; that's one that doesn't count. (*Show the response card and ask respondent to say or point to the answer*) In the last week, how much have you enjoyed watching television?

a lot quite a bit a little not at all

Follow up with a prompt question: Why is that? or Tell me a bit more about that.

For all of the questions I'm going to ask you, I want you to think about the last week.

First I'm going to ask about your feelings. In the last week, have you felt.....

- | | | | | |
|---|--------------------------------|--------------------------------------|-----------------------------------|-------------------------------------|
| 1. cheerful? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 2. worried or anxious? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 3. that you are enjoying life? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 4. frustrated? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 5. confident? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 6. full of energy? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 7. sad? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 8. lonely? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 9. distressed? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 10. lively? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 11. irritable? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 12. fed-up? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 13. that there are things that you wanted to do but couldn't? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |

Next, I'm going to ask you about your memory. In the last week, how worried have you been about.....

- | | | | | |
|---|--------------------------------|--------------------------------------|-----------------------------------|-------------------------------------|
| 14. forgetting things that happened recently? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 15. forgetting who people are? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 16. forgetting what day it is? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |

This is the end of the DEMQOL (interview test) sample version. Full version has 29 question test criteria. Plus an additional test the DEMQOL "Carer" test version.