

Creation of a Brain Health Advisory Group

Background

The Brain Health Advisory Group is a group of people with lived experience of brain and nervous system conditions, such as chronic pain, dementia, a stroke, or those who have an interest in brain health. The group gives advice to our researchers. They help with research ideas, study plans, and how to involve the public. This support is important because it gives researchers feedback early on, even before they apply for grant funding.

What we did

We recruited 10 members with diverse backgrounds and experiences. Some who live with conditions affecting the brain and nervous system and some who care for people with these conditions. Others have a strong interest in brain research. We met with each applicant for a short conversation and chose 10 people whose experiences worked well together. We also ran an introductory session, so that everyone could connect, feel welcomed and make sure expectations were realistic.

The group meets online once a month. Sometimes we hold extra sessions when more researchers ask for support. In each meeting, one researcher presents their work and asks the group three questions. Our team helps the researcher prepare their talk and choose the right questions to ask. We also run the meeting and write notes afterwards so the researcher can use the feedback. So far, ten researchers have met with the group.

What difference did it make?

The Brain Health Advisory Group has filled an important gap in support for researchers. It supports them to include patient and public views at the start of their work, even before funding is available. The group has already helped improve study design, taken part in ethical discussions, created research guidelines to make sure research is more inclusive and commented on several grant applications.

“Everyone brings different views. It lets us use our lived experience in a positive way and influence research early on. It feels rewarding when researchers listen and make changes.” **Group member**

“The discussion helped us redesign our experiments to put patient wellbeing first. We had planned to use stimulation that might make symptoms worse. The group helped us understand why we should avoid this.” **Researcher**

“Meeting the group was essential for my grant application. I needed to hear from people with lived experience. The group made this possible.” **Researcher**