



EDI Action Plan for MS Society Research

Our Progress in 2023

January 2024

1. Introduction

We know that MS doesn't affect everyone equally. And we also know that, across the board, research doesn't include everyone equally. We're taking action to address inequalities across our research programme and beyond into wider MS research. To start this important work, we developed an [EDI action plan for MS research](#) which outlines the work we'll deliver between 2021 and 2024.

This plan is broken down into five areas of focus:



1. MS research careers



2. Our research boards, committees and grants panels



3. Our funded clinical research



4. Our public involvement programme



5. Building the evidence base

We've been working hard to fulfil on our commitments in each of these areas and have been building on our successes and learnings as we go. Now, in 2023, we're pleased to report on our progress for the second year of the plan. Below is a summary of the key activities from 2023 and a snapshot of our priorities for 2024.

Although we've made a huge amount of progress, it's also important to take a step back and reflect on our journey. While we're proud of our work so far, we recognise that we, alongside the broader research sector, need to keep pushing for further change.

Our current action plan ends in 2024. However, our journey won't stop there. We're already thinking about our new action plan that will take us through to 2029. We want to lead by example. Therefore, we were ambitious in our current action plan. We'll continue to be ambitious. But we've recognised that, in some cases, more groundwork is needed before we can turn ambition into action. We've been continuously listening to feedback. And we'll consult with the research community and people affected by MS to ensure that our new EDI strategy has developed as we've learnt. And that it continues to have a tangible impact on MS research and our research community.



2. Improving diversity in the MS research workforce

Innovative and inclusive research is driven by a diverse community of researchers. It's essential we're attracting diverse talent into MS research and providing them with support to achieve their potential.

a. 2023 successes

- For the first time in 2022, we collected demographic information (such as age, gender and ethnicity) for all researchers that applied to us for funding. This year, we became one of only a handful of charities to publicly publish our demographic data. You can read the full report [here](#).
- We've updated the CV section of our application form for our Early Career Fellowship Awards. As an example, instead of a list of publications, we now ask applicants to provide up to five of their most relevant research contributions.
- We've adapted the MRC applicant framework for use by our peer reviewers and panels. So our review processes are more inclusive of people from marginalised backgrounds and people who have followed different career pathways. We've used this throughout the review process for our Career Development Awards since November 2022, refining the framework as we go.
- We've now shared our [position](#) on researcher leave and part-time fellowships.
- We continue to showcase stories of researchers from diverse groups and highlight the inclusive research that's being undertaken by our researchers. Here are four examples:
 - [Meet the researchers who want seldom-heard groups to be at the centre of their research into fatigue](#)
 - [Equality, diversity and inclusion at the ECTRIMS research conference](#)
 - ["Spit in a cup and potentially become part of history in the making!"](#)
 - [Improving MS care for people from minoritised ethnic backgrounds](#)

b. 2024 priorities

- The published demographic data forms part of the first step in identifying barriers to individuals participating and staying in MS research. We said we'd come up with specific actions to increase applications from under-represented groups. But we identified that we don't yet have enough data to make meaningful, informed change. So, we'll compare the second year of demographic data to identify consistent themes regarding how diverse our researchers are. We'll use this combined data to understand what may be driving these themes. And we'll develop an actionable, targeted plan to increase applications from under-represented groups in our 2024-2029 action plan.

- Continue to publish diverse case studies and refine our communications plan to reach a more diverse audience. This communications plan will be reviewed by our [EDI Reference Group](#).

3. Assessing our research boards, committees and grants panels



We need to ensure fair and inclusive research funding processes. All our funding decisions should be made on scientific quality, relevance to MS and our [Research Strategy](#). Our research governance groups help us make funding decisions, set our research strategy and advise us on our larger research programmes. It's important these groups contain diverse voices to make our research strategy and the research we fund relevant to a wider portion of the MS community.

a. 2023 successes

- We collected demographic information from all members of our research boards and the Expert Review Network ([TERN](#)). A full analysis has been published and you can read the full report [here](#).
- We invited Early Career Researchers (ECRs) to observe our Catalyst Awards Round 2 TERN Review Panel meeting in September. They were able to listen to the panel's discussions, to better understand how funding decisions are made. And what makes a successful application.
- We planned to recruit ECRs to each of our advisory panels and groups. This has been more challenging than expected. To tackle this, we've discussed the barriers that exist to participation with our [ECR Network Steering Group](#).
- Appointing an EDI officer to each of our advisory panels and groups has also been difficult. We've written a description of the role and responsibilities of an EDI Officer. And we've begun to ask current members of our groups whether they have the expertise to take on this role. However, currently, no-one has stepped forward. In the absence of dedicated EDI officers on all our panels, we've been including time for relevant EDI discussions at every advisory panel meeting. And to stimulate conversation, all programme leads were asked to give a verbal update on their EDI progress in their yearly progress review meetings.

b. 2024 priorities

- We'll continue to offer ECRs the opportunity to observe our grant review panels. And we'll place a particular focus on encouraging those from under-represented groups to apply for these opportunities.

- Based on feedback from our ECR Network Steering Group, we're developing a plan for facilitating the involvement of ECRs in our governance groups. This includes developing a defined role description and targeted recruitment of ECRs with specific and relevant skill sets.
- We'll continue to make an active effort to recruit people from ethnic minority backgrounds to our governance groups, to ensure that diverse voices are represented.
- We'll undertake targeted recruitment of people with EDI expertise to our governance groups, as vacancies arise.
- Improving the Terms of Reference for each of our governance groups to ensure they're fully inclusive.
- We'll continue to collect and publish demographic data on members of our governance groups.

