



Equality, Diversity and Inclusion Strategy - Action Plan

Statement of Intent – September 2023

Theme: Dementia

The Dementia Theme aims to preserve cognitive health and prevent cognitive decline by refining cognitive, imaging and blood-based biomarkers at-scale in the general population and in people experiencing memory problems.

Dementia affects people from all backgrounds and walks of life, yet ethnic minority groups and those from a lower socioeconomic background are under-represented in clinical trials for dementia. More representative research participants are needed to ensure the universal applicability of the dementia assessments we develop. We have developed the following approach to address this challenge.

Patient and Public Involvement (PPI) and Engagement

Meaningful engagement with underserved groups is built on trust, which takes time and focus. Our approach is to identify the communities central to delivering diverse and inclusive research, and to design engagement programmes with them collaboratively and transparently. Once trust is established, we find members of these communities are more likely to volunteer for PPI projects and seek information about research participation.

We believe this approach will be enhanced by working more closely with the right partners; firstly, with voluntary and community organisations who can help us reach more diverse groups in culturally sensitive and appealing ways. Secondly, by appointing community connectors (people with links to the communities we seek to include in our work) to our PPI Advisory Group. Thirdly, by strengthening our relationships with primary and secondary care to engage with real-world populations.

We are committed to valuing every contact we make within our engagement programmes by giving people the opportunity to be contacted about relevant PPI projects. This builds our relationships with the public and gives researchers better access to more diverse audiences when they require PPI. We will include the NIHR's data diversity questions where reasonable and under the guidance of our PPI contributors.

Research participation

Improving diversity and representation within research cohorts is a priority. The Oxford Brain Health Clinic (BHC), central to the Dementia Theme, gives the patients of memory clinics equal access to advanced clinical assessments, as well as to further research opportunities. More than 90% of BHC patients consent to take part in research, resulting in a highly representative group. We aim to maintain these exemplary consent rates.



As drugs to treat dementia become available, more advanced assessments will be required which are applicable to people from diverse racial and ethnic groups, from diverse social and cultural backgrounds and with different health conditions. We are committed to research collaborations that deliver the participant diversity necessary to develop those assessments.

Staff and leadership

With the ambition of embedding EDI systemically, the Dementia Theme Co-Lead has participated in a pilot of an inclusive leadership training programme. Teams across the theme are implementing a recruitment framework to ensure inclusive practices and are developing handbooks to encourage a positive culture. Staff are encouraged to join working groups dedicated to promoting EDI for staff and students.

Objectives:

Year 2

- Establish and maintain relationships with a network of community connectors to increase the diversity of PPI contributions to the Dementia Theme
- Continue to strengthen our relationships with voluntary, community and health service partners to deliver more inclusive engagement programmes.
- Launch a PPI register using the NIHR's data diversity questions where reasonable.
- Include EDI as an agenda item for the Dementia Theme strategy meetings.
- Explore the inclusion of the NIHR's data diversity questions in BHC patient questionnaires.
- Continue to nurture a positive and inclusive research culture for staff and students in the Theme.
- Partner institutions and clinics in other parts of the UK where populations are more diverse to ensure representative research data.

Year 3 and 4

- Collaborate with researchers in diverse regions of the world to test the generalizability of brain imaging tools on racially and ethnically diverse populations.
- Establish an evaluation framework for EDI within the Dementia Theme

Year 5

Evaluate and review EDI performance with recommendations for future strategy.