EDI Strategy Report 2024 and Final Report (EDI strategy 2021-2024)

Introduction

When we launched our first EDI strategy, we had a clear ambition to address our ways of working to ensure we were there for everyone affected by MS. We recognised that we had become complacent and had even in fact perpetuated the barriers which some people experience in accessing our support and services.

Our EDI strategy was the first step in our EDI journey. A moment to pause and reflect. A moment to create an ambitious plan to address inequality and inequity in our ways of working and for the MS community. It was a genuine commitment to support change. However, we now recognise that we may have been naïve in our understanding of the scale of change we needed to go through to realise our ambitions.

Our ambition remains the same. The creation of an inclusive culture which amplifies marginalised voices to support equity in people's MS journeys. The creation of inclusive services and support so that our community feels represented and can find support with us. And that we continue to challenge to make sure that research into MS considers the diversity of people's experiences and symptoms.

As we stop and take stock of what we have achieved over the last 3 years, it is important to also recognise what we have failed to achieve and how we will learn from this as we move into the next phase of our EDI journey. Since 2021 as an organisation, we have been through a lot of change, with a lot more to come in 2025.

In this report, we share our key achievements in 2024 and over the past 3 years, our reflections on this progress and our plans for our ongoing EDI commitment.

Progress against our EDI Strategy

We have reported on progress against our EDI strategy each year. Further information about our progress in 2022 and 2023 can be found here:

- 2022 EDI strategy report
- 2023 EDI strategy report

Support and promote the voices of people who face discrimination

Our commitment

- To do more to understand the reach of our services
- To focus research on different groups of people with MS
- To campaign on injustices that affect minoritised groups in our community
- To use data and insight to understand the impact of new approaches

Our objectives

- our national and local campaigning proactively calling out inequality
- consideration of EDI impacts embedded in decision-making for Board-level strategic decisions
- all colleagues will have EDI in annual objectives
- a full policy position on reducing inequality amongst people with MS, accompanied by dedicated campaigning
- EDI considerations embedded in all our decision-making and project management processes.
- No more than 5% variation in access to health and care services compared to average for people with MS for:
  - people with MS from ethnic minority backgrounds

  - people with MS who say they are struggling on their income.

What progress have we made?

Campaigning

- We have continued to campaign against inequality for our MS community including the impact of the cost of living crisis on people affected by MS, particularly for those who experience high levels of financial insecurity.
- As a steering-group member of the Disability Benefits Consortium, we collaborate with over a hundred organisations, including small and grassroots groups to advocate for the disabled community. We pro-actively resource DBC capacity in policy development, influencing and securing media coverage.
- When the previous Conservative government proposed scrapping of the Work Capability Assessment and to make it harder for people living with MS who are unable to work to access financial support we pushed back and advocated for our community. In the end, the then government called a General Election before implementing changes.
- During the General Election, we worked with our co-production group to develop our activities and shape our calls for the future government. We also resourced capacity to support the Neurological Alliance's campaign actions throughout the election period, supporting to advocate for the wider neuro community, including rare conditions.
- We will continue to campaign on behalf of the MS community and will challenge inequalities in the experiences of people throughout their MS journey.

Our data and insight

We have expanded our understanding of the MS community and have updated our understanding of the prevalence and incidence of MS across the UK. The dataset we have been using to further our understanding has a lot more insight to provide and we will continue to use it to inform and drive our work. We had aimed to work with an academic institution on a project examining inequality and MS this year but have had to reorganise and change the timings of some of our social research in light of the General Election.

Equality impact assessments

We have developed an equality impact assessment framework to ensure that the impact of our work is understood. These assessments are built into our project planning, our strategy development and as a part of our policy review cycle.

Annual objectives

To support every colleague to find a link between their role and our EDI strategy. Every colleague has an EDI specific objective within their personal development review. This helps to embed EDI principles and approaches across all our work and supports colleague engagement with our strategy.

Our Board also set out their commitments and action plan. Read more about the Board EDI commitment here.

Broadening our reach

Our commitment

- To deliver a programme of bespoke outreach to groups we struggle to engage with
- To build on our insight and research to understand the experiences of MS for people from these groups
- To work with other organisations, giving them a platform and support
- To grow our impact and reach the whole MS community

Our objectives

Year-on-year we wanted to become more representative of society overall in terms of the people who:

- access our services
- engage with us on social media or through our website
- get involved in our work (for example, by campaigning or joining our research network).

What progress have we made?

