



MS Brain Health: A Decade of Impact and the Next Chapter

FROM VISION TO IMPACT

How MS Brain Health has created a better future for people with multiple sclerosis and their families

Since its inception over the past decade, the MS Brain Health initiative has played a pivotal role in advancing a paradigm shift in the management of multiple sclerosis (MS).

Beginning with the launch of the evidence-based health policy report ***Brain health: time matters in multiple sclerosis*** in 2015, the authors have spearheaded a global campaign advocating early diagnosis, timely and effective treatment, proactive monitoring and shared decision-making. The overarching aim is to maximize lifelong brain health in people with MS to reduce disease progression.

Under the auspices of the **Oxford Health Policy Forum** and its HealthScience Communication partner **Oxford PharmaGenesis**, key developments based on recommendations of the report have included the provision of education about MS for the general public, nurses and primary care physicians, the creation of internationally agreed MS care standards and the development of an associated quality improvement (QI) tool to benchmark clinical care.

The health policy report has influenced clinical practice, healthcare systems, patient advocacy, national policy and MS education around the world.

The initiative has continued to grow, with the publication of an updated 2024 ***Brain health – time matters*** report that extends the underlying management principles to two rare, related neuroimmune conditions requiring the same level of urgency as MS for early diagnosis and relapse prevention.

Oxford Health Policy Forum is privileged to have delivered the MS Brain Health initiative to date.

To take it into its next exciting phase requires expertise that is beyond the remit of the policy forum. It is time, therefore, to hand over the baton to other groups with the appropriate experience.

We are delighted to announce that two of our long-standing partners will be embracing the opportunities to move forward in key areas.

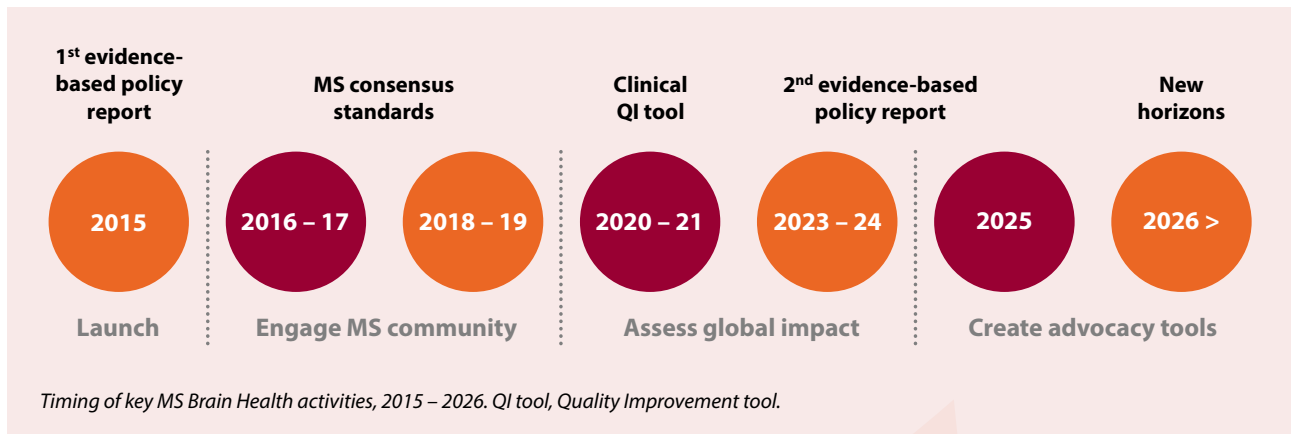
MSIF (MS International Federation), the global umbrella organization for MS societies, will lead the MS Brain Health initiative and strengthen the place of brain health within health policy and advocacy discussions internationally. From 30 June 2026, MSIF will host the **MS Brain Health website** and build on the MS Brain Health legacy by encouraging and supporting its member organizations to integrate the reports' recommendations into national policy conversations. It also aims to secure long-term impact by developing an Advocacy Toolkit to support ongoing action and engagement.

➤ **To continue receiving updates about MS Brain Health** including the Advocacy Toolkit, **you will need to sign up here:** www.msif.org/get-involved/newsletters/

MSBase, an international online registry for neurologists studying MS and other neuro-immunological diseases, will take forward the **QI tool**. The aim is to develop the tool into a digital, web-based resource that can support routine clinical practice, helping healthcare professionals monitor, improve and deliver timely, high-quality care for people with MS around the world.

➤ **To receive updates from MSBase**, please email: info@msbase.org.

MS Brain Health: A Decade of Impact and the Next Chapter



As we prepare to hand over the reins of the MS Brain Health initiative, let us celebrate how this vision began, what it has achieved and the impact it has made.

And let us acknowledge and thank the many groups and individuals who have contributed to the role **MS Brain Health** has played in creating a better future for people with MS and their families.



