Equality, Diversity and Inclusion (EDI) action plan for MS Society research

Our progress from 2021-2024

Table of Contents

We know MS doesn’t affect everyone equally. We also know research doesn’t include everyone equally. Our EDI action plan for MS Society research outlined the work our Research Team would deliver between 2021 and 2024. This action plan was intended to help us support research that better serves all people with MS. And reflect their diverse experiences and needs. In this report, we set out a summary of the progress we’ve made.

Five priority areas

Introduction

We want research to be relevant and open to all people affected by MS. Everyone should have the opportunity to participate in research. And research should sufficiently consider the needs of the whole MS community. Without this, the health solutions our research informs won't be relevant for all.

But we know we have a long way to go to make MS research inclusive. It's a hard challenge that will require complex solutions. In 2021, we launched the first iteration of our Equality, Diversity and Inclusion (EDI) action plan for MS Society research. This was very much about listening, learning and evolving our activity plans as we went. We focused our efforts on gathering data, speaking to other organisations and talking to people affected by MS from all backgrounds. We also took tangible steps to tackle inequality in MS research. This included making changes to our grant funding and review processes. Looking at how we communicate the research we fund. And the channels we use to share these communications.

The first version of the action plan has come to an end. And we're proud to share the progress we've made over the past four years. Below is a summary of our key achievements and the challenges we've faced. And examples of best practice we've seen from the MS research community.

While we've worked hard and made some progress, we know there's much more to do. To truly make sure MS research is inclusive and representative of our entire community, we must set ambitious goals building on our experiences. Both the successes and lessons learned. We're now shaping the next phase of our EDI action plan, which will guide us through to 2029.

There's a long road ahead until we see sector-wide changes. Patient and public involvement (PPI) is now an integral part of medical research in the UK. But it took over 30 years to get here. Just like we did for PPI, medical research charities have an important role to play in setting standards. And in improving research practices to fully embrace EDI goals.

To ensure our efforts remain relevant and impactful, we'll continue to engage with the research community, other charities and organisations championing EDI. And, most importantly, people affected by MS who are currently underrepresented in research. Only by working together, can we hope to drive meaningful and lasting change.

EDI and capacity building

Our plans for supporting our early career researchers (ECRs) and our EDI plans are closely interconnected. We're committed to supporting all our ECRs. Both those from minoritised and non-minoritised backgrounds. This report highlights our initiatives that focus on addressing structural barriers through an EDI lens. However, our broader support for ECRs extends beyond these efforts.

You can find out more about the full range of ECR support on our ECR hub.

MS research careers

Objective

We wanted to increase the diversity of those coming into MS research. Attracting and retaining more diverse talent into the MS research community will drive innovation. And improve the quality and inclusivity of MS research. To do this we sought to develop more inclusive policies and influence research culture. So that a greater range of people can develop successful careers within MS research.

From plan to progress 2021-2024

We identified four areas of our work which required improvement. Making these changes will increase the diversity of the MS research workforce. In our action plan we set our key intended actions for each area of improvement. Here we explain what we've achieved so far in each of these planned areas.

a. 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.

- We developed and implemented a survey to collect demographic information from everyone applying to us for funding. We've analysed data from the past three years looking at the demographics of all lead and co-applicants who apply. And we've looked to see if the success rates vary between applicants from different demographics groups. We've conducted separate analysis looking specifically at ECRs (including PhD students) who apply for and receive our funding.
- However, our small dataset has meant we've had to group people into broader demographic categories when looking at the data annually. This can blur important differences and may mean we're missing the unique experiences of people with distinct identities and challenges. We're now moving to a five-year reporting cycle. This will give us time to collect richer data and capture a more complete picture. This longer reporting cycle will also allow us to track the impact of the strategies introduced through our new action plan. To let us see what's working and where new strategies are needed.
- We've now published aggregated data from the full first three years of our plan, giving us a clearer, more comprehensive view. We're pleased to see equal success rates, regardless of people's ethnicity, age or disability status. We're pleased to see more applications from people from minoritised ethnic backgrounds, but we unfortunately still lag behind the academic sector. Only 14% of our applicants and 13% of our funded researchers are from a minoritised ethnic background.
- We initially planned to use the demographic date to inform the development of a structured plan to address any identified underrepresentation. But EDI is a constantly evolving field. So instead of a fixed plan, we've used the data collected so far to shape a more dynamic strategy. We've taken up opportunities to collaborate and address underrepresentation as they've arisen. We're continually monitoring our data. And we hope the flexibility of our new action plan will allow us to respond to issues and discrepancies as they arise.
- We sponsored two students from the HDR UK Health Data Science Black Internship Programme to undertake an eight-week paid internship with the UK MS Register. The HDR programme aims to tackle the underrepresentation of black researchers within health data science. This collaboration was a huge success, and we'll continue to sponsor students to take part on a regular basis.
- We've partnered with the Daphne Jackson Trust to co-fund a Fellowship for a researcher to return to MS research. This fellowship is designed to support people after they've taken a break of two or more years for family, caring or health reasons.