Services and support

We have seen increased diversity through our Living Well webinars and online services where we are able to collect and monitor demographic data. This has helped us to learn that we can do more across our other services and support. We also started the early stages to work more in partnership with a range of organisations that can make a more compelling offer to a more diverse audience, for example with MS Together relating to younger people and Asian MS. There is a much stronger focus on this way of working in 2025 and beyond. A core element of Mead (one of the transformation programmes) is on how we make our services as accessible as possible to as wider audience as possible. We believe with new ways of working we will begin to see a broader demographic of people getting the support and services they need.

Brand

Our brand is now built on a foundation of accessibility and has been coproduced with our community to ensure it is open and accessible. Our font and colour palette are fully accessible, and inclusivity is considered at every stage of our new brand approach.

We are developing a more inclusive tailored approach to our brand language so that we can be more inclusive in how we can communicate with particular groups within our audiences. We recognise that we need the brand to recognise the breadth of inclusivity isn’t just visual or representation.

Visual representation

We have been working hard at our visual representation across all our engagement activity. In all activity where Brand is involved, we have ensured that representation of MS is realistic, authentic and not just a tick box.

As part of our new brand guidance we are developing, we will be provided so all teams across the organisation can follow the guidance to make sure we are improving the reality of MS across all engagement activity delivered externally by the charity.

EDI calendar

We established an EEDI Calendar to ensure we can recognise a number of important aspects of our audiences and their lives. The calendar will help us support teams around the organisation consider better personalised engagement communications that could resonate deeper.

More inclusive experiences for people affected by MS

Our commitment

- To make sure that any interaction with us is welcoming and accessible

- To create an infrastructure and build insights that consider the experiences of people living with MS, so that the outputs of our work are welcoming and accessible.
- To ensure that our communications are inclusive and tailored to our different audiences

Our objectives

- more and more people every year from minoritised ethnic groups and lower socio-economic groups responding to surveys saying the MS Society is for them.
- more than 5% difference between groups mentioned and overall scores. No more than 10% difference between any group mentioned in the Equality Act 2010 and overall scores.

What progress have we made?

Grow your community

To help support people set up community groups around shared interests we ran a pilot of a new approach, ‘Grow your community’. Following the pilot, which included a survey and a workshop, 61.5% of the people who took part were considering setting up a new MS group. We created some resources to support people in developing their communities which 69% of people said gave them all the information they needed. When we have updated our website functions we will fully launch this function to everyone.

Community focussed events

A key part of our EDI strategy was to do more to engage better with groups within the MS community who are currently underserved and under-represented. We have organised specific events and opportunities for these groups.

As we have run these events we have shared what we have learned and the feedback of people who attended. We have built this into our approach

Recruiting and fostering diverse talent

Our commitment

- To evolve our recruitment, learning and development and talent management to improve the diversity of our staff at all levels.
- To build an approach that attracts diverse candidates.
- To ensure inclusive recruitment and management processes.

Our objectives

- year-on-year increase in diversity of candidates applying for roles
- year-on-year increase in diversity of workforce at all levels
- promotions of people from underrepresented groups at least at equal levels to all other colleagues
- leavers reporting dissatisfaction with EDI issues was not a factor in their decision to leave

What progress have we made?

We have not made the progress we would have liked to in recruiting and fostering diverse talent. This is because we have not had the digital capability to monitor and analyse the relevant data across our recruitment, learning and talent management processes. We also have more work to do in building trust with our colleagues, so they feel safe to share their demographic data. We plan to introduce a new applicant tracking system in 2025 as well as improve our HR management system.

Building an inclusive culture

Our commitment

- To build skills and confidence to identify biases and micro-aggressions.
- To tackle racism and prejudice, wherever it occurs.
- To review our policies to make sure we are supporting and valuing difference.
- To embed EDI through decision making at every level.
- To ensure colleagues have an EDI objective within their formal objectives.

Our objectives

- year-on-year increases in colleagues who report in surveys that MS Society feels inclusive
- colleagues demonstrating increased awareness of EDI issues in their day-to-day work, evidenced by quality of work produced
- Staff surveys showing colleagues more confident in identifying and reporting bad behaviour.
- an overall positive inclusion score of at least 80% of survey respondents
- colleagues who identify as disabled, from an ethnic minority background, or who are LGBTQ+ having the same inclusion score as other staff and volunteers.

What progress have we made?

