

A large, stylized graphic element consisting of a central orange triangle pointing to the right, surrounded by a white outline that forms a larger, irregular shape. The background of the page is white with orange geometric shapes and lines.

**EDI action plan for MS
Society research**

EDI action plan for MS Society research

In our 2020-2024 organisational strategy, we commit to transforming the way we work to put diversity and inclusion at the heart of everything we do. This year we have consulted with people affected by MS and our staff and volunteers to develop an equality, diversity and inclusion (EDI) strategy which sets out how we will deliver on this commitment. Supporting the strategy is an action plan of the activity required across the different areas in which the MS Society works.

The EDI action plan for MS Society research outlines the work the Research team will deliver between now and 2024. This version is our starting point – it has been informed by discussions with MS researchers, published research literature and learnings from other medical research charities. But we will continue to consult with the research community and people affected by MS and refine it as we go. We will report on progress and review and update the actions annually.

Areas of focus

1. MS research careers – attracting and retaining more diverse talent into the MS research community will drive innovation and improve the quality and inclusivity of MS research.
2. Our research boards, committees and grants panels – increasing diversity among our expert advisors will make our research strategy relevant to more people in our MS community. It will also increase the quality and relevance of the research we fund.
3. Our funded clinical research – making the clinical trials and studies we fund more inclusive to people with MS from different backgrounds. This will mean more people will benefit from the outcomes and future health inequalities may be reduced.
4. Our public involvement programme – increasing the diversity of our Research Network volunteers who help shape research. This will contribute to wider relevance and improved inclusivity of research studies and clinical trials.
5. Building the evidence base – we will look at research funding options to learn more about the development and impact of MS in people typically excluded from MS research.

1. MS research careers

We want to increase the diversity of those coming into MS research and develop more inclusive policies and research culture so that a greater range of people are able to develop successful careers.

We collected 24 people's demographic information from 45 applications to our 2021 grant round. Although only a small number of people took part, the gender split (13

out of 24 were women), sexual orientation (3 out of 24 were gay or lesbian) and disability status (6 out of 24 were disabled) of applicants was fairly representative of the UK population. The age range of applicants (32 to 69 years) reflects the typical age range of doctoral researchers but suggests younger researchers are not applying.

We saw the greatest inequality when looking at ethnicity, with 22 of the 24 respondents identifying as White. We need more data to further investigate applicant diversity, particularly to break down the different ethnic backgrounds. For the 2021 grant round, two thirds (30 out of 45) of the applications we received were from lead applicants based at Russell Group Universities or associated hospitals. We do not currently hold demographic data on our grant holders to evaluate the success rates for researchers with different characteristics, but will introduce this monitoring in 2022.

Actions for improvement:

- a. We will collect further data to assess the diversity of our research grant applicants and develop a plan to increase applications from under-represented groups. This will include identifying appropriate communication channels to reach them and showcasing the stories of researchers from these groups to demonstrate research can be a viable career path for a broad range of people.
- b. To increase the number of grant recipients from diverse backgrounds we will review and improve our selection processes. Elements of our existing selection framework, such as a focus on having published research and on career timelines, favours people from certain socioeconomic and cultural groups. We will adapt the MRC applicant framework for use by our peer reviewers and panels, as it has been shown to increase the diversity of successful MRC applicants.
- c. To improve retention of researchers from diverse backgrounds in MS research careers we will update our award Terms and Conditions to be more inclusive. We will develop and communicate positions on part-time fellowships and on maternity, paternity, adoption and carer leave for grant holders to reduce the impact of career breaks on research careers.
- d. We will follow up on our previously funded early-career researchers to identify whether people from certain backgrounds are more likely to be lost from MS research. We'll also identify barriers to career progression among these groups. This work will inform future plans to improve retention of researchers from diverse backgrounds.

2. Our research boards, committees and grants panels

Our research boards, committees and grants panels are made up of experts in the MS research field. They help us set our research strategy and advise us on our larger research programmes. Our grants panels help decide which research projects we should fund. It is important the way we manage our funding is inclusive and includes diverse voices to make our research strategy and funding high-quality and relevant to more people in the MS community. We have already worked to improve the

representation of women on our boards, committees and panels but other characteristics of our members are currently unknown.