When we launched 'Brain Health: Time Matters in MS' a decade ago, few healthcare professionals and healthcare systems had embedded this philosophy into their approach to managing MS. This principle has now grown into a global movement, in no small part due to the extraordinary stewardship of the Oxford Health Policy Forum. OHPF brought professionalism, rigour, diplomacy, and respect for the patient voice to every stage of the journey, from the original policy report through the development of the global brain health quality standards, the quality improvement tool and beyond. I am profoundly grateful to the team for what they have built with us.

As the initiative now enters its next chapter under the custodianship of the MS International Federation (MSIF) and MSBase, I could not be more confident that its principles — early diagnosis, timely treatment, and lifelong brain health — will continue to translate into better outcomes for people with MS, wherever they live.

Professor Gavin Giovannoni
Chair, MS Brain Health



DEVELOPING THE VISION

Establishing the evidence to maximize lifelong brain health in MS

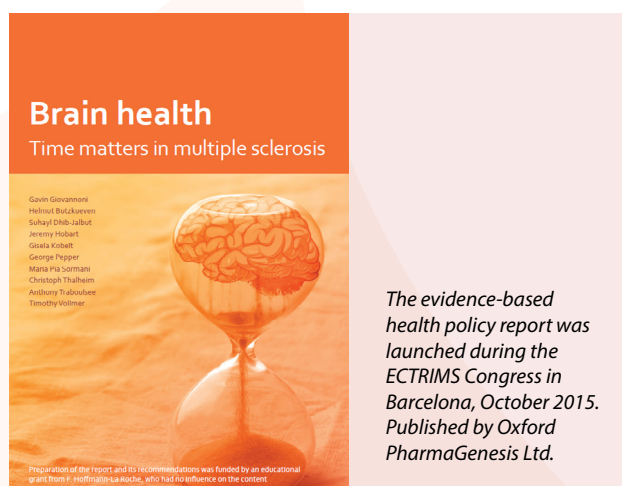


In 2015 Professor Gavin Giovannoni gathered a group of international clinicians, researchers, specialist nurses, health economists and patient advocates.

Supported by an expert writing team from HealthScience Communication partner, **Oxford PharmaGenesis**, they developed an evidence-based health policy report ***Brain health: time matters in multiple sclerosis***.

Launched in 2015, this landmark report introduced a clear and powerful message: **time matters at every stage of MS** and called for a major shift in the way MS is diagnosed, treated and monitored.

The terms 'brain health' and 'neurological reserve' began to take hold in the MS community. The report's calls to action galvanized healthcare professionals, patient organizations and patient groups to seek improvements and change in MS care at local, national and international levels.



BUILDING THE VISION

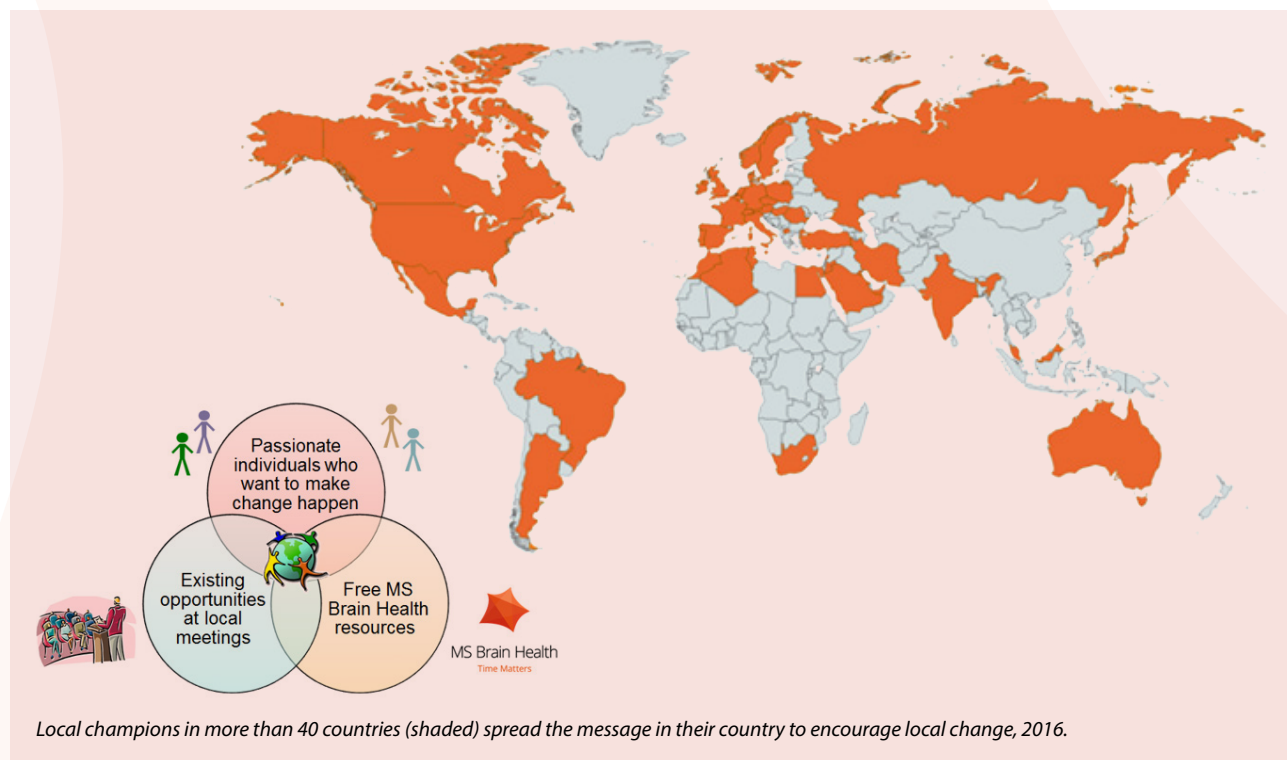
Engaging the global MS community in MS Brain Health