- We continuously make efforts to showcase the stories of researchers from under-represented and minoritised backgrounds. For example, Raghda Shaban Tawfeeq Al-Najjar's work on lifestyle and the risk of developing MS.

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.

- We wanted to make our application processes more inclusive of people who've taken less "traditional" career paths. Or who've experienced other personal circumstances, barriers or challenges that might have impacted their publication record. We've piloted a change within our Catalyst and Early Career Fellowship Awards. This changes how we ask about research outputs in the CVs of applicants applying to us. We shifted the focus away from the number of publications being the main marker of success. And instead, we now ask applicants to describe five research outputs relevant to their proposal. Following the success of this pilot, we're now rolling this approach out across all our awards.
- We'd planned to introduce information on the impact of unconscious bias into our review guidance and panel meetings. We ultimately didn't do this because universities already provide training on recognising unconscious biases. So we reflected that replicating this training may not add anything new for our reviewers. And that we may have more impact if we focused our efforts in other areas of our action plan.

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.

- We've shared our position on researcher maternity, paternity, adoption and carer leave and on part-time fellowships.
- We now fund two Doctoral Training Centres with the aim of supporting a positive PhD experience for students, who then continue their careers within MS research. We wanted to ensure these Centres equally support the retention of students from all backgrounds. We asked applicants to explain how they planned to support the inclusive recruitment of their PhD students. And how they'd create an inclusive research environment. Reviewers were asked to assess their plans as part of the final funding decision. This approach is now being rolled out across our research programme grants to be assessed via annual reporting.

d. To 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.

- We had initially planned this action to focus on developing a tool for data collection and monitoring. This would then help to inform the development of a new plan to improve retention. But as we grew in our learning we realised that this form of monitoring requires long-term follow up. This involves many variable factors. Including tracking and monitoring ECRs potentially long after they've finished working on a project we've funded. There are multiple barriers to doing this. These include loss of contact with ECRs, and limited resource and capacity within the team for such long-term tracking and monitoring. We're now in the process of exploring how we could integrate this follow up into our existing processes and data collection tools.

We're exploring ways to use the available information on trends in workforce retention across the wider bioscience sector. This should identify opportunities for collaboration and innovative interventions.

Example of our impact

Supporting junior black scientists with their career development

The HDR UK Health Data Science Black Internship Programme aims to tackle under-representation of black people within health data science. They do this by providing an opportunity for students to undertake an eight-week paid internship. During this, the students complete a practical project under the guidance of experienced health data scientists. We funded two of the four HDR UK Wales interns. Joy Amobi and Laura Khaukha completed projects within the team at the UK MS Register, under the supervision of Dr Rod Middleton. Both Joy and Laura now hope to continue their career in health data science. You can read more about their experiences in our research blog.

"At first, I felt discouraged to apply for internships because I wasn't sure I would get accepted as someone who's from a minority background. But then I saw the HDR UK Black Internship programme on LinkedIn and thought "this is for me". Because people of colour still have
to get into programmes like these. And seeing an internship that is meant for people like me was so important and helpful.
I think these internships are incredibly important. Even if I hadn't applied for it, just seeing the representation alone makes me feel seen. In fact, it has opened doors for me – I've gained real-world experiences of working as a data scientist and I had the opportunity to go to events and network with people."

