MS Society equity, equality, diversity and inclusion (EEDI) in research action plan

2025-2029

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Foreword

Our vision is clear: we want a world free from the effects of MS. But getting there isn't simple, because MS is anything but simple.

In the UK, more than 150,000 people live with MS. Each one of their journeys is unique. People are diagnosed at different ages, experience different symptoms, respond differently to treatments, and face different challenges.

The reason for these differences starts with the condition itself. The biology of MS is complex, unpredictable and varies from person to person. But the biology of the condition doesn't act alone. It's shaped by the biology of the person living with it and their life circumstances. This includes:

- Genetics
- Race and ethnicity
- Sex and gender
- Age
- Income
- Level of disability
- Major life events like pregnancy
- The support of family, friends and healthcare professionals

This complexity is why MS is deeply personal, and why no two people experience it in the same way. But research hasn't always reflected this complexity. We have gaps in our understanding of the biology of MS and how it progresses in different people. And how easily people can access the treatments and care they need.

We want better treatments, care and support that works for everyone. So research must reflect the full diversity of people living with MS in the UK.

That means diversity in who takes part in research, and diversity in who drives it. Both matter. The people who participate in research are important. But so are the voices shaping research: researchers, people affected by MS and decision makers. Because, together, they decide which questions are asked, how studies are designed and what research is prioritised. If their perspectives don't reflect the diversity of people affected by MS, the solutions won't either.

As the UK's largest charitable funder of MS research, we're committed to funding inclusive research. We need to explore how the differences between people shape their experience of MS. To do this, we're taking a holistic approach and looking at every part of the research process.

Together, we want to work towards a future free from the effects of MS. One that truly reflects the diverse, complex, unique journeys of everyone affected.

Definitions

Equality means giving everyone the same opportunities, and making sure no one is treated unfairly because of who they are. It also means taking action to remove barriers, both visible and invisible, so everyone can participate fully.

Equity means recognising and addressing the unique needs and barriers that different individuals or groups may face. It's about understanding these differences and making adjustments to help level the playing field.

Diversity means respecting and valuing the differences between people. It includes recognising different identities, backgrounds and experiences, and making sure everyone has equitable access to opportunities and decision making. Diversity also means actively working to address under-representation.

Inclusion means creating an environment where everyone feels respected, valued and able to contribute. It makes sure that diverse voices are heard and that different perspectives are considered. And that everyone feels a sense of belonging and can reach their full potential.

Marginalised groups are communities or individuals that experience social, economic, and political disadvantages. This could be due to their race, ethnicity, religion, sex, gender, sexual orientation, disability, or the amount of money they have. These groups often face exclusion or discrimination, leading to them having less access to resources, opportunities and support.

Under-represented groups are communities or individuals who have limited representation and voice in society, education, politics and decision-making processes. This includes research. It's usually marginalised groups that're under-represented.

Our EEDI in research action plan

This is the second iteration of our EEDI in research action plan. Our first plan ran from 2021 to 2024. During that time, we learned a lot about how to influence EEDI within MS research. We also better understand the ongoing challenges and we've made some real progress. You can read about our progress so far in our 2021-2024 EEDI in research progress report and our 2021-2024 demographic data report.

Since 2021, the world and the research landscape have continued to change. We've seen new opportunities and wider conversations about equity and representation in science and in healthcare. And in society more broadly.

Before writing this new plan, we took time to pause and reflect on these changes. We looked at what's changed, where momentum is being built, and where barriers still exist. We listened to researchers and people affected by MS. We asked ourselves: where are we making progress? What's been slower than we hoped? Where do we go next, and how do we get there?

To guide our thinking, we worked through a "theory of change" approach. It helped us think about the long-term difference we want to make. And the practical steps needed to achieve it. The result is this updated action plan, running from 2025 to 2029. It builds on what we've started and gives us a clear roadmap to help us reach our goals. It gives us refreshed priorities, practical steps, and a focus on real impact.

Our plan is more than a set of actions. It's a renewed commitment to deliver MS Society research that better serves all people with MS. It reflects their diverse experiences and needs. And gives a broader range of researchers and people affected by MS the opportunity to contribute to research.

Our priority areas

Our plan is driven by a long-term vision. We want a more diverse, inclusive, equitable research system that improves the lives of everyone affected by MS.

To support this vision, we've identified four priority areas where we can make meaningful changes towards this goal.

