

## **Beliefs about dementia: Development and validation of the Representations and Adjustment to Dementia Index (RADIX)**

When people develop a health condition such as dementia, they can respond to the changes they experience in very different ways. People develop their own beliefs about what the condition is, what causes it, what will happen over time, and what can be done about it, as well as their own ways of coping. In this study we wanted to explore how people diagnosed with dementia understand the condition and adjust to living with it. To do this we developed a new questionnaire to measure the beliefs people with dementia hold about the condition and what is happening to them: the Representations and Adjustment to Dementia Index (RADIX).

To develop the RADIX we first interviewed 64 people living with dementia to understand how they viewed the condition and the changes they were experiencing, and how they coped with this. The questions included in the RADIX were developed from what people told us in these interviews. We then showed the RADIX to an advisory group of people with dementia and carers, the ALWAYSs group, and asked for their feedback. The ALWAYSs group suggested ways of making the instructions clearer. We also asked five people with dementia to complete the RADIX to see what they thought of the questions. We used this feedback to make changes and improve the questionnaire.

We then included the RADIX in the IDEAL survey. IDEAL follows a large group of people with dementia and their carers over time to explore what helps people to “live well” with the condition. To make sure the RADIX was fit for purpose, we analysed the responses of 385 people with dementia who had completed the RADIX as part of the IDEAL survey. To make sure the questions would elicit consistent responses, we asked 20 people with dementia to complete the RADIX on two separate occasions four weeks apart. We found that the RADIX provided reliable and consistent information.

Healthcare professionals could use the RADIX to find out more about how people diagnosed with dementia understand the condition and what kinds of support would be most useful. This would make it easier for them to talk to people about dementia and its effects. It would also help them to identify how best to offer support.

This is a summary of a [research article](#) which appeared in the **American Journal of Geriatric Psychiatry** in February 2018.