



**MS Society  
Research Strategy  
2018-22**



# Foreword

The MS Society continues to be at the forefront of research delivering real change for people living with MS. We achieve this by putting people with MS and their expertise in MS at the heart of our work.

Recent years have seen a rapid expansion in the treatment options for people with relapsing forms of MS. We now need to see the same for people living with progressive MS. At the same time, we remain committed to furthering understanding of risk factors and potential prevention strategies, symptom management, and developing a robust evidence base for service provision.

Our 2018–22 strategy sets out the MS Society’s framework for delivering in all these areas over the next five years. It continues to be directed by people living with MS and the research priorities they have set for us.

We will build on previous achievements by continuing to invest in innovative science, supporting the most promising individuals and ideas. Working together, we hope the coming decade will translate recent insights in immunomodulation, myelin repair and neuroprotection into effective treatments for everyone. We will also ensure everyone benefits from scientific advances, by

improving understanding of how access to treatments, support and services can be optimised.

We are grateful to all the research network members, clinicians, scientists and professionals who contributed to the development of this new strategy, ensuring we remain at the forefront of global efforts to stop MS.



Professor Sir  
Andy Haines



Stuart Nixon  
MBE

Co-chairs, MS Society Research  
Strategy Committee

“It gives me hope that passionate people are working relentlessly to find out more about MS. It’s just a matter of time before lives are changed”

*Ghazia Ahmed, Research Network member*

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# Background

We have a bold ambition to Stop MS and with that ambition comes the need to build on the advances and knowledge we've gained through funding high quality research that will have an impact on people affected by MS.

Over the past 10–15 years progress in the field of MS has been unprecedented. This has been unmatched by any other condition with a neurodegenerative component and has meant that outcomes for people affected by MS have been transformed. There are more than a dozen disease modifying treatments for people with relapsing MS available on the National Health Service and several treatments for progression in late stage clinical trials or approved or under consideration for licensing by regulatory authorities across the world. There are also numerous symptom management interventions that have been developed, tested and are available to people with MS.

Alongside that, our knowledge of the condition has improved with much more now being understood about the molecular pathways and underlying pathology that drive the progression of the condition, the varied symptoms that occur as a result of MS and the impact that they have on the lives of people affected. We are now in a position to begin moving into the era of experimental medicine in progressive MS, with insights gained from clinical studies feeding back into our understanding of the biology that underpins the condition.

Understanding about the risk factors involved in development of MS is also improving with genetic and epidemiological studies highlighting a number of risk factors at play. Work now needs to focus on how these risk factors interact to influence the risk of developing the condition so that we can begin to implement strategies to prevent it.

There are great opportunities to build on this progress and make a step change in how we treat and support people with MS so that, eventually, through combination treatments, we can stop MS. We are committed to increasing our funding for MS research over the course of this strategy through our Stop MS Appeal and to fund research in new and innovative ways with the ultimate goal of stopping MS.





## Research environment

As well as the many changes we've seen in MS research, the research environment has also changed significantly over the last 10–15 years. Advances in digital technology mean that access to new technologies, information, new collaborations and diversity of opinion are greater than at any time in our history. Opportunities for cross-sector, multi-disciplinary collaborations are strong and will encourage innovation to thrive.

It is crucial that the MS community embraces these opportunities but this comes with challenges. One specific challenge that the research community will face is understanding the impact that the UK exiting the European Union will have on research, regulation of medicines and, ultimately people affected by MS. We will be working in partnership through the Association of Medical Research Charities to monitor and respond to ongoing challenges and opportunities.

Below are some other key questions that together, the MS research community will need to address if we are to rise to these challenges. Throughout the time period of this strategy we will be working with the research community to address these questions and ensure MS research remains relevant and impactful.

- How best can the MS research community share and utilise new and more detailed data sources for the benefit of people with MS?
- What are the knowledge and evidence gaps that we need to address to accelerate progress in MS research?
- What are the skills gaps in the research workforce that we need to fill in order to accelerate development, translation and uptake of novel discoveries?
- What opportunities exist to influence regulatory and research pathways to accelerate research?
- What can MS researchers learn from other fields or other disease areas?
- How can we begin to address the challenges associated with co-morbidities and what will an aging population mean for people with MS?
- How best can researchers and funders promote innovation in MS research?