Joy Amobi

HDR UK Black Internship Programme Intern

Example of good practice

Improving socio-economic diversity in science outreach

Our Edinburgh Centre for MS Research is located near Craigmillar. Craigmillar is one of the most deprived areas in Europe, where more than 80% of children qualify for free school meals. Through their partnership with the IntoUniversity programme, Edinburgh University has built a relationship with one of the local schools in Craigmillar. PhD students, Julia van de Korpt and Kellie Horan, visit this school to coach science students one-to-one. We fund this through the Edinburgh Centre for MS Research. The Centre also supports the school's Christmas appeals, food banks and provides the school with repurposed computers. The young, multi-national research community at our Edinburgh Centre has inspired the students, families and teachers. With more students studying science. And more families getting involved in science days in the community.

"As soon as I started my PhD here at the Edinburgh MS Centre, I immediately volunteered to be a Science Mentor at the local secondary school Craigmillar. As someone who attended a disadvantaged school and whose parents did not complete school/university, I understand the barriers young people in deprived areas face in accessing science and am passionate about supporting them.

"As a science mentor, I work one-to-one with students during weekly sessions to support homework, exam preparation, and revision strategies. Beyond this, what makes the program special is the opportunity to informally discuss university and career paths, offering encouragement and serving as relatable role models to show that anyone can become a scientist."

Kellie Horan

PhD Student in Regenerative Medicine at the Edinburgh Centre for MS Research

Our research boards, committees and grants panels

Objective

Our research boards, committees and grant panels are made up of experts in the MS research field and people affected by MS. They help us set our research strategy and advise us on our larger research programmes. It is important the way we manage our funding is inclusive and includes diverse voices. Strategic decision making based on a variety of perspectives has been shows to lead to improved outcomes and outputs. These governance groups need members with diverse experiences to make sure our research funding research benefits the whole MS community.

From plan to progress 2021-2024

We identified three areas of our work which required improvement. This will help us ensure a diversity of perspectives are included in our research governance and decision making.

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 decide 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.

- We developed a demographic data survey that was circulated to all members of our governance groups. So far, we've analysed and published data from the first two years of our plan, 2022 and 2023, as standalone annual reports. We've now published the aggregated data from the full first three years of our plan. This will give us a clearer, more comprehensive view. Alongside our demographic data report for our research workforce, we're now moving to a five-year reporting cycle.

- We're pleased to see a near-equal gender split across our governance members. And we're pleased to exceed our original target with 12% of our governance members coming from ethnically minoritised backgrounds. But we're aware that more work is needed in this area. We currently have no members from Black, African, Caribbean or Black British backgrounds. We'd also like to see more younger people becoming peer and lay members of our governance groups. This is important since we know people are often diagnosed with MS in their 30s and 40s.

b. To make sure our all board, 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.

- We've reviewed and amended the Terms of Reference for most of our boards, committees and panels to use more inclusive language.

- We have further improved the inclusivity and accessibility of all our meetings. We've invited members to tell us about any reasonable adjustments they need. And briefed the chairs on these where appropriate and with the consent of the individual. We've reviewed and updated our meeting processes to improve inclusivity during meetings. For example, we've changed the speaking order in our panel meetings. And given lay members, who are often people with MS, more time to share their perspectives.

- We explored adding an EDI officer to each of our governance groups. But we were unable to fill these roles from within the existing membership. We're still considering whether we should recruit new members to fill this role. But in the meantime we've taken other steps to embed consideration of EDI throughout our governance and decision-making processes. This includes asking applicants to outline their plans and grantees to report on them. For example, annual review meetings for our infrastructure grants now include discussion of progress on EDI plans.

c. We will add two additional member roles to each of our boards, committees and panels for early career researchers (ECRs) 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.

- We weren't able to fill these roles. ECRs reported that they didn't feel like they had the right skills, experience or confidence to contribute effectively to the panels. Instead, we've now invited ECRs to join the TERN panel meetings in an observatory role. We're now looking to expand this opportunity to our other governance groups and to give priority to ECRs from underrepresented backgrounds. The immediate aim is to support the careers of researchers from underrepresented backgrounds. Longer term we hope this work will lead to a more diverse workforce from which to recruit to our governance panels.