EDI training

We recruited an EDI trainer who has developed our expanded EDI training programme. A top-down approach with delivery starting with the Board. This will be followed by sessions for our executive, leaders and managers, all staff and volunteers in selected roles. The training programme has been designed based on insights and experiences gathered from across the organisation. The aim of the programme is to increase awareness of EDI related issues, provide people with the tools and knowledge to challenge and be active allies. And importantly to create behavioural and cultural change. As part of the training we will develop a plan to ensure that anyone who joins the organisation as staff or a volunteer has the same experience.

Challenging and tackling prejudice

Over recent years, as we have built our confidence as an active ally for our community we have experienced several instances of transphobia and homophobia. We do not tolerate any form of prejudice or discrimination. These awful experiences have taught us a lot about how we prepare and respond to future incidents. But more importantly how we protect people from our community so that they feel safe and supported as they share their stories and experiences. We are more aware of the importance of sharing diverse stories throughout the year and not just during particular awareness months or weeks.

Our policies and guidance documents

As our policies enter the review cycle they are all now required to contain an equality statement and have an equality impact assessment conducted on them. We are ensuring that our policies are inclusive, which includes using inclusive and gender-neutral language.

We have also introduced some new guidance documents to help our managers support colleagues more inclusively. These include guidance around;

- Religious inclusion
- Transitioning at work
- How to have sensitive conversations
- Reasonable adjustments

We have also published an EDI glossary to support colleagues understanding of language and terminology. Those terms which may cause offence and may be outdated as well as more inclusive terms.

Sharing stories and experiences

We have continued to hold ‘Lunch and Learn’ and ‘Inspiring Story’ sessions for colleagues. These sessions give colleagues the opportunity to hear different stories, experiences and perspectives. The focus of these sessions have included trauma and triggering, the social model of disability, trans awareness and inclusion, neurodivergence.

We have also created several support groups. These peer support groups are less formal than our staff network groups but all also challenge us to do more to support colleagues. Our support groups are for;

- Menopause
- Grief
- Baby loss and fertility journeys
- Neurodiversity

Supporting our staff networks

We currently have three staff networks which provide support for colleagues and allies.

- Reach – Race Ethnicity and Cultural Heritage – for colleagues from minoritised ethnic groups
- Spectrum – for LGBTQIA+ colleagues
- Purple – for disabled colleagues

While each network is an autonomous group which manages and runs itself in the way its members choose. We provide budget each year which the network chairs can use to pay for events or resources for their members. We also supported each of the network chairs to take part in the Radius training and have an additional place reserved for any future chairs.

ION partnership

To upskill our managers to provide better support to our neurodivergent colleagues and neuroinclusion we will be partnering with the Institute for Neurodiversity. We will work with them to delivery training around neuroinclusion, removing barriers for neurodivergent people, specialist resources and support services.

Recruiting and retaining diverse volunteers

Our commitment

- To widen our reach and attract a more diverse audience of volunteers.
- To break down the barriers to volunteering ensuring roles are flexible.
- To build a more inclusive volunteering culture.

Our objectives

- volunteer diversity increase in line with the UK population. We want our volunteer numbers to rise from 7% of volunteers being from non-White British backgrounds to 14%. And we want to see our average age decrease from 53 to 47.
- informal feedback that tells us our culture feels more inclusive

- volunteers who leave us not disproportionately being from under-represented groups.

We’ll use Leavers’ Survey data assessed against baseline data to assess this, including volunteers leaving from under-represented groups not citing EDI issues as a factor. We’ll use qualitative feedback from the Leavers’ Survey to assess this.

What progress have we made?

Volunteer Diversity

Significant progress has been made to diversify our volunteer network. At the end of 2024, 46% of all applicants were from a non-White British background, the average age range of new volunteers was between 31-40 and 11% of those are affected by MS, overall 20% identify as having a disability. 75% of prospective volunteers are from England with the remaining being either homebased or based in the Devolved Nations.

Targeted volunteer development work across the organisation has demonstrated in the importance of creating a variety of roles to attract a more diverse volunteer base. In May 2024 the development and recruitment of a Data and Governance volunteer had, 14 applications, 90% between ages of 18-40, 30% from Asian or Asian British and 70% from Black, Black British, Caribbean or African heritage.

Work to develop a volunteer role in the community was started at the the end of 2024, to provide support to Regional Development Officers to run focused events with ethnic minority groups, including attendance at Melas across the North of England in 2025.

The launch of Assemble, our volunteer management system in 2025 will support us to capture more consistent and accurate volunteer EEDI data across our volunteer network, not just those who are prospective volunteers or new to volunteering with us. We are also introducing a Volunteer Management Framework which will improve training and resources to Volunteer Managers to provide more effective support to volunteers and volunteer recruitment practices.