1. **MS research careers**
2. **Our advisory and funding panels**
3. **Our funded research**
4. **Our public and participant involvement (PPI) programme**

Each priority area is guided by a long-term goal that extends beyond the lifetime of this five-year plan. To help us move towards these goals, we've set realistic aims for where we want to be by 2029. As well as practical actions to get us there. This combination of ambition and action gives us a clear path forward. We're making progress in the short-term while keeping our sight on the long-term difference we want to make.

At the heart of this plan there're four principles that'll guide everything we do.

Our principles

1. Listen and learn

We'll actively seek out diverse lived experiences. We'll make space for open conversations. And we'll make sure the research we fund is shaped by the needs of the people it's meant to help.

2. Work with others

Collaborations make our impact bigger. By working with people and organisations who have the right experience and resources, we can achieve greater, longer-lasting results.

3. Be dynamic and responsive

Society and the research landscape are constantly changing. We commit to regularly reviewing our approach, learning from what works (and what doesn't). And adapting as new challenges and opportunities come up.

4. Generate and be informed by evidence

We'll continue to fund research that helps us better understand how MS affects different people. But building a stronger evidence base isn't just about funding individual projects. It's about embedding EEDI across every stage of the research ecosystem. All four of our areas of focus work together to strengthen the evidence we rely on. We'll use this evidence, along with expert knowledge and the real-life experiences of people affected by MS, to guide our work. And make sure our actions are informed, thoughtful, and responsive to the needs of our community.

Our Vision

A more diverse, inclusive, equitable MS research system that improves the lives of everyone affected by MS

Our priority areas

- **MS research careers**
- **Our advisory and funding panels**
- **Our funded research**
- **Our public and participant involvement programme**

Our long-term goals

- A research workforce that reflects the diversity of the wider UK research workforce. And where everyone has equal access to funding, opportunities and career progression, no matter their background
- Advisory and funding panels that draw on diverse experience to make inclusive and unbiased decisions that better serve the whole MS community
- Research that actively considers the diversity of the MS community. And provides opportunities for people from all backgrounds to take part so that findings are relevant for everyone living with MS
- People affected by MS, from all walks of life, help shape our research programme. So, the research we fund truly reflects the needs and realities of the whole MS community

Our principles

- Listen and learn
- Work with others
- Be dynamic and responsive
- Be informed by evidence

Focus area one: MS research careers

What's the problem?

People from marginalised and under-represented backgrounds often face barriers that make it harder to enter, stay and progress in a career in research. Especially into senior leadership roles. This means the MS research workforce, like the wider UK research sector, isn't as diverse or representative as it should be.

Why is this important?

Everyone should have an equal opportunity to contribute to and succeed in research. When we create a system where all researchers can succeed, no matter their background, we open the door to better science.

A more diverse research workforce brings a wider range of experiences, ideas and perspectives to the table. This helps us spot gaps in knowledge, challenge assumptions. And make sure research reflects both the complexity of MS and the diversity of people affected by it. The result is more relevant research questions and more inclusive study design. And ultimately, outcomes that have a bigger impact for everyone affected by MS.

What's our goal?

We want a research workforce that better reflects the diversity of the wider UK research workforce. And where everyone has equal access to funding, opportunities and career progression, no matter what their background.

Our aim for 2029	How will we get there?
We see a more diverse pool of researchers applying for our grants, with every applicant having an equal chance of success	**We'll continue to monitor and publish data on who applies for and receives our funding** **Why:** To identify where groups are under-represented **We'll take targeted action where we see under-representation or lower success rates for obtaining funding** **Why:** To remove barriers and make sure every researcher has an equal chance of success **We'll continue to publish case studies of researchers from marginalised backgrounds** **Why:** To increase visibility and showcase the research and career pathways of researchers from marginalised backgrounds **We'll continuously review our funding policies and processes** **Why:** To remove biases and make sure funding decisions are fair, consistent and based on merit
MS researchers from marginalised groups are better supported throughout their careers	**We'll ask applicants and award holders to explain how they're creating diverse and inclusive research environments. Including the recruitment and training of staff and students** **Why:** To support all MS researchers to thrive **We'll pilot an accessibility grant to help researchers who have additional needs** **Why:** To reduce practical barriers preventing people from participating in conferences and events **We'll scope partnership funding specifically for researchers from marginalised groups** **Why:** To provide dedicated resources that address gaps in access to funding and career support **We'll identify and highlight leadership training and career development opportunities offered by other organisations for researchers from marginalised groups** **Why:** To provide researchers with the skills, networks and support needed to progress into senior roles **We'll increase the diversity of our ECR Network Steering Group.** **Why:** To make sure the support we offer our ECRs reflects a wide range of experiences and perspectives

Focus area two: Our advisory and funding panels

What's the problem?

