



Equality, Diversity and Inclusion Strategy - Action Plan

Statement of Intent – September 2024

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 design engagement programmes, collaboratively and transparently, with our target communities. Once trust is established, we find members of these communities are more likely to volunteer for PPI projects and seek information about research participation.

In year 2, we maintained our relationship with The Clockhouse Older Adult Group in one of Oxford's most deprived areas. Together we have spent time experiencing the brain health benefits of social connection and outdoor activity. Members of the group have taken part in our PPI activities and enquired about participating in research studies.

We began building relationships with our neighbours around the Asian Cultural Centre and the Central Oxford Mosque in early 2024. Individuals from Oxford City Council and Oxford Community Action were helpful facilitators. Collaborating across Themes, and with local partners from Alzheimer's Research UK, The Alzheimer's Society and MIND, we have held our first health-themed social get-together with women and children from the community. There will be further quarterly events which we hope will form the backbone of a sustained and mutually beneficial relationship, that results in more members of this community getting involved in research over time.

We continue to work with Dementia Oxfordshire to involve people with dementia and their carers in our PPI projects. We have also expanded our network of regular PPI contributors to include greater diversity, though there is more work to do.

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. We explored the possibility of incorporating the NIHR's data diversity questions in BHC patient questionnaires, but they did not feel appropriate for a clinical service.

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 3

- Continue to build 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
- 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 4 and 5

- Collaborate with researchers in diverse regions of the world to test the generalizability of brain imaging tools on racially and ethnically diverse populations
- Explore how objective setting and prioritization can be improved through engaging with more 'lived experience leadership'
- Establish an evaluation framework for EDI within the Dementia Theme
- Evaluate and review EDI performance with recommendations for future strategy.

