

EDI action plan for MS Society research – Our progress in 2022

- Research has some unique challenges when trying to be more diverse and inclusive. To begin to tackle this, we developed an EDI action plan for MS Society research to expand on our commitment to diversity and inclusion in the Organisational EDI strategy. The plan explains how we can improve the diversity and inclusivity of:
 - the research we fund
 - the research community we support
 - our research knowledge about the impact of MS in people typically excluded from research

Below is a summary of some of the key updates of 2022 and a snapshot of the priorities for 2023.

We're pleased with the progress we've made so far. We've been really encouraged by the enthusiasm across the research community for our work and we've continued to listen and learn and reflect on what we do. But we've encountered a number of challenges. We've also realised that, in some cases, more ground work is needed before we begin to turn this into action. We want to continue building on our progress in 2023.

Improve diversity in MS research workforce

2022 successes

- We've developed and implemented a survey to collect demographic information, for example age, gender and ethnicity, for all researchers that apply for our funding
- We've updated our application forms to be more inclusive, including encouraging descriptions of career breaks (for example maternity and paternity leave) and mitigating circumstances (for example chronic illness or disabilities)
- We're showcasing stories of researchers from different groups. In 2022 we focused on researchers from ethnic minority backgrounds and disabled researchers

Raghda Shaban Tawfeeq Al-Najjar told us how she used the UK MS Register to turn big dreams into big data

Hannah Morris-Bankole told us what it's like to be a researcher and someone living with MS

2023 priorities

- Publish a more detailed analysis of the collected data to show how diverse we currently are
- Come up with specific actions to increase applications from under-represented researchers
- Redesign the CV section in grant application forms to be more inclusive

Our progress in 2022

2. Improving diversity in our research boards, committees and grants panels

2022 successes

- We've discussed our EDI action plan with all our research groups. We've also discussed adding Early Career Researchers (ECRs) and an EDI officer to each of the panels and groups. This was well received and we'll be putting together a plan to begin recruiting these roles, thinking about the individual needs of each committee
- The demographic survey has been circulated to all members of the research boards and the Expert Review Network, a group of people affected by MS and research or clinical experts in MS
- The data shows women make up over 50% of our panel members. But there is low representation from those from ethnic minority backgrounds, 92% of our panel members are White

2023 priorities

- We'll make an active effort to recruit people from ethnic minority backgrounds to our panels to ensure that diverse voices are represented
- Recruit ECRs and recruit or appoint an EDI officer to each of our groups

3. Making our clinical trials more inclusive

2022 successes

- We've added a requirement that our new clinical trials must collect and report on the characteristics of participants
- Grant applicants must now explain how they'll ensure that people taking part in their research are representative of people with MS in the UK

2023 priorities

- Review and improve our research communications plan to ensure people from all backgrounds know about opportunities/ ways to take part in research. And understand how research works
- Working with the Octopus trial team to improve diversity amongst participants.



Our progress in 2022

4.Increasing diversity in our patient and public involvement (PPI) programme

2022 successes

- We've held a number of outreach events to share information about research and how people are affected by MS. In November we took part in a webinar with Asian MS to promote involvement in research. This led to 10 new Research Network sign-ups
- We updated our guidance for researchers to encourage them to include money to pay PPI members for their time in their budget. We hope this will lead to more paid PPI opportunities in the future

2023 priorities

- Continue to reach out to communities with a <u>new pilot event in South London</u> in collaboration with Parkinson's UK and Alzheimer's Society. We'll evaluate the success of this events and put together learnings for future events
- Once internal policies and procedures are in place, we'll include demographic questions in the Research Network sign-up form so that we can check how diverse the network is

5.Build the research knowledge of MS

2022 successes

- We've supported the <u>ADAMS study</u>, inviting the team to attend talks and events to raise awareness
- We're committed to funding a project to improve our understanding of people's experience of MS care and how to improve healthcare and information provision for people from ethnically diverse groups. The project will focus on people who identify within the Black British and South Asian ethnic groups, who live in socially deprived areas of London and Yorkshire

2023 priorities

- We'll encourage applications from researchers who designed studies focusing on MS in under-researched groups.
 We'll also encourage applications from researchers who created strategies to encourage recruitment of participants from diverse backgrounds
- Develop a statement that explains our recommendations to include costs associated with recruitment in underserved groups within grant applications

If you have any questions please email us: research@mssociety.org.uk

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