Our advisory and funding panels don't yet reflect the full diversity of the MS community or the wider UK research workforce. And there're opportunities to improve the way EEDI is considered and embedded in decision-making processes.

Why is this important?

Our advisory and funding panels shape MS research with every decision they make. When these decisions are made by a group that lacks diversity of thought, expertise and lived experience, research can fall short. It may unintentionally reinforce bias and fail to address the needs of the whole MS community.

Representation alone is not enough. Decision-makers also need the right skills, resources and confidence to make fair and inclusive decisions. With the right mix of people and skills, panels are better able to recognise and challenge bias. They can identify gaps in knowledge and prioritise projects with inclusive study designs.

By supporting our panels, we create a system where strong EEDI plans are recognised and rewarded. This sets a benchmark for best practice and encourages researchers to design more inclusive research. Ultimately, leading to research that better reflects the complexity of MS and produces richer, more relevant data. And builds a stronger evidence base for better treatments, care and policies.

What's our goal?

We want advisory and funding panels that draw on diverse experience. They make inclusive and unbiased decisions that better serve the whole MS community.

Our aims by 2029	How will we get there?
Our advisory and funding panels better reflect the diversity of the UK academic workforce and our Research Network	**We'll continue to monitor the diversity of our panels** **Why:** To identify gaps in representation **We'll take further corrective actions if groups of people are under-represented** **Why:** To ensure fair and balanced participation **We'll make our recruitment approach more transparent and widen its reach** **Why:** To make sure opportunities are open and accessible to more people **We'll scope a 'buddy scheme' to support ECRs to join The Expert Review Network (TERN)** **Why:** To reduce barriers to participation and support greater ECR involvement in our panels **We'll address barriers that prevent Research Network members from marginalised groups joining our panels** **Why:** To make involvement accessible and equitable for all Research Network members **We'll work with other charities to find sector-wide solutions** **Why:** To tackle systemic challenges that can't be solved by one organisation alone
Members of our advisory and funding panels have the skills and confidence to better consider, evaluate and champion EEDI in funding decisions	**We'll develop guidance for grant reviewers on how to assess the quality of EEDI plans** **Why:** To make sure EEDI is assessed consistently and fairly across all funding decisions **We'll dedicate time in advisory panel meetings to discuss EEDI** **Why:** To build a culture where EEDI is championed and embedded into decision making **We'll improve our meeting practices to make sure all voices are heard equally** **Why:** To avoid bias, encourage different perspectives, and make better informed decisions

Focus area three: Our funded research

What's the problem?

Not all MS research fully considers the differences in how people experience MS. And some groups of people are consistently under-represented in research. This includes:

- People living in rural areas
- People with higher levels of disability
- People with less education or money
- Older people
- People from minoritisied ethnic groups
- Pregnant people
- Anyone who already experiences other health inequalities. For example, reduced access to healthcare professionals and services.

Why is this important?

MS affects everyone differently. Our biology, environment, and life circumstances all influence how MS develops, how symptoms are experienced, and how people respond to interventions.

Research must ask the right questions and include representation from across the whole MS community. Without this commitment, we may miss important biological and social differences that exist between people. This means research findings may not be relevant to everyone. And we risk developing treatments and care that work for some people, but not for others.

Applicants need to be asked the right questions about how they'll embed EEDI into every part of their research. Including study design, the methods used and the recruitment of participants. With the right guidance, support and resources, applicants can create meaningful EEDI plans that strengthen their research.

Inclusive research helps make sure the results of research reflect the full complexity of MS. It reduces the risk of overlooking important differences and leads to better outcomes for everyone. This is true across all types of MS research from laboratory studies to clinical trials.

What's our goal?

We want research that actively considers the diversity of the MS community and provides opportunities for people from all backgrounds to take part. So that findings are relevant for everyone living with MS.