Research, research funding and clinical trials

Our commitment

- To collect and report data on the diversity of clinical trials and research programme participants.
- To understand the barriers to recruiting people with MS from diverse backgrounds into research studies.

What progress have we made?

Diversity of clinical trial participants

We’ve added a requirement that our new clinical trials must collect and report on the demographic characteristics of their studies participants. We’ve also developed resources, now available on our EDI hub, to support more consistent data collection and reporting.

We’re working with Award holders to support them to report their data to us. And we’ve now received the first sets of demographic data on participants from clinical research we fund.

Clinical study grant applicants must now explain how they’ll recruit a diverse group of research participants, who are representative of people with MS in the UK. We also added a question to all application forms asking applicants to describe how they've considered EDI in their public engagement and outreach activities. This means all applicants are now required to consider EDI in their applications. And not just those recruiting participants. This may help to raise awareness of research and encourage a broader range of people to take part in the future.

Diversity of those taking part in our research programmes

The UK MS Register and Tissue Bank teams attended the MS Society EDI reference group. The group provided feedback on both programme's communication and engagement plans. The teams have used this feedback to refine their plans to improve representation across their cohorts.

The UK MS Register has been collecting demographic data from its participants. We worked with the Registers Executive Oversight Committee to set targets to push for improvement. This data has now been publicly reported within MS Matters. The Register team have also developed a communications and engagement strategy. This strategy aims to improve representation of people who provide their data via the online portal or via their clinical records. This strategy is reviewed annually by the Executive Oversight Committee.

The MS Society Tissue Bank applied for ethics approval to collect demographic data from their living donors. They're now reaching out to all registered donors to ask them to provide their ethnicity.

Understanding and addressing barriers to recruiting people from diverse backgrounds to research studies

We've regularly consulted with the EDI Reference Group to inform how we can best deliver an inclusive research programme. In addition, we've facilitated several of our funded researcher programmes to consult with the EDI Reference Group, to receive feedback on their communication and recruitment plans.

We've recently established a new EDI Advisory Group for Research which include representatives from the MS clinical research sector, MS community-based organisations, EDI and research funding experts.

We're helping the Octopus trial team to work through the NIHR INCLUDE ethnicity toolkit. We helped the trial team to host a workshop with people affected by MS. This workshop explored the barriers to participation. The team have now actively implemented strategies to address these barriers and are continually exploring new ways to improve representation in Octopus.

We scoped different ways for how EDI activities can be meaningfully implemented within research to support inclusive recruitment. And scoped the costs of these activities. We increased the value of our Award rounds and changed our application guidance to allow costs for EDI activities as 'eligible' costs. Costs to upskill or recruit staff to better deliver and evaluate these activities are also eligible.

For more information see our EDI research action plan report

General EDI commitments

Our commitment

- To make sure we progress our plans.
- To build our insight in seldom heard groups of people living with MS.

Our objectives

- implementation of standardised EDI demographic data collection
- co-ordinated data collection and insight research work to broaden the breadth and depth of insights and evidence.
- Year-on-year improvement in the breadth and depth of data and insight we gather and use to understand different lived experiences, our progress and impact, and for decision-making.
- Greatly improved understanding of;
- the experiences of people affected by MS, staff, and volunteers from different minoritised groups
- the most effective role we can play in responding to them

What progress have we made?

Standardised data collection

We now use the Daisy guidance questions to ask people about their sensitive personal information. This means that we ask people for this information in a consistent way. But we have also improved our consideration of when it is and is not appropriate or relevant to ask people for this information.

Our EDI reference group

This group has been an incredible partner as we have begun our EDI journey. Set up in 2018 this group of people living with MS helped to shape and develop our EDI strategy. But since 2022 the group has expanded as we have welcomed more members, more people living with MS, people with a personal connection to MS and EDI experts. The group has supported some key projects and now also support and feed into the research EDI action plan. We have also created a new volunteer role, to make sure we are elevating and amplifying voices from this group across all our work. This volunteer is part of the EDI reference group but also sits on our EDI activity group. They are an additional voice to bring the perspectives and experiences of the EDI reference group to our organisation wide EDI implementation group. This group have helped shaped our organisational strategy and have shared their priorities for areas of EDI focus moving forward.