Example of our impact

Lay chair for panel meetings

We had the privilege of having Chris Rafaluk chair the 2024 Data Discovery Award (DDA) review panel meeting. Chris is an experienced lay member of the UK MS Register's Scientific Steering Committee and has previously reviewed our DDA applications.

We felt it particularly appropriate to have a lay chair for the DDA review panel. This is because PPI can often be lacking in these applications, which focus on data science. The viewpoint of people affected by MS is important in data science. These projects rely on people joining and engaging with the UK MS Register, and other databases, as their MS progresses. Seeing high quality relevant research using these databases is vital for the continued motivation of participants.

Our intention through this action plan priority area was to ensure EDI concerns are raised in relevant discussions. And to ensure inclusive governance. It's encouraging to see the adjustments we've made translate into the role of chair being accessible to our lay members.

This was the first time a lay member has chaired any of our review panel meetings and it proved to be a tremendous success. Having Chris lead the discussion, as someone who lives with MS, enriched the conversation and decision-making process. As a result, the funded awards were provided with detailed feedback that improved their PPI plans. And made their research plans more relevant to the needs of the MS community.

"Chairing the DDA meeting made me realise how important the role of the Chair is - they're there to guide the group, keep us on track, and ensure the meeting achieves its purpose. They make sure everyone's voice is heard. A project can be scientifically excellent, but we need lay reviewers to add the context and make sure that people living with MS will actually benefit from a proposed project."

Chris Rafaluk
Research Network Member

Our funded clinical research

Objective

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 aren't 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 major role in widening out study participation. Helping to include more diverse populations. This can include supporting the implementation of inclusive trial design and sharing best practice. And building relationships with communities who have been underrepresented and underserved by clinical trials.

From plan to progress 2021 to 2024

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.

- We're co-funding REFUEL-MS. REFUEL-MS is developing an app-based digital treatment to provide personalised ways of managing fatigue for people with MS. The research team has now published a scientific-peer reviewed commentary. This addresses the complexities of diversity and inclusion in behavioural trials for MS.
- Researchers from our co-funded DELIVER-MS trial and the Octopus trial are calculating an accurate demographic breakdown of the UK MS population. This will help us understand how representative our clinical studies are. This will inform actions to address barriers to participation for underrepresented groups.
- We co-supervised an MSc student project to 'Evaluate the existing literature on inclusivity in UK-based multiple sclerosis clinical trials, combined with a qualitative research investigation into barriers for ethnic minority participation, using the MS-STAT2 trial as a case-study'"

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 toolkit.

- We developed an EDI hub on our webpage. This hub contains resources and best practice examples. These are designed to help researchers better consider the diversity and representation of people taking part in their clinical study.
- We added an EDI section to applicant guidance documents to highlight the importance of EDI in clinical research.
- Clinical study grant applicants must now explain how they'll recruit a diverse group of research participants, representative of people with MS in the UK. We've also added a question to all application forms. We ask 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 MS research and encourage a broader range of people to take part in the future.
- We scoped different ways for how EDI activities can be meaningfully implemented within research. 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.

- We now require all new clinical trials to collect and report on the demographic characteristics of their studies' participants. We've developed resources to support more consistent data collection and reporting, which is available on our EDI hub.
- 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 participated in the MESSAGE sex and gender project. This project developed a policy framework to make sure differences in sex and gender are considered in research. It's important that women, transgender and intersex people are considered in the design of research. This is particularly relevant in MS which affects almost three times as many women as men. People's sex and gender have an impact on health and disease, the symptoms they experience and the treatments they receive. It's vital we understand these impacts to ensure treatment and care is safe and effective for everyone living with MS.
- Initially, we considered implementing recruitment targets using the baseline data collected from the trials we fund. However, target setting is very complex and nuanced. For example, some trials recruit certain groups of people on purpose, with a relevant scientific rationale for why they do that. And some trials recruit a very small number of people in a specific location. Therefore, we've now moved away from the idea of setting targets. And instead, support our researchers to consider diversity and representation for their individual trial.

c. Provide support to increase the number of registered participants in the MS Register and Tissue Bank from ethnic minorities and other underrepresented groups of people with MS. Initially, we will review data from people currently involved and consider setting future targets linked to action plans.

