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CLINICAL MANIFESTATIONS

POSTER PRESENTATION

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NEUROPSYCHOLOGY

# A patient-centred approach to translate remote cognitive assessments into clinical practice

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## Abstract

**Background:** Despite a proliferation of computerised and remote monitoring assessments offering opportunities to provide valuable data to researchers and clinicians, there are significant concerns about feasibility of such tools within a clinical population. A patient-centred design is essential to ensure these tools are effective and well tolerated by a memory clinic population, whilst producing high quality data. Our aim was to integrate Patient and Public Involvement (PPI) systematically in the development of a remote monitoring study for patients of the Oxford Brain Health Clinic (OBHC; O'Donoghue et al., 2023).

**Method:** A comprehensive approach was taken to engage people living with dementia and mild cognitive impairment, their relatives, as well as volunteers interested in dementia research. This was achieved through a workshop and survey to explore the relevance of the research and potential assessments, by user-testing methods to refine study design, by co-producing the study aims and documents with a lay member, and through regular consultations with a PPI panel to review progress and practical considerations (Table 1).

**Result:** PPI activities were instrumental in shaping the research, with two key themes emerging: relevance of outcome measures and choice. The need for clear, relevant, prognostic information was stressed, alongside high-priority outcome measures such as daily activity, memory, relationships, and care needs. Contributors highlighted the importance of choice in the types of assessments, the means of participation, and to what extent there should be relative involvement. Contributors suggested improvements to digital tasks including increasing device compatibility and the need for analogue alternatives. This resulted in a study design which maximises patient/relative choice while collecting data relating to high-priority outcome measures. This study design was found by our PPI consultants to be generally acceptable and feasible.

**Conclusion:** By integrating PPI, we have created a patient-centred remote monitoring study that is reflective of the needs and preferences of patients and their relatives. Although embedding PPI requires time and resources, it is invaluable for studies involving digital assessments within clinical populations and significantly shaped this research, challenged existing assumptions, and led to more acceptable outcomes, which should ultimately result in greater inclusion.

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*Table 1: Summary of PPI activities and outcomes in development of OBHC remote follow-up study. Integrating different PPI activities throughout the research cycle led to the development of a patient-centred remote monitoring study which promotes participant choice, to maximise data collection in a way that works for patients and their relatives.*

| Aim | Format | Findings | Impact on research |
|---|---|---|---|
| Explore relevance of research topic and potential outcome measures. | Workshop - contributors shared personal experiences of the memory clinic, suggested improvements, and impacts of diagnosis. | Contributors noted feelings of fear, frustration and abandonment following diagnosis and the need for more clear and personalised information about diagnosis and prognosis. | These insights reinforced the relevance of research to identify prognostic markers of brain health and formed the foundation for subsequent PPI activities. |
| Identify which outcome measures are most important to patients and their relatives. | Survey- contributors rated, ranked, and provided feedback on potential outcome measures identified in the workshop. | High priority outcome measures identified e.g. daily activity, memory, care needs. Importance of choice stressed when informing patients about potential changes in outcome measures. | Inclusion of standardised and non-standardised questionnaires, and cognitive assessment to capture relevant outcome measures. Participants to be given a choice in which assessments they want to complete. |
| Review research methods and progress for ethical concerns and practical considerations. | Quarterly meetings with PPI advisory panel - contributors consulted on study design including purpose, structure (format, frequency and length of assessments), and the role of an informant. | Stressed need for choice in means of participation, with digital tasks optional for those who are willing/able. Relative involvement was considered important for patient support and to provide collaborative data, but patients should choose whether to consent to this. | To increase flexibility and promote participant choice, an optional consent model was developed with analogue alternatives to digital tasks. A nominated relative can choose to complete questionnaires about the patient and themselves, with the patients consent. |
| Feasibility and acceptability of study design, including clarity of instructions and usability of digital tasks. | Multiple rounds of feedback with dry-runs of recruitment conversations, consent processes, telephone-based questionnaires and tasks, and beta-testing of digital tasks. | Suggested improvements to clarify instructions, reduce assessment length, increase compatible devices supported, and discussions of potential design biases regarding visual impairments/dexterity. | Changes to improve user experience included creating a separate instructions and FAQ document and ensuring digital tasks can be completed on a range of devices including smartphones, tablets and laptops/PCs. |
| Ensure the study documentation is accessible to a non-academic audience. | A PPI consultant (AL) wrote first drafts of several key documents in preparation for ethical review and provided feedback on later drafts. | The PPI contributor co-produced the study title, aim, protocol and patient facing documents to ensure they are well-developed, clear and aligned with the results of our PPI work. | By co-producing documents with the PPI consultant, we believe we have created documents which are lay-appropriate and participant friendly while maintaining scientific rigour. |