# Our goals and priorities

In 2014 the MS Society completed a widespread consultation process with people affected by MS to determine our long-term organisational goals. These goals are detailed in our [organisational strategy](#) and underpinned by our research programme. They are briefly outlined below.



## 1. Effective treatments

People with MS will have access to effective treatments for their condition, including treatments which can slow, stop or reverse the accumulation of disability.

## 2. Responsive care and support

People with MS, including those being diagnosed, will have access to support that is responsive to their needs, and recognises them as equal partners in their care.

## 3. Preventing MS

Progress in research means that fewer people will develop MS.

## 4. Quality information

People affected by MS will have access to high-quality information that meets their needs.

## 5. A strong community, independent lives

People affected by MS will be able to live their lives, strengthened by a community that ensures no one has to face MS alone.

## 6. Supporting families and carers

The families and carers of people with MS will have access to the support they need.

## 7. Greater certainty about the future

People with MS will have greater certainty about how their condition will progress.

In addition, our research priorities are determined by people affected by MS and health care professionals and are incorporated into our organisational goals. In 2012 we completed a James Lind Alliance Priority Setting Partnership, identifying our top 10 research priorities. Our research programme has since focussed on these priorities outlined below and will continue to do so.

1. Which treatments are effective to slow, stop or reverse the accumulation of disability associated with MS?
2. How can MS be prevented?
3. Which treatments are effective for fatigue in people with MS?
4. How can people with MS be best supported to self-manage their condition?
5. Does early treatment with aggressive disease modifying therapies (DMTs) improve the prognosis for people with MS?
6. Is Vitamin D supplementation an effective DMT for MS?
7. Which treatments are effective to improve mobility for people with MS?
8. Which treatments are effective to improve cognition in people with MS?
9. Which treatments are effective for pain in people with MS?
10. Is physiotherapy effective in reducing disability in people with MS?





# Themes

For the purposes of this strategy we have grouped our research priorities into themes.

## Slowing, stopping and reversing the accumulation of disability

Access to treatments, including treatments that slow, stop and reverse accumulation of disability over time is our number one organisational goal. Underpinning this goal is identifying and testing treatments that can benefit those people living with progressive forms of MS where disability is gradually worsening.

Despite the fact that most people living with MS are living with the progressive form of the condition, there are still no treatments available on the National Health Service that can slow progression, representing a major unmet need. Research into progression has been an area of strength for the MS Society research programme and we intend to build on that strength as we move forward into our new research strategy.

In order to stop MS it is important to tackle not only the immune component of the condition, but also the neurodegenerative component. Strategies in identifying neuroprotective pathways, including myelin regeneration, hold promise in slowing progression in people with MS. With over a dozen treatments on the market with an immune modulatory or immunosuppressive effect, we believe efforts should be put into understanding neuroprotection and identifying, developing and testing potential neuroprotective treatments in people with MS.

“The latest research and treatments in the pipeline are exciting – they all take us closer to beating MS”

*Siobhan Jarvis,  
Research Network member*

We will:

- Fund high quality research and develop tools and models to improve our understanding of mechanisms of disability progression
- Work through the International Progressive MS Alliance to improve our understanding of progression, develop outcome measures and biomarkers to support faster more efficient trials and improve wellbeing
- Fund work to identify and select candidate drugs for clinical trials both novel and repurposed drugs
- Develop and grow our clinical trials programme, investing in efficient clinical trials aimed at slowing, stopping or reversing progression



## Risk reduction and prevention

Ultimately, our goal is to prevent MS for future generations. However, progress in this area of research has been slowed because of a lack of understanding of the various risk factors associated with MS and their relative importance and potential interplay.

In an effort to catalyse and speed developments in this area, we held an international prevention workshop in 2015. The workshop resulted in four key recommendations to the MS Society and other research funders.

1. The MS Society and other MS charities should review their messaging around smoking and lifestyle to ensure that these recommendations are clear to first and second degree relatives of people with MS.
2. The MS Society should explore setting up an international working group looking at developing prevention trials in MS including identifying funding sources for such trials.
3. The MS Society should follow the plans of EBV vaccine trials in the USA and investigate whether MS prevention could be included within the scope of these trials.
4. More research should focus on the fundamental biology involved in various risk factors associated with MS as well as evaluating emerging theories such as the influence of gut bacteria on the risk of developing MS.

