

Oxford Brain Health Clinic Follow-up Study

Background

The Oxford Brain Health Clinic (OBHC) gives NHS patients a full check of their memory when there are concerns about their memory. This includes a brain scan, memory tests, and the option to join research. The results help doctors make a diagnosis.

This case study explains how we involved patients and families to create a new study. It follows people over time to see how their memory, behaviour, and daily life change after their OBHC appointment.

What we did

We collaborated with people who have memory problems, their relatives, and volunteers. We used different methods:

- **Workshop:** People shared what getting a diagnosis was like and suggested memory clinic improvements.
- **Survey:** People chose which outcomes mattered most to them, like memory, mood, daily tasks, driving, and care needs.
- **Advisory group:** A group met every few months to help shape the study and think about practical and ethical issues.
- **Writing documents together:** A public member helped us write the ethics form and all patient documents in clear, simple language.
- **User-testing:** Volunteers tested the sign-up process and tasks. Because of this, we realised we needed to improve instructions and make tasks easier to use.
- **Sharing results:** A public member helped write conference materials and spoke at events. The advisory group also helped pick out the main messages from the study results.

What difference did it make?

The involvement of patients and the public changed the study in important ways:

- People said they wanted clearer information about what their diagnosis meant for their own future and priorities. So, the study focus changed from diagnosis to **prognosis**, helping people understand what might happen over time.
- Because everyone could take part, no matter their diagnosis, the study became **more inclusive**. People could choose which tasks to do and how they wanted to do them: online, on the phone, or in person. They could also choose how much a relative was involved.
- Instructions and tasks were made shorter, clearer, and easier to use on different devices. This improved completion; 81% of people finished the tasks they started.