

Evaluating 'living well' with mild-to-moderate dementia: co-production and validation of the IDEAL My Life Questionnaire

How do we know whether someone with dementia is 'living well'?

National dementia strategies talk about 'living well' with dementia, but

- we need to know what 'living well' means to people with dementia; and
- we need an easy and reliable way to measure whether somebody is 'living well.'

Questionnaires used in research studies measure similar things, like quality of life or well-being. Mostly, people with dementia were not involved in developing these questionnaires.

We wanted to create a questionnaire that reflects the experience of living with dementia. We wanted to co-produce the questionnaire with people living with dementia so that it reflects real-life experiences. We wanted the questionnaire to be scientific, so researchers can trust it. We wanted it to be easy for people to complete.

We formed a co-production group with nine people living with dementia. They called themselves the DEAR group. DEAR stands for Dementia Experts into Action Research.

The DEAR group looked at various questionnaires and tried them out. They decided that their own questionnaire should:

- be accessible
- take no more than 10-15 minutes to complete
- have only a small number of options to choose from
- use positive wording
- focus on how you feel at the time (not 'in the past week' or 'within the last month')

The researchers had gathered information from over 1500 people with dementia to understand more about what 'living well' looks like. They also asked people 'what does living well mean to you?' There were 1314 people with dementia who answered this question in their own words.

The DEAR group and the researchers used these answers to develop the statements for the questionnaire. An example of a statement is 'I have people to talk to.' People answering the questionnaire say how much they agree or

disagree with each statement.

They started with 230 statements. They discussed all the statements and chose 41 to try out.

The researchers asked 53 people to answer the 41 statements. The researchers and the DEAR group looked at which ones were most useful. They chose 12 statements for the next stage of testing.

The researchers asked 136 people with dementia to answer the 12 statements and say what they thought about them. They removed the two statements that worked least well. This left 10 statements.

The researchers compared the results from the set of 10 statements to results from other questionnaires used in research. The results are similar enough to give us confidence, but different enough for the new questionnaire to be useful.

The DEAR group decided on the final layout of the questionnaire. This included the design and the order of the statements. They also chose the title My Life Questionnaire.

We now need to use the My Life Questionnaire in different settings so we can understand more about 'living well' with dementia. Involving people with dementia made the questionnaire better and easier to use. We should include people with dementia when creating something for them to use.

This is a summary of a [research article](#) which appeared in **Dementia** journal in July 2023.