The publication of the report created a unique opportunity for strengthening relationships between MS communities and uniting in calls for change.

A Steering Committee was set up to develop long-term strategic plans, set objectives, guide ongoing activities and seize opportunities to share the report recommendations globally.

The MS Brain Health initiative gathered momentum as healthcare professionals, MS organizations, patient groups, clinics, people with MS and care givers embraced the importance of the report's therapeutic strategy to improve treatment and outcomes for people with MS.

Brain health 'champions' were established in over 40 countries to give regional and local talks, secure endorsements, promote the policy recommendations and spread the message that time matters at every stage of MS.



ADVANCING FROM VISION TO IMPLEMENTATION

Advocating MS Brain Health evidence to bring about change

The report provided healthcare professionals, people with MS and advocates with the evidence and tools to push for change in health policy and treatment at national and local levels.

Changes in national policy and clinical practice were advocated at the European Parliament and in Serbia, Norway and Australia.

Resources were produced for those involved in MS care, including guides for general practitioners and primary care providers, resources for MS nurses and MS teams.

Information and advice were disseminated in 22 languages for people with MS, including the practical ***Brain Health: a guide for people with MS*** and ***Six ways to lead a brain-healthy lifestyle***.

Since 2016, MS Brain Health has been part of the **Multi-Stakeholder initiatives**, a project led by the European Charcot Foundation.



Professor Gavin Giovannoni advocating for policy change at the European Parliament 2017, promoting the importance of **timely intervention** in MS. Report co-author Gisela Kobelt also set out the **economic case** for early intervention.

Why is this important?



MS is the most commonly acquired neurological disease in young adults around the world with over 2.3 million people affected.

25,600 Australians live with MS and over 7.6 million Australians know or have a loved one with this potentially debilitating disease.



There is overwhelming evidence that MS is caused by an **autoimmune** process with **both genetic and environmental contributors**.



The average age of diagnosis is only 30 and around 75% of those affected with MS in Australia are female.



MS causes significant and chronic disability to people in the prime of their lives and therefore has a substantive health burden and economic cost to the Australian health system.



The direct and indirect costs to the Australian community are increasing and now exceed **\$1.9 billion every year**. Nearly 50% of this figure is through the lost productivity of Australians living with MS and their carers.



MS Australia and MS Research Australia urged Australian government ministers to make MS an election commitment in 2019.

ADVANCING FROM VISION TO IMPLEMENTATION

Creating an MS care standards framework and quality improvement tool

Defining the care standards

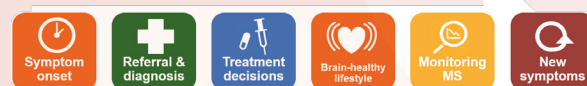
In response to the MS Brain Health report recommendations, a panel of international MS neurologists recognized the need for consistent, global brain health quality standards to underpin the delivery of timely, coordinated MS care.

Using a modified evidence-based Delphi process, they defined three time frames, **core**, **achievable** and **aspirational**, reflecting minimum, good and high-quality care standards, respectively.

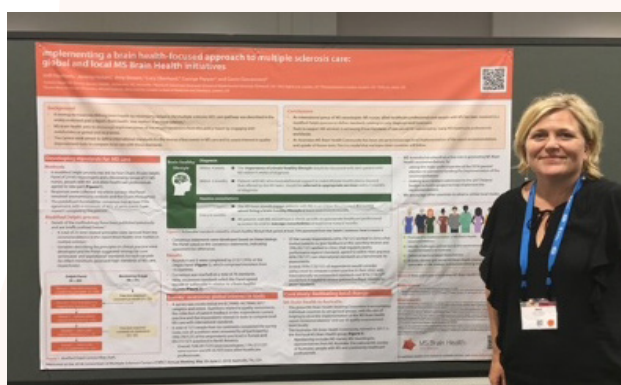
MS nurses, people with MS and allied healthcare professionals provided insights, ensuring the recommendations reflected perspectives from multiple stakeholders.