Since the prevention workshop, we have worked towards implementing these recommendations. We will continue to fund research into risk reduction and prevention and, wherever possible, work in partnership to further research in this area.

We will:

- Fund research into the cause of MS, exploring the sequence of events that lead to the development of the condition.
- Fund research to investigate risk factors associated with MS.
- Scope ongoing work in the area of risk reduction and prevention to inform future funding in the field.
- Communicate risk factors of MS to first and second degree relatives of people with MS.

“The amount of research being undertaken is very encouraging and hopefully will eventually lead to discovering the cause of MS and consequently finding a cure.”

*Mandy Cormack,  
Research Network member*

## Symptom management

Priority symptoms which have been specifically identified through our James Lind Alliance partnership are: fatigue, pain, cognition and mobility. The majority of our care and services research funding has focussed on these symptoms, though we have not specifically excluded funding research into other symptoms of MS.

We have begun to explore new models of funding in the area of symptom management with an emphasis on multidisciplinary groups of individuals working together to identify and address barriers to progress in symptom management. We will continue to evaluate our symptom management programme and build on it, with a particular emphasis on the implementation of research findings into practice.

We will:

- Scope new funding models to develop and test interventions to improve symptom management.
- Evaluate and, if appropriate, reframe the Care and Services research programme with an increased focus on implementation of research findings into practice.
- Identify and fund underpinning work required to advance research into our priority symptom areas.
- Bring in perspectives of researchers and people with other long-term conditions and investigate opportunities for cross-condition working in symptom management research.



## Self-management and implementation

Numerous studies show that self-management is beneficial to people with long-term health conditions and that it can also benefit the health and social care system. Advances in digital technology mean that there are new opportunities to develop and encourage self-management amongst people affected by MS, delivered both by the health system and by the third sector. Our research in this area benefits from drawing on novel techniques and advances in other fields but challenges remain with implementation and uptake.

We will:

- Evaluate the self-management research we have funded to understand barriers and facilitators to implementation.
- Actively work to address the barriers to implementation of research into practise, including funding research to understand those barriers.
- Work with the MS community to identify, implement and evaluate new self-management tools for people living with MS.
- Scope self-management opportunities, drawing on perspectives from other fields or from the field of MS in other countries to identify novel, innovative models to test and deliver.

“I find knowing as much as possible about MS helps me to come to terms with having the conditions. Know your enemy – knowledge is power”

*Gwen Covey-Crump,  
Research Network member*





## Predictive markers of MS

Some people with MS have expressed a desire to know, on an individual level, how their MS is likely to develop over time. This knowledge would help people to make informed decisions about their treatment choices and plan for the future. There is currently no way that the course of MS can be predicted with 100% accuracy, though certain factors can predict a more or less severe course of MS.

For the purposes of this strategy, we will focus on the need for the identification and development of biomarkers that predict progression and the understanding of what factors predict treatment outcomes. Achieving this goal will enable shorter more efficient clinical trials to speed treatment development for people with progressive MS.

We will:

- Fund research to understand what factors affect long-term progression in people with MS with the aim of identifying biomarkers that predict progression.

## Research infrastructure

We currently fund a number of infrastructure programmes that support the work of the research community including the MS Society Tissue Bank, the UK MS Register and the MS Society MRI Scanner in Queens Square, London. We recognise the importance infrastructure plays in supporting ours and others research programme and we will continue to fund infrastructure where it adds value.

We will:

- Continually evaluate and improve our infrastructure programmes.
- Where possible, work in partnership and bring in cost recovery models or sustainability plans to ensure efficiency and value for money for the MS Society.
- Continue to apply good governance to our infrastructure programmes to ensure the research community can access them in a fair and transparent way.





# Ways of working

We have identified the following ways of working that will enable our research programme to have the greatest impact.

## Speeding translation

- Our purpose in funding research is to have a positive impact on the lives of people affected by MS. Progress in research can lead to changes in treatments and services and we want to ensure that change happens as quickly as possible. Actively identifying barriers and facilitators to translation and framing our research programme to address those is an important part of what will make our programme impactful.
- Throughout our programme and across the spectrum of research that we fund, we will put emphasis on speeding translation of research into practice.
- We will ensure the research we fund has mapped out clear pathways to impact and that the researchers we fund understand and appreciate the importance of translating their work for the benefit of people with MS.
- We will ensure research we fund uses the current and evolving evidence base around implementation science to inform design and implementation of research into practise.
- We will embrace and encourage others to adopt methodologies that enhance translation, for example, implementation research, action research and improvement science.
- We will take account of the health and social care environment in which findings need to be implemented and consider that as part of our funding model.