Our aims by 2029	How will we get there?
We provide researchers with the tools and resources they need to design and deliver more inclusive research	**We'll ensure our grant application process asks relevant questions about EEDI and provide guidance to help applicants plan effectively** **Why:** To encourage applicants to build thoughtful EEDI plans and to give panels the information they need to assess their quality **We'll share resources and examples of best practice for inclusive research design through our online EEDI Hub and at in-person events** **Why:** To give researchers practical guidance and real-world examples they can use to make their own research more inclusive **We'll scope funding options to support the additional costs of inclusive research design** **Why:** To remove financial barriers that stop researchers from making their research inclusive
Our researchers have a clear understanding of who (and who isn't) represented in their studies	**We'll develop guidance to help researchers collect and share demographic data** **Why:** To make sure demographic data is gathered in an appropriate and consistent way **We'll require study leads to share demographic data on who takes part in their research as part of their annual reports** **Why:** To hold ourselves and our researchers accountable for improving representation **We'll analyse and publish aggregated demographic data from across our funded studies** **Why:** To highlight where the gaps exist, track progress over time and encourage greater inclusivity
We support researchers to reduce barriers that prevent people from taking part in their research	**We'll facilitate connections between people affected by MS from marginalised groups, researchers and healthcare professionals** **Why:** To help build trust, improve understanding, and make research more accessible to people who're often excluded **We'll review how we communicate about our funded studies, with a focus on reaching people from marginalised groups** **Why:** To make sure opportunities reach people from marginalised groups **We'll develop content that addresses barriers to participation** **Why:** To give people clear information and reassurance they need to feel confident to participate

Focus area four: Our patient and public involvement (PPI) programme

What’s the problem?

Our Research Network doesn’t reflect the diversity of the MS community. We also know people from marginalised backgrounds are less likely to take part in PPI activities or stay involved over time. We want people affected by MS, from all walks of life, to help shape our research programme. So, the research we fund truly reflects the needs and realities of the whole MS community.

Why is this important?

Our Research Network is made up of people affected by MS who use their lived experiences expertise to shape and guide MS research. To make sure it reflects the needs and experiences of people living with MS. This involvement is distinct from participation in clinical studies. Our Research Network members help us decide which research to fund. And they collaborate with researchers, helping them design, deliver and talk about their research.

At its core, our Research Network exists to put the voices and needs of people with MS at the heart of MS research. If our PPI programme doesn’t reflect the diversity of the MS community, then we fall short of this purpose. When some voices and needs go unheard, we risk missing the priorities and needs of everyone affected by MS. Especially those most affected by gaps in knowledge, healthcare access, and health inequalities.

Inclusive PPI helps us challenge bias and assumptions, identify gaps in knowledge and design research that’s both accessible and relevant. And better able to improve care, treatment and quality of life for all people with MS.

What’s our goal?

We want people affected by MS, from all walks of life, to help shape our research programme. So, the research we fund truly reflects the needs and realities of the whole MS community.

Our aims by 2029	How will we get there?
We’ve increased the diversity of our Research Network and better understand how people want to engage with it	**We’ll continue to monitor the diversity of our Research Network membership** **Why:** To identify gaps in representation **We’ll take further corrective actions where we see under-representation** **Why:** To remove barriers and make sure the Research Network reflects a wide range of voices and experiences **We’ll co-produce a communications strategy to help us better engage with people from under-represented groups** **Why:** To make sure our messaging and opportunities reach people and resonate with them **We’ll increase the ways people can complete the Research Network training** **Why:** To remove barriers and make it easier for more people to get involved **We’ll create regular feedback opportunities for Research Network members** **Why:** To understand their experiences and continuously improve the Network
More Research Network members from marginalised groups express an interest in PPI opportunities. And we help people stay involved once they join	**We’ll develop processes to track expressions of interest, selection and retention in PPI opportunities** **Why:** To understand who’s engaging, where barriers exist, and why people drop out **We’ll work with researchers to broaden how they do PPI and engage with people** **Why:** To create more inclusive and flexible opportunities that suit different needs and preferences **We’ll showcase examples of strong PPI impact and inclusive practices** **Why:** To highlight what works and encourage other researchers to adopt inclusive approaches **We’ll develop a payment policy to support people to take part in our involvement activities** **Why:** To reduce financial barriers that prevent people from taking part **We’ll pilot a scheme to create partnerships between community organisations and researchers** **Why:** To build trusted links with people from marginalised groups and open new routes to involvement

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.
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