



# Impact of Public Involvement in Research

## Carers Shaping Dementia Research

Frontotemporal dementia (FTD) often affects people under 65 and brings major challenges for family carers. The FTDToolkit project is creating an online resource to help carers manage symptoms and support their wellbeing. To make sure the research reflects real experiences, the team involved a carer in shaping the study.



The research team held **two online meetings** with a carer to review questionnaires and interview questions. The carer suggested clearer wording, added explanations, and recommended extra questions to make the materials more relevant and easier to understand.

Their feedback led to important improvements, such as clarifying medical terms, explaining why certain questions are asked, and adding questions about other health issues that might affect behaviour.

**This input made the study more sensitive to carers' needs and showed how small changes in language can make research more accessible.**

*The carer described the experience as meaningful and valued the chance to share their lived experience of frontotemporal dementia to help shape the research. They appreciated being asked whether the questions and terminology 'made sense' and felt the process ensured the study was relevant to real families.*

### Find out how you can get involved in research

For more information, visit our website or scan the QR code:

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