- 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.
- 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.

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.

- We sort feedback from the MS Society's EDI Reference Group on our research communication strategy. And we've updated our approach to raising awareness of clinical trials and research opportunities with new audiences based on this feedback.
- We regularly create content highlighting the need for greater diversity in clinical research. And the steps being taken to make clinical research more inclusive. This has included an interview with Dr. Andrea Stennett in MS Matters. It highlighted many of the barriers to inclusive participation in research and steps being taken to remove these barriers.

Example of our impact

Improving diversity of Octopus participants

The Octopus trial has an important role in making research participation inclusive. We're supporting the Octopus trial team to recruit people from minoritised backgrounds. Together we will better make sure their results are relevant to everyone with MS. Together with the Octopus trial team, we hosted an EDI workshop. We consulted with people affected by MS to discuss the barriers to participation 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 for people with MS who may struggle to have an MRI. And training for radiographers in how to support them.
- Non-digital methods of registering interest in Octopus to avoid exclusion of people with limited access to technology.
- Factsheets explaining there are no animal products within the tested medications. And how you can take part in the trial if you need to fast for religious reasons.
- Increasing the number and variety of communication channels to reach people who may not have taken part in clinical trials before.
- Building in regular feedback from trial participants to continuously identify barriers to participation as the trial progresses.

"In the Octopus trial we have looked at EDI in several ways. Firstly we ran a workshop to scrutinise the process and communication of the trial to see if we were being inclusive. Secondly we have studied whether people expressing an interest in participating had the same characteristics as those ultimately enrolled. Finally, we continue to use data on the Stage 1 cohort to inform an EDI action plan for Stage 2.

It is morally and scientifically important that we take steps to ensure that MS trials are inclusive. We need to challenge any barriers that prevent the participation of people from particular groups."

Emma Tallantyre

Recruitment Lead for Octopus

Example of good practice

Cambridge Centre of Excellence

Ethnic diversity is relatively low in the East of England. However, Cambridgeshire includes both some of the country's most affluent and most deprived areas. The East of England also has some of the longest distances to reach clinical trials. To enable more people to participate in clinical trials, the Cambridge Centre of Excellence is exploring solutions including:

- Telephone or video appointments
- Mobile phlebotomists that can travel to your house to do blood tests
- Covering the costs of travel to the hospital.

The Centre also holds annual symposium at Cambridge University to inform people with MS about their research. To engage with people who are unable to travel longer distances, they also host outreach events in people’s local communities. They’ve held these in areas of high deprivation (outside Norwich, North Peterborough, Great Yarmouth). And up to 100 people have attended. They used these opportunities to highlight local MS services and promote participation in research.

The Centre has also introduced MS-EQUAL. This is an innovative research project allowing people with MS to volunteer for studies via an online consent form TRUSTED).

This allows researchers to reach out to people who have signed up to CONSENTOR and ask if they want to participate in research. CONSENTOR also includes a consent to contact people who view the form but haven’t signed it.

This means they can compare people who sign up to CONSENTOR with people who view the consent form but don’t sign it. By doing this, the team can identify any under-represented groups and work to understand why they don’t want to participate.

CAMBRIDGE CENTRE
FOR MYELIN REPAIR
founded by the UK MS Society

Our public involvement programme

Objective

Patient and Public Involvement (PPI) is now firmly embedded as standard practice across the health research sector. But making sure that PPI is truly inclusive remains a challenge. As well as making sure that diverse voices are meaningfully involved throughout the research process.

People affected by MS are at the heart of our research programme. Our Research Network is a group of people affected by MS. We work in partnership to shape our research strategy, contribute to our funding decisions and inform the approach taken by studies. We need to improve the diversity of our Research Network to ensure voices of the whole MS community are heard. We need to ensure the needs of all individuals and communities will be met by our research programme. And it can't be done without diverse representation across all PPI activities. Increasing the diversity of our network will contribute to improved inclusivity of our funding decisions. And the design of research studies and clinical trials.

From plan to progress 2021 and 2024

We identified two areas of focus to improve the diversity of our PPI programme.