For the first time, an international consensus on a timing framework of benchmarks in the MS care pathway was reached with a choice of levels to suit local needs and resources.

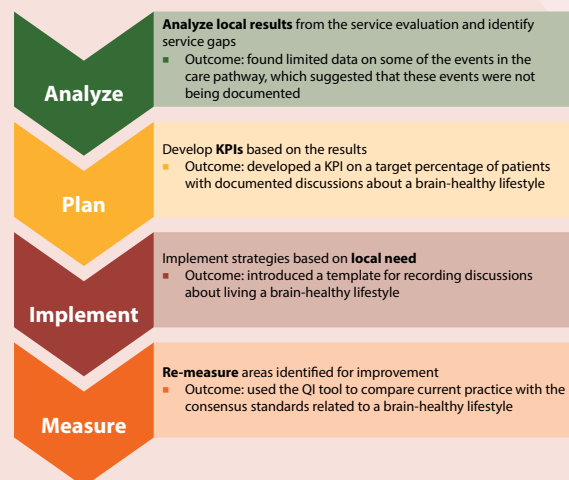
These widely adopted standards identify areas for improvement and provide MS teams with measurable targets for diagnosis, treatment and monitoring timelines.



Consensus standards for the timing of key events in the MS care pathway, 2018.



Jodi Haartsen, co-author, at poster presentation for developing standards for MS care, CMSC, Nashville, May 2018.



Stages in a QI programme to implement the consensus standards. KPI, key performance indicator; QI, quality improvement.

MS Brain Health global quality standards: MS nurses' role in development and implementation. Poster presented virtually at the CMSC meeting, August 2020, by Jodi Haartsen.

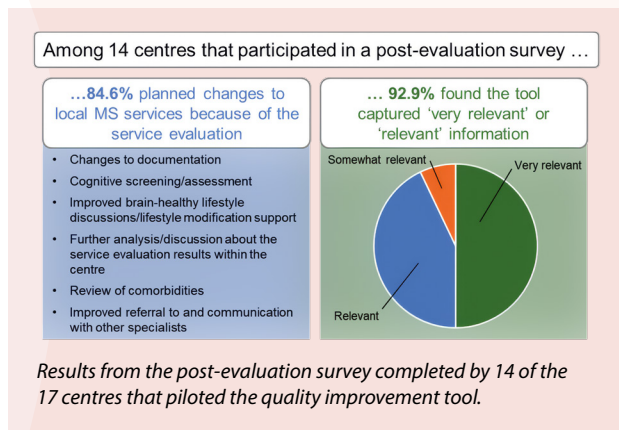
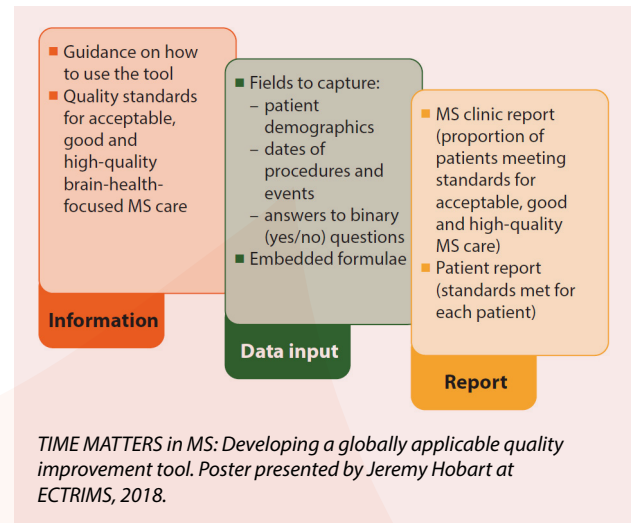
Developing a QI tool to benchmark clinical standards

To support the MS Brain Health internationally agreed standards, a **quality improvement tool** (QI tool) was developed to enable MS centres to track and refine the timing of key events in the MS care pathway and facilitate consistent practice evaluation and improvement.

In 2020, the Excel-based QI tool was piloted in 17 leading MS centres in 14 countries to explore its usefulness for service improvement in various healthcare settings.

A post evaluation survey revealed that responders found the tool relevant, easy to use, with around 85% planning changes to local MS services as a result of the service evaluation.

Together, the clinical standards and QI tool provide MS centres with the means to record current practices, assess them and re-audit to measure progress, with the potential to revolutionize the care pathway for people with MS.



