



Understanding progression of symptoms in frontotemporal dementia while supporting carers' wellbeing and skills: The FTDToolkit

Changes, Benefits and Learning from Public Contributors:
Public Involvement Impact Case Study

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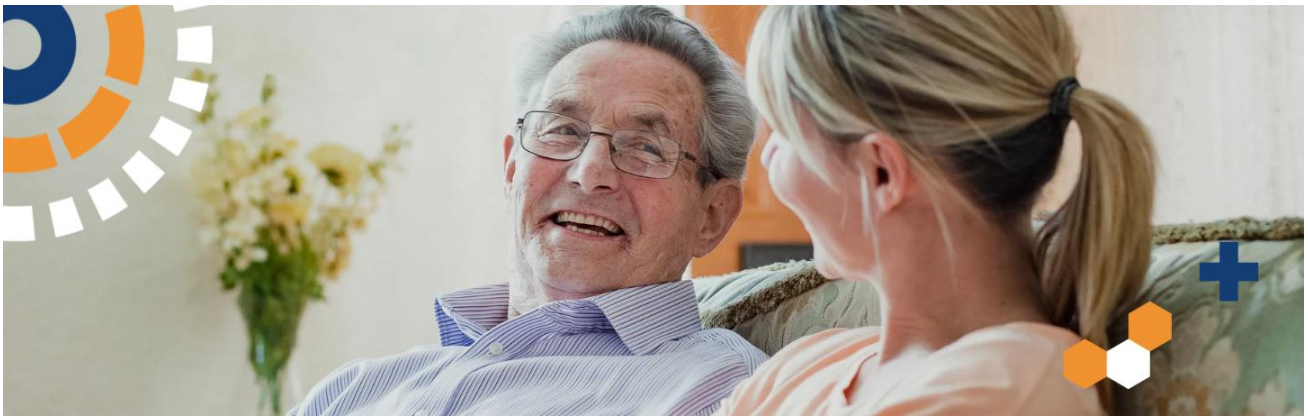
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Introduction

The UK National Standards of Public Involvement are used as a framework for the ARC EoE Public, Community, Involvement, Engagement and Participation (PCIEP) Strategy and includes 'impact'. We define 'impact' as "**the changes, benefits and learning**, gained from the insights and experiences of patients, carers and the public when working in partnership with researchers and others involved in NIHR initiative's" (*NIHR Patient and Public Involvement Impact Working Group, 2019*). Through this, we seek improvement by identifying and sharing the difference that public involvement makes to research.

The ARC EoE PCIEP Impact Case Studies are used to evaluate the impact of PCIEP on ARC EoE research and to highlight the changes, benefits and learning gained from partnership working and public involvement in ARC EoE.

Public contributors have been invited to co-produce the case studies and the perspectives of public contributors are included in the case study.



Public Involvement Impact Case Study: Understanding progression of symptoms in frontotemporal dementia while supporting carers' wellbeing and skills: the FTDDToolkit

What problem is this research addressing?

Frontotemporal dementia (FTD) is a leading cause of young-onset dementia in people under 65, marked by changes in behaviour, language, and executive function. For carers, behavioural symptoms such as disinhibition, impulsivity, and apathy, create significant challenges, often leading to high levels of stress and poor mental health. Healthcare professionals also struggle with FTD's varied subtypes, due to the difficulty to diagnose outside specialised centres and the limited evidence on interventions and approaches on effective care management.

Currently, there are no comprehensive non-pharmacological interventions to support carers of people with FTD, including those with additional motor symptoms (FTD-MND).

The FTDDToolkit project aims to:

- Evaluate an online platform for monitoring symptoms, disease progression, and carers' wellbeing.
- Develop an online psychoeducational intervention (*FTDDToolkit*) to support family carers on the management of FTD symptoms. The intervention aims to include informational modules on FTD symptoms and modules on strategies on symptoms' to upskill carers on the management of FTD.

Overall, the *FTDDToolkit* has the potential to improve daily care, enhance carer wellbeing, and support better outcomes for carers and people with FTD.

How were the public involved in this research?

We conducted two PPIE meetings with the current carer of a person living with FTD to review the study materials, gather their input, and ensure the content resonated with their experience. The carer was first approached by a nurse involved in the patient's care, after which the research team contacted them to arrange the meetings.

Both consultation meetings were held online. In the first meeting, a research team member presented the project's aims and its two components, a questionnaire study and an interview study. They then worked with the carer to update the questionnaires, refining wording and phrasing to improve clarity and relevance. In the second meeting, the carer reviewed the interview topic guides, helping to refine and finalise the questions to ensure they were meaningful and appropriate.

What were the outcomes of public involvement in this project?

For the questionnaire study, the carer suggested expanding the introduction to one of the questionnaires (ALSFRS-R) in order to clarify its purpose and to note that not all the listed symptoms assessed may be relevant to every participant, but that the project aims to gather as much information as possible. They also recommended rephrasing the questions on breathing/respiratory function in the ALSFRS-R for clarity, and clarifying the meaning of "disorganised behaviour" in one of the questions of the FRS. In addition, they suggested adding "temporal lobe FTD" as an option for diagnosis in the demographic section.

For the interview study, they suggested adding some other questions to the topic guides, such as; *Is there any other relevant healthcare problem the person you care for might have? Does the person you care for been previously diagnosed with any psychological or mental health problems, such as depression or anxiety? (this question aims to identify any long-standing issue that might also be causing behavioural symptoms and would be good to have them under consideration)*

How did public involvement influence the project overall?

Regarding positive effects, their input directly shaped the study materials, making questionnaires and interview guides clearer, more relevant, and most importantly, more sensitive and receptive to the lived experience of FTD.

Regarding negative effects, some feedback highlighted limitations of widely used clinical tools (e.g., ALSFRS-R) that cannot be fully adapted. In addition, engaging only one carer so far limited the potential diversity of perspectives; future work will expand involvement to include more carers and possibly people living with FTD where appropriate.

Overall, it is very important to involve carers early on and at multiple points; to capture evolving perspectives and be aware of take into consideration how specific terminology or clinical language can create barriers and result in a lack of engagement unless clarified.

What was the feedback from public contributors involved in this project?

The carer involved in the PPIE meetings described the experience as meaningful and valued the opportunity to contribute their lived experience of frontotemporal dementia to shape the research. They appreciated being asked whether the questions and terminology "made sense" to them, and highlighted that the process helped ensure the study felt relevant to real families.

What are the reflections and learning from public involvement in this research?

What went well:

Involving a carer early in the study ensured that the study materials were grounded in lived experience. Their feedback led to meaningful changes, such as clarifying language, rephrasing questions, adding options to reflect the realities of FTD, and the use of plain language. In addition, holding meetings online made involvement accessible.

Key challenges:

To date, involvement has been limited to a single carer, which may not capture the full diversity of perspectives within the wider FTD community

What would we do differently?

Although we made efforts to invite additional carers for PPIE, the inclusion of multiple other participations would further help grow, strengthen and synthesise our research findings. Equally, scheduling regular consultations throughout the project, rather than relying on one-off meetings would also help ensure that input and feedback continues to inform study materials and decisions as the work steadily progresses.

What can we learn from this experience

Even minor wording adjustments or clarifications can make questionnaires and interview guides much more accessible for participants.

The case study template is informed by GRIPP 2-SF (Staniszewska et al., 2017)

For more information, visit the [project webpage](#)

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