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.

- We developed and implemented a survey to collect demographic information from our Research Network members. We were pleased to see that both the gender distribution and the geographical spread of network members matches that of the UK MS population. But we know there's still much work to be done. Only 16% of our members are aged less than 40 years old and there's very low representation of people with MS from Black, African, Caribbean and Black British backgrounds.
- We started outreach events to share information about research and how people are affected by MS. This included the Asian MS webinar focused on diversity in clinical trials. This webinar directly led to 10 new Research Network sign-ups.
- We've built relationships with community–based organisations. Including Talks with MS, Asian MS and The Nerve of my MS. And attended their events to promote the Research Network to a wider audience.
- We've continued to work closely with partner organisations to develop best practice around inclusion in PPI. We were also involved in developing the ~~IN~~VISIBLE - Diversity in PPI film. This is a tool to promote the value of PPI to a range of audiences. The short film was co-produced with people living with long term conditions from Black African, Black Caribbean and South Asian communities. Including people affected by MS.
- We've not been able to do the expected level of proactive outreach and recruitment with younger people. There have been multiple barriers to doing so, including limited resources and capacity. We're also aware that there is a need to better communicate of the value of joining the Research Network in this group. As they may have more limited time for PPI activities.
- Our outreach efforts have not had the impact we hoped for on the diversity of the Research Network. The Research Network has received a good reception at community events. However, we need to develop our process for translating this into sign-ups. We need to further address other barriers within the Research Network ways of working beyond raising awareness. This includes the accessibility and inclusivity of our induction training programme.

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.

- We routinely consult with the MS Society’s EDI Reference Group. We’ve changed our ways of working and the support we provide, based on their feedback. This has included updating the format of our monthly research opportunities email. And making this information also available verbally via a monthly zoom call.
- We’ve reviewed of all our Research Network training and guidance documents to improve their accessibility.
- The planned payment policy hasn’t yet been published. This is due to organisation wide transformation projects. These are impacting on the capacity of the core teams needed in the development of the payment policy.

Example of our impact

~~I~~NVISIBLE - Diversity in PPI film

In partnership with several medical research charities and Egality Health, we were involved in the development of ~~I~~NVISIBLE - A spoken word film on why diversity in PPI and health research matters for everyone.

"We know that diverse ethnic groups are under-represented in health research, which can mean healthcare treatments and services are less safe, accessible, and effective for these groups.

Through this project, our aim was to increase the number of people with lived experience from diverse ethnic groups who are actively involved in health research and ultimately improve health treatments and services.

Co-producing this film along with people from the communities we were trying to reach was critical to truly capture their experiences and shape the narrative of the film. Working with poet Duke Al was especially befitting as he was able to transform our insights and develop a spoken word piece that captured the voices and stories of several people, whilst being thoroughly engaging!

One of the strongest aspects of this project was its truly collaborative nature. Tackling health inequalities is a persisting challenge that requires us to go beyond traditional ways of working and bring in people from all walks of life to lend their expertise and contribute in different ways. We hope to see many similar collaborative projects in 2025 and beyond!"

Bhuvan Majmudar Projects and Partnerships Manager at Egality Health Ltd.

Example of good practice

REFUEL – MS

We co-fund REFUEL-MS. REFUEL-MS is a research project developing an app-based digital treatment for fatigue. Inclusivity is a core value of the REFUEL-MS programme, guiding the involvement model and collaboration with the Patient Advisory Group.

The team co-produced a cultural competency framework to ensure equitable and effective delivery of their digital intervention. This framework is implemented through training for healthcare professionals ensuring the intervention is tailored to the diverse needs of the MS community.

They have also set up a clear plan for monitoring and evaluating their PPI impact.

You can find out more about how they centre the voices of seldom-heard groups in our research blog

Building the evidence base

Objective

Under-representation in MS research has left us with gaps in our understanding of MS in certain groups of people. We're working to improve the inclusivity of MS research. And we can also work to fill specific gaps in our understanding of MS in communities previously excluded from research studies. We need to make sure we understand the biology of MS and how it affects all people with MS.

Our plan was to stimulate the research community to investigate MS in under-researched groups. Starting initially with people from ethnically minoritised backgrounds and then broadening out to other groups as our understanding grows.