Special thanks and recognition go to Professor Jeremy Hobart, Professor Helmut Butzkueven, Professor Tjalf Ziemssen and Jodi Haartsen for their tireless efforts to drive forward the development and testing of the QI tool.


TURNING THE VISION INTO GLOBAL IMPACT


Shaping clinical care around the world


Since its publication in 2015, *Brain Health: time matters in MS* has evolved from an evidence-based health policy report into a global movement influencing clinical practice, healthcare systems, patient advocacy and MS education. Above all, it is improving the lives of people with MS, creating a better future for them and their families.


Advocating at national level


By 2019, the health policy report was already making an impact at national level.

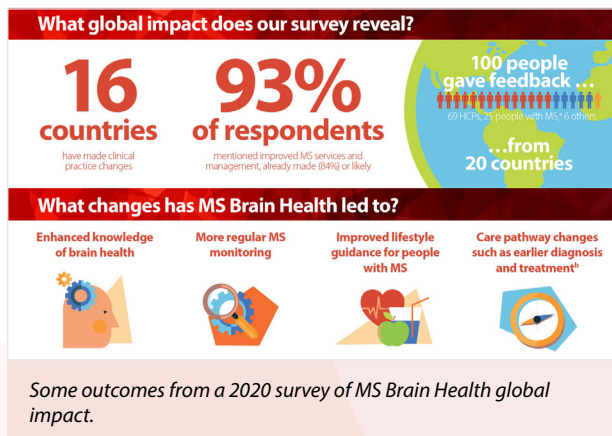
 The importance of timely intervention in MS was promoted to policymakers at the European Parliament in 2017, including a presentation on the economic case for early intervention.


 In Norway, the report influenced policy, practice and behaviour, leading to a reduction in time to diagnosis.

 In 2019, the Australian government acknowledged the importance of timely MS care, a brain-healthy lifestyle, and the need to increase investment in MS research.

 By 2021 in New Zealand, the impact of local advocacy could be seen in changed treatment protocols: people with MS and EDSS score of ≤ 6 now had access to disease-modifying therapies.

 In Serbia, the report was shared at the highest level of government. The number of MS patients treated more than doubled, with many having greater access to treatment options.

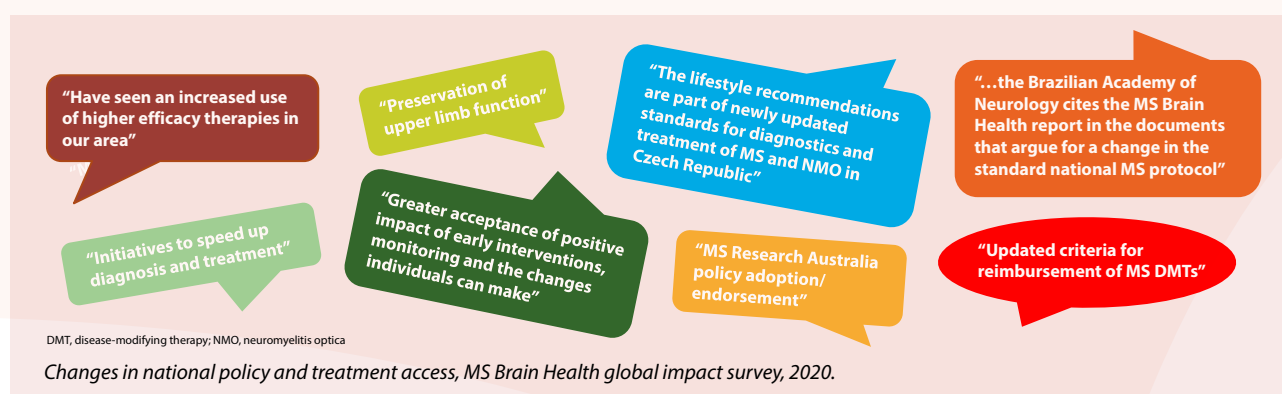


 MS Society UK ran a quit smoking campaign as part of its 2018 national public health Stoptober campaign in response to MS Brain Health's *Six ways to lead a brain-healthy lifestyle* leaflet.



The **MS Brain Health awards** were celebrated in 2022 and 2023 to recognize individuals, MS

organizations and healthcare teams actively engaged in championing the importance of brain health and timely intervention in managing MS. Awards were given for Patient Organization, Patient Advocate, Team, Individual, and Innovation and helped showcase the global advocacy efforts, sharing experience and resulting wider engagement.



DMT, disease-modifying therapy; NMO, neuromyelitis optica

Changes in national policy and treatment access, MS Brain Health global impact survey, 2020.