4. Making our clinical trials more inclusive



Clinical research doesn't currently represent all people affected by MS, leading to treatments and services that are not appropriate for everyone. It's essential to understand the needs of different communities and the barriers that exist that prevent their inclusion.

a. 2023 successes

- We're co-funding [REFUEL-MS](#) and supporting the team with their communications strategy. Diversity is an important aspect of REFUEL-MS. And the team are doing in-depth interviews with people from seldom heard, under-represented groups, to ensure they can fully understand the social care needs of everyone living with MS.
- [The UK MS Register](#) have been collecting demographic data from its participants. We've worked with the Register's Executive Oversight Committee to set targets to push for improvement in the diversity of people with MS who engage with the Register. These will be reported against yearly.
- We've been helping the [Octopus](#) trial team to work through the [NIHR INCLUDE ethnicity toolkit](#). This toolkit provides guidance to support trial teams to improve inclusion of people from under-represented groups in their clinical trials.

Spotlight – Improving diversity of Octopus participants

Octopus has an important role in widening out study participation. We're supporting the Octopus trial team to recruit people from diverse backgrounds to make their results widely applicable to people with MS. And to think about what challenges there are to make this possible. Together with the Octopus trial team, we hosted an EDI workshop consulting with people affected by MS to discuss the barriers to participation in Octopus and strategies for how these can be overcome. This led to clear actions that are being implemented into the design of Octopus.

A snapshot of these actions include:

- Additional provisions for those needing assistance with written and spoken English. For example, people with low vision, English-speakers with low literacy and non-English speakers.
- Developing resources to support radiographers and people with MS who may struggle to undergo an MRI.
- Non-digital methods of registering interest in Octopus to avoid exclusion of people with limited access to technology
- Factsheets detailing the absence of animal products within the tested medications and the approach to religious fasting during the course of the trial.
- Increased number and variety of communication channels to reach people who may not have previously engaged with clinical trials
- Build in regular feedback from trial participants to identify barriers to participation as the trial progresses.

b. 2024 priorities

- Continue to review our communications plan to ensure people from all backgrounds know about opportunities and ways to take part in research. And understand how research works.
- Share case studies showcasing best practice examples of researchers considering EDI in their research.
- Exploring face to face events with people from under-represented communities to increase awareness of current research opportunities.
- Publish guidance to help our new clinical trials to collect and report on the demographic characteristics of participants.
- In 2024 we'll get a first look at the diversity of participants enrolled in Octopus so far. This data will be reviewed by relevant Octopus advisory panels. And strategies

put in place to increase representation from people from any under-represented groups.

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



People affected by MS are at the heart of our research programme. Our [Research Network volunteers](#) help shape MS research to make sure it's relevant to everyone affected by MS. Therefore, it's essential that our Network is diverse, containing as many voices as possible to ensure the needs of individuals and communities of people are considered in our research strategy and the research we fund.

a. 2023 successes

- We've developed and implemented a survey to collect demographic information for our Research Network members.
- We've engaged with our [EDI Reference Group](#) several times this year to receive feedback on our plans and ways of working. We've made several changes based on this feedback including:
 - Our welcoming email to new Network members now includes an invite to share with us any access or reasonable adjustments that would facilitate their involvement.
 - Network members can now request the monthly research involvement opportunities via post or a telephone call, if email is less accessible to them.
 - We've changed the format of the monthly email to make it more accessible and inclusive

b. 2024 priorities

- We'll publish a detailed analysis of the collected demographic data from the Research Network to show how diverse we currently are.
- Face to face initiatives at local MS groups and engagement events, to raise awareness of the network with those who don't engage online as much.
- Targeted recruitment of people from under-represented groups to the Network. We're working with our EDI Reference Group to help identify appropriate media channels for engagement.
- Scope the appetite for face to face events with people from under-represented communities to increase awareness of current research opportunities.

Spotlight – Pilot event in South London

We partnered with Parkinson’s UK and the Alzheimer’s Society to deliver a [research outreach event](#), specifically aimed at the Black community in South London. This event was held at Lambeth Town Hall in March 2023. People were able to talk with stallholders including local support groups, neuro physiotherapists, benefits advisors and clinical researchers. And hear from a panel of people affected by each condition who shared their real life experiences with participation in clinical trials.

Most importantly, the people who attended the event were able to meet and hear from people with similar experiences, connect with each other and share their own individual journeys, in some cases for the very first time.

The atmosphere allowed people to share and ask questions about their experiences in research and healthcare. And a common barrier to participation became clear. A lack of trust in healthcare environments due to systemic discrimination had left people feeling isolated and unheard by healthcare professionals.

We can’t repair this trust overnight. But we hope the learnings we gain and the connections we build through events like this will help us to implement changes that empower people to feel more comfortable engaging with healthcare professionals, to manage their own conditions and participate in research. Treatment and support services can only help everyone when research includes everyone.

6. Build the research knowledge of MS



Consistent under-representation in MS research means there are gaps in our understanding of MS in certain communities of people. We want to stimulate the research community to fill in these gaps to make sure we understand the biology of MS and how it relates to all people with MS.

a. 2023 successes

- We continue to support the [ADAMS study](#) looking at the genetics of MS in Black and South Asian people, inviting the team to attend talks and events to raise awareness.
- There has been increasing interest in diversity in MS research from the wider community. We have seen an increase in applications to our grant rounds for research into under-represented groups and their needs. This means we haven’t needed to develop a targeted call for proposals.

b. 2024 priorities

- We'll continue to encourage applications from researchers who have designed studies focusing on MS in under-represented groups. We'll also encourage applications from researchers who created strategies to encourage recruitment of participants from diverse backgrounds.

If you have any questions please email us:

research@msociety.org.uk