Actions for improvement:

- a. By the end of 2022 we will have 50% women and at least 10% from ethnic minority backgrounds across all our research governance boards and committees collectively. We will collect and review data on other characteristics like disability status, geography, career status and sexual orientation to consider if additional targets are necessary. We will introduce the same targets for The Expert Review Network who support our funding decisions. We will strive for similar levels of representation within our smaller committees and panels but not set definite targets, due to their size and the need to represent specific professional expertise.
- b. To make sure our all boards, committee and panel members can contribute and stay engaged we will review and improve all relevant Terms of Reference for inclusivity. We will add an EDI Officer role to our committees to ensure EDI concerns are raised in all relevant discussions
- c. We will add two additional member roles to each of our boards, committees and panels for early career researchers from different backgrounds. This will increase the diversity of our panels and support a growing, more diverse group of experienced researchers to make up future panels.

3. Our funded clinical research

Clinical trials and studies across many conditions including MS predominately recruit White people from higher socioeconomic backgrounds. This can ultimately lead to healthcare solutions that are not appropriate or effective for people from other backgrounds. People from other backgrounds are also not directly benefitting from participating in trials (for example increased engagement with and active management from clinicians).

As a funder of several clinical trials in MS, we can play a role in widening out study participation to include more diverse populations. We can also share best practice in recruiting diverse groups of people with MS to influence the recruitment to MS studies that we do not fund.

Actions for improvement:

- a. Support research to evaluate the inclusivity of UK MS research and understand the barriers to research participation among people with MS from ethnic minorities and low socioeconomic backgrounds.
- b. Improve participation of people from ethnic minorities and lower socioeconomic groups in our funded clinical trials, including 'Octopus' our new clinical trials platform. Include a requirement for our future funded trials and studies to collect and report on the characteristics of participants and encourage study teams to use available resources, like the NIHR INCLUDE

ethnicity toolkit. We will work with our funded trials on action plans and consider setting future targets as appropriate.

- c. Provide support to increase the number of registered participants in the MS Register and Tissue Bank from ethnic minorities and other under-represented groups of people with MS. Initially, we will review data from people currently involved and consider setting future targets linked to action plans.
- d. Increase awareness and understanding of research opportunities among people under-represented in MS research. Run focus groups with different community groups to understand how they access information and then audit and improve our communication methods to better reach them. Tell research stories to highlight barriers to participation to demonstrate research can be open to all.

4. Public involvement in research

Our Research Network volunteers help shape MS research to ensure that it is meaningful and relevant to people affected by the condition. Research Network members also help to make sure clinical studies consider the needs of participants.

Anecdotally, we know the network does not reflect the diversity of the MS community in the UK. This means the needs of some individuals and communities are not considered in the design of research studies. Increasing the diversity of this network will contribute to improved inclusivity of research studies and clinical trials.

Actions for improvement:

- a. We will work alongside our volunteer team, other charities, through the AMRC and with local community groups to increase the diversity of the Research Network. We will collect demographic data on the Network to identify under-represented groups and set a baseline from which to measure progress. We will start by proactively engaging younger people with MS and people from ethnic minorities.
- b. We will assess the Research Network for areas that could be more inclusive, for example, how we advertise the network, the specifics of the role description and developing a position on paying for public contributors into grants to address socioeconomic barriers.

5. Build the evidence base on MS in under-researched groups

As we work to improve the inclusivity of MS research, we can also work to fill specific gaps in our understanding of MS in communities previously excluded from research studies. We are already doing this for people with more advanced MS through our funding of trials like ChariotMS and the International Progressive MS Alliance. We also want to stimulate the research community to investigate MS in other under-research

groups, starting initially with ethnic minorities and then broadening out to other groups as our understanding grows.

- a. Scope mechanisms to encourage and fund new research to understand MS in groups have been excluded or under-represented in MS research.

Our action plan

1. MS research careers

Outcome	Actions
a Increase the number of research applicants from diverse backgrounds	<ol style="list-style-type: none"> 1. Introduce demographic monitoring for all our grant applicants and recipients and report on these figures publicly by December 2022 2. Use collected demographic information to inform a plan to increase applications from under-represented groups by March 2023 3. Showcase the stories of researchers from different groups including minorities and disabled researchers by December 2022
b Increase the number of grant holders from diverse backgrounds	<ol style="list-style-type: none"> 4. Adapt the MRC applicant framework for use by our career development application reviewers and our review panel by our 2022 grant round 5. Introduce information on unconscious bias into our review guidance and panel meetings by the end of 2021
c Increase the number of researchers from diverse backgrounds who are retained in MS research careers	<ol style="list-style-type: none"> 6. Review and update our award Terms and Conditions to be more inclusive, including developing positions on part-time roles and maternity, paternity, adoption and carer leave by the end of 2022
d Better understand the factors that contribute to people leaving MS research	<ol style="list-style-type: none"> 7. Follow up the careers of our funded early-career researchers to identify factors contributing to researchers from different groups leaving MS research by June 2024

