



NEUROPROGRESSIVE  
AND DEMENTIA

## Involving Patients and the Public in Research

An active patient and public involvement group of 200 people support the work of the Dementia and Neuroprogressive Disease Network NDN.



Dementia is one of the foremost public health challenges worldwide. As a consequence of improved healthcare and better standards of living more people are living for longer. This means that the number of people with Alzheimer's disease, vascular dementia, and other types of dementia is expected to double over the next 30 years. Research offers hope. It is only through research that we advance understanding of the disease, develop effective treatments, improve care and hopefully one day find a cure. For research to progress, patient and public involvement is vital.

Our patient and public involvement group help shape, support and promote research providing valuable insight, advocating the value of research and providing a real-life view of participation in research studies. Activities include:

- Participation in study oversight groups
- Trial website review and feedback
- Feedback on proposals from individual researchers
- Presenting or exhibiting at conferences
- Focus group involvement
- App testing for researchers

*"Our patient and public involvement group provide the stimulus for engagement in studies, thoughtful consideration of how pitfalls are overcome and a wealth of experience to help people overcome their fears about participating in research. It is great to have people involved and the wider perspective this group adds to our work is invaluable."*

**Peter Connelly**  
Network Champion

**If you are interested in becoming part of our patient and public involvement group contact:**

✉ [Tay-UHB.SDCRNteam@nhs.net](mailto:Tay-UHB.SDCRNteam@nhs.net)

**Or stay up to date with the work of the network**

🌐 [www.nrs.org.uk/Dementia](http://www.nrs.org.uk/Dementia)

🐦 [@NRS\\_NDN](https://twitter.com/NRS_NDN)

# Join Dementia Research

The Neuroprogressive and Dementia Network is committed to working with partners across the UK and Europe to accelerate the pace of dementia research. This includes supporting Join Dementia Research, a nationwide online and telephone service which helps people take part in research studies by connecting those with and without dementia with researchers.



Anyone aged 18 years or over can sign up themselves, or on behalf of someone else, either by:

- registering online at [www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk)
- contacting the helplines of **Alzheimer Scotland (0808 808 3000 – free to call, open 24 hours a day, 365 days a year)** or **Alzheimer’s Research UK (0300 111 5 111)**.

By signing up to the service, people give permission for researchers to contact them with details of studies in their area that match their profile. By registering, people do not have to take part in any studies and can opt-out at any time.



*“Being part of the trial is important to me because it is a way of being involved in the process of finding new treatments and, eventually, a cure, for dementia. It is also a way of giving back what my wife and I received when she had dementia. There is always a warm welcome from the staff at my six-monthly visits. While there are testing questions to be answered they are asked in a friendly way and I always come away with a sense on having been cared for.”*

**A JDR Ambassador and study participant**



NHS Research Scotland promotes and supports excellence in clinical and translational research in Scotland so that patients can benefit from new and better treatments. The Neuroprogressive and Dementia Network is part of a national network of topic and specialty groups set up to provide strong infrastructure and world class clinical and academic expertise across a number of key therapeutic areas. These networks act as the interface between the research community, the NHS and patients themselves, facilitating the development, set up and completion of high quality clinical research studies across Scotland.

 [www.nrs.org.uk](http://www.nrs.org.uk)  [communications@nrs.org.uk](mailto:communications@nrs.org.uk)  [@NHSResearchScot](https://twitter.com/NHSResearchScot)

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