From plan to progress 2021 and 2024

We identified one area to focus our efforts in order to start to fill these knowledge gaps.

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

- We continue to fund the ADAMS study. This research project is investigating the genes of people with MS from non-European ancestries. So, we can get a better understanding of MS risk factors. We've supported the team by promoting the study on our communications channels. We also invited the team to attend talks and events to raise awareness.
- In 2023, we funded a project looking into the barriers people from minoritised ethnic backgrounds experience. Namely, when accessing treatment and support for their MS. You can find out more in our research blog.
- Women's health is an under-researched area across all of medicine, including MS. To address these evidence gaps, we're funding multiple early-stage research projects that focus on improving our understanding of MS in women. These include a project on DMTs during pregnancy and a study about the menstrual cycle and MS symptoms.
- Since 2023, we've been supporting an ESRC PhD fellowship looking at how people diagnosed with MS experience their first symptoms and primary care visits. This'll help us better understand how the pathway to an MS diagnosis is influenced by social factors. Such as race, ethnicity, gender and socioeconomic deprivation. In their final year, the student will do an internship with the Research and External Affairs team at the MS Society. This will help their findings influence policy. They'll also work with the MS Society's Research Communications team to share their findings with people affected by MS through various channels. This will help to raise public knowledge and awareness.
- Using data from the UK MS Register, our researchers published several papers. These include:
    - Research into the social determinants of health. You can find out more in our research blog.
    - Research about how a person's socioeconomic background impacts on their ability to access disease modifying therapies (DMTs).
    - Research into the relationship between ethnicity and MS
- We planned to develop a targeted call for research proposals addressing MS in under-researched groups of people. But, over the past three years, we've increased our communication on this issue more broadly. In addition, events such as the covid pandemic and the Black Lives Matter movement have increased awareness of this issue. These factors combined contributed to a significant increase in the number of applications we received focused on filling these knowledge gaps. Without launching a targeted call. We therefore prioritised our efforts on delivering other areas of the action plan.

Example of good practice

The UK MS Register

The UK MS Register is the world's first register, for any condition, to combine information from people about their MS, with their clinical and NHS data. The Register currently has over 17,000 members, who are asked to regularly update the Register with information on their treatments and the impact MS is having on their lives. To continuously improve the diversity and inclusivity of the Register, the team have implemented the following actions:

- Recorded and published demographic data to recognise and address underrepresentation in MS research, prioritising diverse voices.
- Developed an engagement strategy centred on inclusive representation and data collection.
- Prioritised inclusive data collection, including the creation of consent packs in multiple languages. And explanations for how your data will be stored, accessed and used by researchers.
- Collaborated with organisations like Asian MS and "My MS My Way" to engage with people from minoritised ethnic backgrounds.
- Worked with researchers investigating EDI in MS research. For example, the ADAMS study.

"Only if we do research that accurately represents the community can we have a meaningful impact on the lives of people with MS. And we need to do better. Continuous evaluation and improvement is key—we need to regularly examine ourselves, not just in the mirror, but by seeking feedback from others. EDI can't be an afterthought. We need to keep asking ourselves:

- Are we still doing the right thing?
- Are we addressing all aspects?
- Are we adapting properly to what the community needs?"

Rod Middleton

Principle Investigator at the UK MS Register

What's next?

We're proud of the commitment and progress we've made so far. And just as proud of the lessons we've learned along the way.

We know our work isn't done. We're excited to be moving on to the next iteration of our EDI Action Plan 2025-29. We'll be continuing to focus on the areas to maintain momentum on the progress we've made.

Over the next five years, we'll build on our successes, identify new opportunities, and learn from any challenges.

Language used in this report

Language, knowledge, and ideas are constantly evolving. People have complex, multidimensional identities. And we recognise there's no perfect way to communicate in a way that fully captures the diverse experiences of all people. In this report, we strive to be mindful of this. And avoid oversimplification or grouping people together.

We're always open to learning and evolving. And we welcome your feedback. Both on the report itself and the language we use within it. If you have any thoughts you'd like to share, please don't hesitate to contact researchnetwork@mssociety.org.uk

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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