- "Have seen an increased use of higher efficacy therapies in our area"
- "Initiatives to speed up diagnosis and treatment"
- "Preservation of upper limb function"
- "Greater acceptance of positive impact of early interventions, monitoring and the changes individuals can make"
- "The lifestyle recommendations are part of newly updated standards for diagnostics and treatment of MS and NMO in Czech Republic"
- "MS Research Australia policy adoption/endorsement"
- "Updated criteria for reimbursement of MS DMTs"
- "...the Brazilian Academy of Neurology cites the MS Brain Health report in the documents that argue for a change in the standard national MS protocol"

* EDSS - Expanded Disability Status Scale.

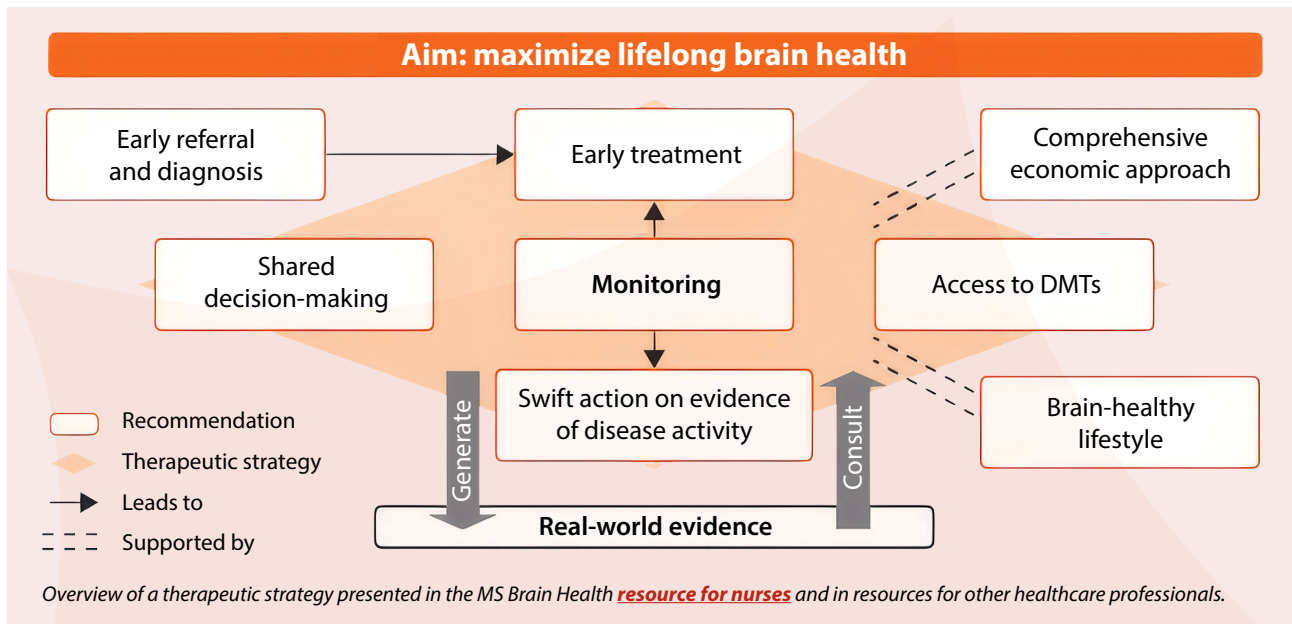
Influencing clinical practice

The report has significantly influenced the MS healthcare community by reinforcing the importance of early diagnosis, rapid treatment initiation, regular monitoring and proactive disease management.

It has helped shift treatment philosophy towards preserving lifelong brain health and reducing disability progression.

The report recommendations have impacted MS care standards, led to the creation of benchmarking tools and quality improvement initiatives.

The initiative has also encouraged multidisciplinary and patient-centred care approaches, integrating cognition, mental health, lifestyle and rehabilitation into routine MS management.



“More availability of disease-modifying treatments for all MS patients equally”

“Helped with establishing rapid pathways for newly diagnosed to be seen and commenced on treatment”

“Directed the focus of our organization’s advocacy work”

“We have made sure politicians and health planners have copies of brain health. We are also participating in three centres in using the MS Brain Health auditing tool and look forward to the results”

“MS Brain Health has certainly changed the way that leading MS neurologists view best practices in MS care”

“We have used MS Brain Health to ensure all of our staff and people with MS understand the importance of advocating for better care”

Changes in clinical practice attributable to the report recommendations. MS Brain Health global impact survey, 2020.

Depression, Anxiety, Sleep disorders, Cognitive impairment, Vertigo, Painful loss of vision, Involuntary crying/emotions, Unstable vision, Impaired speech, Double vision, Impaired swallowing, Stiffness and painful spasms, Sexual problems, Tremor, Bladder problems, Clumsiness, Bowel problems, Poor balance, Sensitivity to temperature, Pain, Fatigue, Exercise intolerance

A guide for general practitioners and primary care providers highlighted the importance of **recognizing MS symptoms and referring promptly** to a neurologist.