Social Justice Collective report

We commissioned the Social Justice Collective to undertake a review of the impact of our EDI strategy on our culture. In a series of focus groups, 1:1 interviews and through a survey. They listened to the experiences of our colleagues and highlighted priority areas for focus that marginalised colleagues wanted to see us address. From this we have developed an action plan to tackle these and will make sure we provide opportunities to pause, reflect and listen to our staff.

Accessibility project

We commissioned Accessible by Design to undertake an audit of our internal digital accessibility. There was a particular focus on helping us to understand the accessibility of the software and technologies that we use every day. The recommendations from this audit will help us to improve our internal digital accessibility and the accessibility of the ways in which we communicate with each other. We will develop accessibility training, a digital accessibility policy and an internal minimum standard of digital accessibility.

Reflections and learnings

As part of our EDI strategy we committed to an independent audit to understand which of our commitments we had and hadn't made progress against.

Summary of key learnings

- We need our EEDI objectives to be more specific and measurable so we can better measure and monitor progress.
- We need to ensure clear communication and handover so we keep momentum even when staff change.
- We need to be ambitious but realistic in what we can achieve.
- EDI needs to be integrated into everything we do in a meaningful and accountable way.

Reflections from our EDI lead (Amy Reeve led the EDI strategy from 2021-2024)

It has been an honour to work at the MS Society. When I started I came into a new role, a role that the Society had not had before. A role that was part of their commitment to EDI. I am incredibly proud of what I have achieved during my time here, but definitely wish I had achieved more.

There is a genuine commitment to change here at the MS Society and it has been amazing to watch more and more colleagues feel confident to raise EDI concerns or focusses in so many meetings and projects. I know that the work will continue, guided by someone new.

Here are the 5 things I am most proud of:

- The EDI reference group – in my time as EDI lead the EDI reference group has expanded in size, but also in the amount of work that they contribute to. It is an incredible group of people, most of whom have a personal connection to MS. We have had some supportive, challenging, heart-warming, fun conversations. But the thing that has shone through all of them is the commitment of the group to the MS Society, but to see it do better to address inequality and inequity. I will miss our conversations and being a champion for the group across the wider organisation.
- Our EDI training – I cannot and will not take any credit for the EDI training programme we now have in place. That is all due to Paula, our EDI trainer. But, I am proud that we have now delivered our expanded EDI training offer. This has been something that has been a long time coming. Bringing an expert EDI trainer into the organisation will mean that we can address some of the behaviours which impact colleagues' experiences, but also expand awareness of EDI topics.
- Our EDI hub – On Axon, our internal website, we have developed the EDI hub. A one stop shop for anything that you might need related to EDI. And we have developed some amazing things to go in there. An EDI glossary, transitioning at work guidance, guidance on religious inclusion, information about our support groups, and it is also where you can find our equality impact assessment. It's been great to build this hub over the last couple of years and populate it with some resources to help promote inclusivity.
- My colleagues – Over the last two years I have noticed that there was increasingly less need for me to speak up about EDI in meetings. More of my colleagues now feel confident to challenge and ensure that projects are viewed through an EDI lens. I am proud that many more of them champion EDI and are more active allies, standing with marginalised colleagues against inequality and inequity. I am proud to have been able to support our colleagues and for the relationships and friendships I have made during my time here.
- Our approach to accessibility – We have developed accessibility checklists for physical spaces and events. As well as a minimum standard for accessibility. We have recently completed a business systems accessibility audit with Accessible by Design. We will be

developing a minimum standard for our internal digital accessibility and an accessibility policy. This will ensure that we consider accessibility across all our technology and software. But I would like to see the MS Society do more to normalise disability and promote accessibility.

What now?

We learnt a lot from the EDI strategy but 2 of the main learnings were:

- That we needed to include a focus on equity, and not just equality, to make sure that different people get different support depending on what they need
- That EEDI needs to be more central and integrated into everything that we do

That's why we're no longer having a standalone EDI strategy but putting equity, equality, diversity and inclusion at the heart of our organisational wide strategy. And integrating it through everything we do in creating a future free from MS.

Our approach

MS doesn't discriminate and nor do we

We know MS affects everyone differently. It is a complex condition shaped not only by biology. But also social, economic, cultural, geographical and systemic factors. We believe everyone affected by MS regardless of background, identity or circumstance deserves to be seen, heard and supported in a way that is meaningful to them. As well as have the chance to get involved and make a difference.

We are committed to creating a world where no one in the UK faces MS alone, no matter who they are. That's why we're putting equity, equality, diversity and inclusion at the heart of our strategy. And integrating it through everything we do in creating a future free from MS.

Find out more on our website here