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Adapting A Toolkit For Older People Using Social Care Services

HOW DID THIS RESEARCH STUDY COME ABOUT?

Over half a million older people in the UK are supported by publicly-funded social care services. These services help with day-to-day living in people's own homes, in care/nursing homes and other settings.

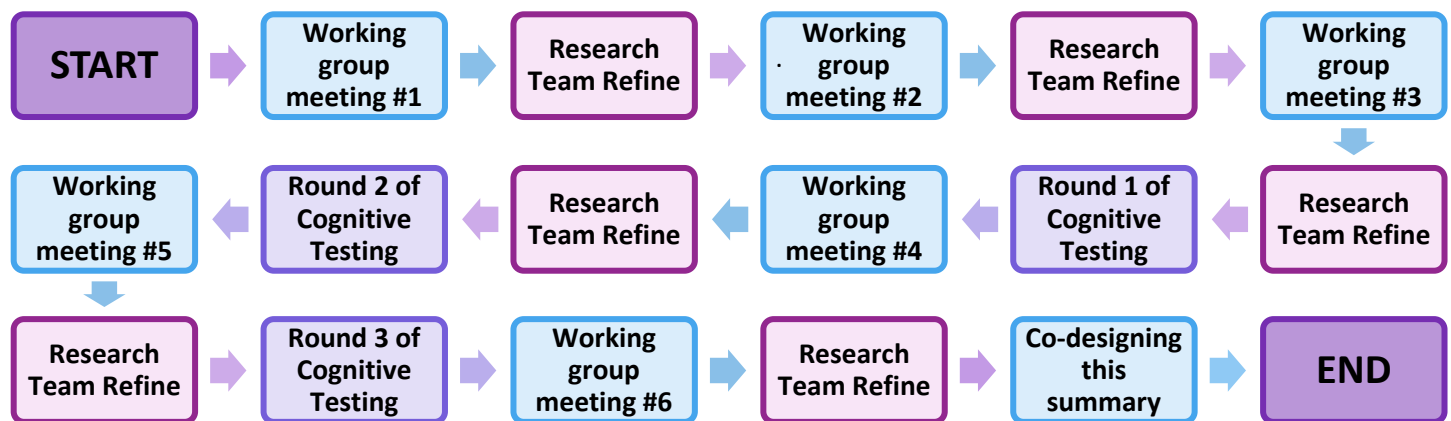
The Adult Social Care Outcomes Toolkit (ASCOT) has been widely used to measure the impact of social care on the quality of life of people supported. However, some older people find the questionnaire difficult to complete.

This study wished to enable more older people to complete the questionnaire themselves, so that they can tell care providers, policy makers and researchers how they feel about social care services they receive.

WHAT WE DID:

A group of older people, primarily those living with dementia, and their supporters/carers came together as a 'working group' to adapt an existing version of the ASCOT toolkit for this age group. The new version was then tested with people who find questionnaires difficult to complete. We had several meetings to refine the tool.

The working group met for a total of 20 hours, reviewing all aspects of the toolkit in detail and were keen to ensure that different opinions and experiences were taken into account. This lay summary was also co-developed by the working group. You can watch a video of working group members sharing their experiences on <https://tinyurl.com/People-with-lived-experience>



WHAT WE FOUND:

The working group substantially redesigned the questionnaire. They made changes to the wording of the questions and response options, the amount of content on each page and its layout, and the overall style. After each 'round' of cognitive testing with older people supported by social care services, findings were brought back to the working group. The working group then discussed the findings and agreed to further changes. These included illustrations being removed, changes to question ordering, further clarifying some of the wording and others.

The final version of the adapted toolkit is substantially different from the standard version and the easy-read version previously designed for people with learning disabilities.

GOING FORWARD:

This work shows the importance of designing outcome measures together, co-creating with older people living with dementia or sensory difficulties, and with their carers/supporters.

Future research should investigate how this co-designed easy-read toolkit may enable more people to independently report the impact of social care services on their quality of life.