Empowering people and patient organizations

The vision of MS Brain Health is to create a better future for people living with MS and their families.

The report has:

- Empowered people with MS to seek timely treatment, regular monitoring and active participation in treatment decisions.
- Provided practical resources and guides for living a brain-healthy lifestyle.
- Inspired patient organizations and patient-led initiatives to better understand the impact of MS and advocate for improved care.
- Increased awareness of the need to manage 'hidden' symptoms of MS that impair brain health, such as sleep disorders, fatigue, depression and anxiety.



A grid of six orange boxes, each containing an icon and a recommendation. The recommendations are: 'Keep as active as you can' (heart icon), 'Keep your weight under control' (scale icon), 'Keep your mind active' (open book icon), 'Avoid smoking' (no smoking sign icon), 'Watch how much you drink' (wine glass icon), and 'Continue taking other medicines your doctor has prescribed' (pill box icon).

Six ways to lead a brain-healthy lifestyle - pivotal recommendations for people with MS.

Much has been done ... but there is still much to do in raising awareness and educating society to improve patient care to create a better future for people with MS.



MS Brain Health has completely transformed how I understand MS. For too long, the conversation around MS has been dominated by discussions on physical decline. The campaign has shifted that focus - highlighting the importance of protecting brain health and recognising the 'invisible' cognitive effects of the disease.

After all, our brains are who we are. And in MS, looking after it matters just as much as managing physical symptoms. What's especially encouraging is seeing this message become part of mainstream MS care, and for that I am grateful.

Rachel Horne

Journalist with MS, Founder of the Rachel Horne Prize for Women's Research in MS



MS-Perspektive, my German podcast, is based on the MS Brain Health Report recommendations. With > 245,000 downloads, it is lovely to help make a difference for people living with MS and change their perspective from going downwards to enjoying life.

Nele von Horsten

MS Brain Health Patient Advocate Award winner, 2022



Creating a global movement

Over the past decade, the initiative has developed into a broader global movement in brain health advocacy.

The report recommendations have been endorsed by MS organizations, specialist nursing organizations, patient groups and major organizations in the field of brain research and treatment around the world.

Timely intervention, proactive monitoring and lifestyle optimization have been featured in specialist publications examining global brain health priorities, including *Journal of Neurological Sciences* and *Journal of Neurology*.

The World Federation of Neurology's World Brain Day in 2023 highlighted **brain health as a global priority**, citing the growing evidence base for prevention and early intervention across neurological conditions.

MS Brain Health has undoubtedly played a pivotal role in communicating widely the need to protect brain health in people with MS.



2015 report recommendations endorsed by over 50 professional, advocacy and patient organizations.



Oxford Health Policy Forum, Oxford PharmaGenesis and MS Australia receive a highly commended award at the PRIME Award for Sustained Excellence for the MS Brain Health initiative Sydney, Australia 2023.



World Brain Day 2023 promoted brain health as a global priority.



Applying a football analogy, I feel that the impact of 'MS Brain Health' has been like bringing on a 'playmaker' (like Gazza, Messi, or Jude Bellingham) to the MS landscape. The initiative has changed the direction and pace of play. The MS community now talk about how #timematters; neurologists who want to 'sit back and wait' are often seen as behind the times.



Ryan Jones
Helpline and Information
Officer at MS-UK, and lives with MS

UPDATING THE EVIDENCE BASE

Building on the latest MS research and extending the reach to other rare neuroimmune conditions

Since the 2015 *Brain health: time matters in MS* report launch, there have been advances in our understanding of MS, improvements in practice standards, policy and scientific developments and new disease-modifying treatments. Therefore, a review and update of the evidence base was warranted. This led to the publication in 2024 of ***Brain health - time matters*** – a second report, endorsed by 37 organizations.

This report also expands beyond MS, to include other, related neuroimmune conditions: NMOSD and MOGAD*. Although these rare, disabling diseases have similar symptoms to MS, they have different underlying drivers of the disease process.

The 2024 report recognizes the progress made in policy, treatment advances and scientific avenues, but highlights the need for continuing advocacy to achieve better standards of care globally.

Its recommendations echo many of the themes from 2015 – **timely diagnosis, early treatment, regular monitoring**, and taking a **person-centred approach to care** regardless of economic and geographical barriers or medical condition.

The hope is that governments, healthcare systems and society will work together to improve care, treatment and support so that everyone living with MS, NMOSD and MOGAD can have better health and quality of life.

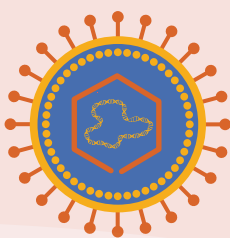
The key is to start somewhere; even small changes can make a difference to individuals, families, societies and economies.