## Involving people affected by MS

Involving people affected by MS in everything we do is our way of working and helps to ensure our research is high quality and relevant. We have an active involvement programme that supports and fosters co-production of our programme and others. We strive to create a model of best practise in involvement and co-production.

- We will continue to grow and improve upon our involvement activities, improving our Research Network, striving towards more meaningful involvement.
- We will support and train people affected by MS so they can meaningfully take part in our decision making processes.
- We will support the research community to incorporate involvement in the research that they do.



“It’s a new world of cooperative research involving the patients.”

*Sue Polson, Research Network member*

## Partnerships and collaborations

Partnerships and collaborations are vital to our research programme for four main reasons:

- to foster innovation in research
- to create research programmes that are greater than the sum of their parts
- to enable us to leverage knowledge and funding from others into MS research
- to bring efficiency savings

We believe that partnerships with government, industry and other third sector partners are crucial in making the changes we want to see for people with MS.

The MS Society has an active portfolio of collaborative programmes which has grown over the course of the previous research strategy. Examples of successful funding collaborations through the course of our previous strategy include our active involvement in the Progressive MS Alliance, collaborations in clinical trials with the National Institute for Health Research and the National MS Society in the USA, collaborations with the British Council (BIRAX) and Medical Research Council career development fellowships.

We also aim for the research we fund to be collaborative and actively encourage collaboration across the community. It is important that we continue to expand this if we are to make our research investments go as far as possible.

- We will continue to develop funding models that support collaborations between a wide range of stakeholders from different institutions and disciplines.
- Remain cognisant of developments in research on both a national and international scale and promote collaborative working internationally
- We will increase the number and size of our collaborations and partnerships with other research funders both nationally and internationally, developing cross-condition collaborations where it adds value.

“I am so glad that there is now an international focus on progressive MS”

*Richard Eke, Research Network member*

## Capacity building

Research cannot be successful without encouraging the right individuals with the right expertise. This means that the career pathway into and through MS research should be supported. It also means that people from other fields with capabilities that will move the MS research field forward should have a pathway to enter MS research.

Through our grant round and collaborations, the MS Society funds PhD students and junior/career development fellowships to actively encourage researchers into the field of MS. It is important that we continue to build on this

- We will actively identify the capabilities required to ensure MS research remains at the cutting edge and work to bring people with those capabilities into the field.
- We will review our capacity building offering to researchers and aim to develop programmes that add to our current schemes.

## Using, building and communicating evidence

Using and adding to the existing evidence base is vital in order to speed progress in research. We will ensure our research programme does this and that we, as an organisation, use the existing evidence base to inform our work. It is also vital that the outcomes of research, both positive and negative and disseminated and communicated to both the research community and people affected by MS.

- We will actively work to identify gaps in the evidence base and, where appropriate, commission work to fill those gaps.
- We will ensure the research we fund takes current evidence into account, including evidence on implementation of research into practise.
- We will require our grant holders to publish both positive and negative findings of their work to add to the evidence base.
- We will continue to, and will support the research community to, communicate research findings to inform and educate people affected by MS in an evidence-based way.



# Research governance

Good governance is important in ensuring that we fund high quality and relevant research that has an impact on people with MS. The research we fund will be peer-reviewed and of high quality with a clear pathway to impact mapped out. The individual projects and programmes within our research programme will be overseen by panels and management boards comprised of experts from both within and outside the field of MS as well as people affected by MS.

Our Research Strategy Committee will provide advice to the MS Society Executive on strategic direction. The MS Society will develop milestones against the objectives set out in this strategy and the Research Strategy Committee will input into progress against strategy on a regular basis. We understand the importance of remaining responsive to innovations and

new opportunities in MS research and will review and adjust our milestones in consultation with the research community and the Research Strategy Committee as appropriate.

We will continue our membership and involvement with the Association of Medical Research Charities and ensure we meet the standards of best practice in research governance.





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