

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.

3. De-briefing after the interview:

3.1 Explain that all the questions have now been answered.

3.2 Ask whether person with dementia/carer has any questions that he or she would like to ask. Answer any questions and thank the person with dementia/carer for taking part

4. Possible queries and responses - general:

4.1 doesn’t want to complete the questionnaire

Tell the person with dementia/carer that participation is entirely voluntary. They are being asked to complete the questionnaire because it will help us to *understand more about what people think is important for quality of life*. If they still do not want to participate stop the interview and thank the person with dementia/carer.

4.2 stops completing the questionnaire because he/she does not understand

Specific prompts for not understanding or querying are given on the next page. In general if the person with dementia/carer does not understand a particular question, re-read it verbatim, but do not re-phrase the question. If the person with dementia/carer does not understand the response options, re-read the response options verbatim but do not re-phrase them. The question and the response options can be re-read as many times

as is necessary, but if it is clear that the patient or carer does not understand then do not continue.

4.3 is concerned that someone will look at his/her answers

Reassure the patient/carer that all of his/her responses will be kept confidential to the research team. Explain that names will be replaced by a study number so that the questionnaires are completely confidential.

4.4 asks you to interpret a question

Specific prompts for not understanding or querying are given on the next page. In general re-read the item verbatim. Do not try to explain an item. Suggest that the person with dementia/carer base his/her answer on what he/she thinks the question means. Re-phrasing or interpreting a question can bias results. It is very important that the questions are read verbatim and only the standard prompts are used (see specific prompts given on next page).

4.5 answers “don’t know” or wants to miss out a question

Acknowledge that it can be hard to choose a response, but encourage the patient/carer to choose the response option that *most applies to him/her*. If a patient/carer wants to miss out an item, explain to the patient/carer that all the questions are very important. They should try to answer all of the questions. If the patient/carer still does not want to answer a particular item, assure the patient that it is alright, then go on to the next item.

4.6 wants to know the meaning of his/her answers

Tell the patient/carer that all information is helpful and that there are no right or wrong answers. Remind the patient/carer that all the information is kept confidential and that we will look at what everybody says together rather than anybody’s questionnaire on its own.

4.7 asks why both patient and carer must complete the questionnaire

Explain that sometimes patients and carers have a different view. Both are useful and by asking questions to both carer and patient we can get a more complete picture of how people feel.

5. Possible queries and responses – specific:

5.1 if person answers simply “yes” instead of choosing one of the four response options:

- repeat the response options and ask him/her to choose one
- if still say “yes”, ask him/her to choose from one of the three positive response options (ie *a lot*, *quite a bit* or *a little*) and record the one that they choose
- if still not clear which response option he/she means, repeat the three positive options again and record the one that he/she chooses
- if the person says two positive response options ask them to choose one and record it
- if necessary repeat the question verbatim

5.2 if person answers simply “no” instead of choosing one of the four response options:

- repeat the response options and ask him/her to choose
- if the person still just says “no” check with him/her if that would be “*not at all*”
- if necessary repeat the question verbatim

5.3 if person responds using their own phrase or form of words that is not one of the response options:

- repeat the question and the response options verbatim and ask them to choose one of the response options
- if they still don’t use one of the response options but are answering in a way that is relevant to the question, reiterate that they need to choose one of the four response options
- if they still don’t choose one of the response options, then accept their answer, but don’t score it, mark the questionnaire as missing and move on to the next questions

5.4 if person responds using the phrase “not a lot”:

- ask if they mean “a little” or “not at all” and record the answer given
- if the person is unable to choose between these two options then accept their response but don’t score it. Record the item as missing and allocate the appropriate code. Move on to the next question.

5.5 if person misunderstands question (ie answering something else entirely):

- repeat question and response options
- if the person still appears not to understand the question go on to the next question

5.6 if person explicitly queries what a question means:

- do not re-phrase or interpret any question
- repeat question and response options verbatim
- suggest that he/she bases their answer on what he/she think it means
- if the person is still querying or appears not to understand go on to the next question and reassure him/her that they're doing very well and its fine to go on to the next question

5.7 if person refuses to answer a question:

- accept his/her refusal and reassure the person that it is alright not to answer. Go on to the next question.

5.8 if person answers in terms of ability/functioning rather than subjective perception:

- accept his/her answer and then ask how much he/she worries about that particular activity and repeat the response options.

5.9 if carer queries a "feeling" question saying that they cannot know:

- tell the carer that there is probably noone else who knows the person better. They should just give the answer that best describes how they think their relative has felt.

5.10 if person doesn't understand the general QoL question at the end:

- repeat descriptive sentence in question book and repeat question
- if the person still appears not to understand say "*In the last week how would you rate your quality of life overall?*"
- if the person still appears not to understand say "*thinking about your life in the last week would you say it was...very good, good, fair or poor?*"
- if still not able to answer accept the non-response, assure the person that it is alright and thank him/her for taking part