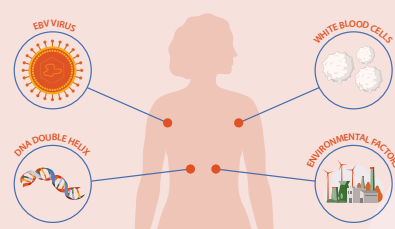
Brain health – time matters 2024 report: Multiple sclerosis (MS), neuromyelitis optica spectrum disorder (NMOSD), myelin oligodendrocyte glycoprotein antibody-associated disease (MOGAD) and related conditions.



New insights into disease origins may change prevention and care



- Epstein-Barr virus (EBV) + genetics + environment: A 'multi-hit' model is gaining traction:
- EBV is now confirmed as a necessary trigger for MS, but not the only one.
- Vaccines or antivirals targeting EBV could reduce MS risk.
- Research is ongoing into infectious links in NMOSD and MOGAD.



Looking to the future; new insights into disease origins may change MS prevention and care.

* NMOSD - neuromyelitis optica spectrum disorder; MOGAD - myelin oligodendrocyte glycoprotein antibody-associated disease.

MOVING FORWARD

Stay engaged with MS Brain Health

As the MS Brain Health initiative enters its next phase, we encourage all our MS Brain Health supporters and contributors to stay involved and engage with our partners in furthering its aims.

MSIF will provide continuity and links to the materials on the MS Brain Health website. The development of the high-impact toolkit will provide MS organizations with the evidence, tools and confidence they need to advocate for policy change. It will help to frame brain health as a policy priority, support engagement with decision-makers, strengthen the use of real-world data and patient-reported outcomes in policy debates, and demonstrate the societal value of early intervention.

To continue receiving updates about MS Brain Health, including the Advocacy Toolkit, **you will need to sign up here: www.msif.org/get-involved/newsletters/**

MSBase plan to develop the Excel-based clinical tool into a web-based resource, increasing clinical access worldwide.

We hope many clinicians will support and utilize the next iteration of the QI tool to improve health outcomes for people with MS.

To receive updates from MSBase, please email: info@msbase.org.



Please **stay involved** and continue to make a difference.

THANK YOU AND AU REVOIR!

So many people have given their time and expertise to lead and promote the MS Brain Health initiative.

We cannot list everyone, but we are truly grateful to each of you: the authors, working groups and Steering Committee members who formed the cornerstone; the endorsers of each report for all their support in spreading the word; countless individuals, and professional and patient organizations who have built on the foundations.

We extend special thanks to the following:

Former **Oxford Health Policy Forum** Board members: Christine Marking and Graham Shelton.

Our Oxford Health Policy Forum Leaders: Ruth Bentley, Emma Georgiou, Kajsa Wilhemsson, Lindsay Perera.

Past and present policy team members of our HealthScience Communication partner **Oxford PharmaGenesis**, including Dani Amos, Simon Birmingham, Rachael Chandler, Harriet Crofts, Lucy Eberhard, Sarah Griffiths, Heather Lang, Katharine Murkett, Emily Stock.

Our policy advisers: Christine Marking, Nick Fahy, Kajsa Wilhemsson.

Our media and PR consultant: Sue Radford.

Our freelancers: so many people have contributed to our work over the years. We thank you all for your expertise.

Our main funders who provided independent grants or sponsorship that made these activities possible: AbbVie, Actelion Pharmaceuticals, Alexion Pharma GmbH, Alexion, AstraZeneca Rare Disease, Biogen, Bristol Myers Squibb, Celgene, F. Hoffmann-La Roche, Horizon (now part of Amgen), Merck Healthcare KGaA, Merck Serono, Multiple Sclerosis Society (MS Society UK), Novartis Pharma AG, Roche Serbia, Sanofi.

We acknowledge with gratitude the encouragement and support for our work over many years from the late **Professor Giancarlo Comi**, former President of the European Charcot Foundation, and collaboration with other MS initiatives.

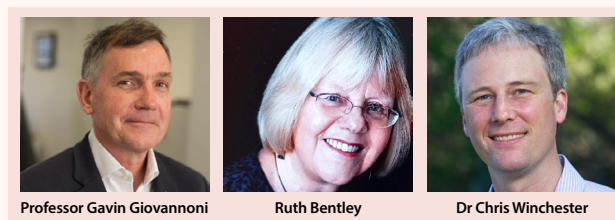


Professor Gavin Giovannoni supporting an event for people with MS following the ECTRIMS conference in London, 2016.

Last, but not least, we are hugely indebted to the vision and tireless commitment of the campaign initiator and Chair, **Professor Gavin Giovannoni**.

The impact of MSBH was only possible thanks to all of you.

Our heartfelt thanks and good wishes, from the Oxford Health Policy Forum CIC Board of Directors.



Professor Gavin Giovannoni

Ruth Bentley

Dr Chris Winchester