2. Our research boards, committees and grants panels

Outcome	Actions
<p>a Across our boards, committees and panels, we will have an average representation of 50% women and at least 10% from ethnic minority backgrounds</p>	<ol style="list-style-type: none"> 1. Collect demographic data our research governance boards, committees and The Expert Review Network and report aggregated data (not at an individual board level) by March 2022 2. Conduct focused recruitment to vacant positions to meet targets by January 2023
<p>b Improve the running of our boards, committees and panels to be more inclusive</p>	<ol style="list-style-type: none"> 3. Add an EDI officer role to each committee to ensure EDI concerns are raised in all relevant discussions by the end of 2022 4. Review and improve all relevant Terms of Reference for inclusivity by the end of 2022
<p>c Build up a more diverse pool of MS researchers for future panels</p>	<ol style="list-style-type: none"> 5. Add two additional member roles to each of our boards, committees and panels for early career researchers from different backgrounds by June 2023

3. Our funded clinical trials and studies

Outcomes	Actions
<p>a Understand which groups of people with MS are under-represented in clinical research</p>	<ol style="list-style-type: none"> 1. Support a Master’s degree project at University College London into inclusivity in UK-based multiple sclerosis clinical trials by the end of 2022 2. Include a requirement for collecting and reporting characteristics of participants for any new funded clinical studies to set a baseline and monitor changes from 2022
<p>b Improve participation of people from ethnic minorities and lower socioeconomic groups in our funded clinical trials</p>	<ol style="list-style-type: none"> 3. Require grant applicants to explain how they will work to ensure that people taking part in their research are demographically representative of the UK MS population from 2022 4. Work through the NIHR INCLUDE ethnicity toolkit with the Octopus team to reduce barriers to participation by people with MS from ethnic minority backgrounds by the end of March 2022 5. Use evidence from the Master’s project to inform guidance and support for MS researchers to consider recruitment targets for under-represented groups by the end of 2024.
<p>c Increase the diversity of participants in the MS Register and Tissue bank</p>	<ol style="list-style-type: none"> 6. Include a requirement to collect and report on participant characteristics in annual reports by July 2022 7. Review baseline data of people on the MS register to consider diversity action plans and setting future targets by December 2023
<p>d Increase awareness of research opportunities among under-represented groups of people with MS</p>	<ol style="list-style-type: none"> 8. Use our understanding of how different communities access information to improve our research communications plan by December 2022 9. Tell three research stories to highlight barriers to participation by December 2022

4. Public involvement in research

Outcomes	Action
<p>a Increase the diversity of the Research Network and our public involvement programme</p>	<ol style="list-style-type: none"> 1. Collect demographic data on the Research Network to set a baseline and identify under-represented groups by December 2021 2. Work across charities and through the Association for Medical Research Charities to build connections with local, diverse communities by June 2022 3. Build on volunteer consultation evidence to do proactive outreach to ethnic minorities and younger people with MS by June 2022
<p>b Improve the inclusivity of the Research Network role</p>	<ol style="list-style-type: none"> 4. Review Research Network role description and ways of working for barriers to inclusivity by June 2023 5. Develop a position on costing PPI contributor payment into grants to address socioeconomic barriers by June 2023

5. Build the evidence

Outcomes	Action
<p>a Encourage and fund new research to understand MS in groups have been excluded or under-represented in MS research.</p>	<ol style="list-style-type: none"> 1. Scope options for funding or partnering on studies to improve the evidence base on MS in people from ethnic minorities by the end of 2022 2. Use the outcomes from outcomes 3a and 3c to identify other groups excluded or under-represented in MS research. We will develop mechanisms to fund research into these groups in future years by the end of 2024.

We're the MS Society.

Our community is here for you through the highs, lows and everything in between.

We understand what life's like with MS.

Together, we are strong enough to stop MS.

mssociety.org.uk



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 **Let's stop MS together**