Improving MS diagnosis globally: Recommendations for the MSIF movement

A report by:

Nick Rijke with with input from Multiple Sclerosis International Federation members

December 2025

Overall aim of the project

To carry out a scoping study analysing where the MSIF movement should focus its activities (2026 onwards) to have an impact on improving MS diagnosis globally.

Project objectives

1. To produce a summary of what is known about barriers to accessing an accurate diagnosis of MS as early as possible across the world, and potential interventions to address these barriers.
2. Based on an understanding of the capabilities and capacity across the MSIF movement, develop evidence-based recommendations about where MSIF and its members should focus activity in the next 2-5 years to have the greatest impact, and where other parts of the MS community (e.g. researchers, health professionals, decision-makers) can have a role to play in improving access to diagnosis.

The healthcare problems

- Diagnosis of MS can still take too long, from first symptoms to formal diagnosis, which is a barrier to early intervention and treatment.
- Diagnosis of MS is complex, involving multiple tests and is becoming more complex, with more tests in the mix, if not always required.
- Accuracy is important. Using an MS treatment for a mimic condition can be dangerous, even fatal.
- Numbers of people being diagnosed varies greatly from country to country, but with a pattern that diagnosis can be very difficult in many low-income countries. Access to diagnostic services also differs within countries, typically between large cities and rural settings and between differing sub national jurisdictions.
- On a personal level, experience of diagnosis can also be complex and is often difficult, even traumatic – both for the person being diagnosed and those close to them.

Our goals

1. MS diagnosis is achieved early in the course of disease.

2. MS diagnosis benefits from a high level of accuracy – false positives and negatives are both rare.

3. Increase the diagnosis rate of MS, particularly in countries where MS has been under-diagnosis, historically, so that more people who have MS are able to get a diagnosis.

4. People experience diagnosis as well as we can reasonably expect.

Project Methodology

The project work was all done in 2024 and 2025

Steering group

MSIF appointed a steering group to agree the project brief, including setting out the objectives and methods. The group helped to revise the report following consultation with the Board and others. The members are:

- Dominika Czarnota-Szałkowska Polish MS Society
- Tenille Luker – MS Australia
- Viktor von Wyl – MS-Gesellschaft (Switzerland)
- Sumaya Afif – ABEM (Brazil)
- Nashwa Rabea – MS Care (Egypt)

Light touch literature review

Searches were conducted on keywords, using academic and public facing data sources, throughout the project as questions arose or evidence was required.

With Andrew Soloman, in partnership with MSIF and others, having recently published an excellent overview of the barriers to diagnosis, this paper does not attempt to replicate that work. Where that and other published literature is particularly relevant, it is referenced in the text. Similarly, the Brain Health group (also including input from MSIF) recently published a further paper that included a section on barriers to and improving diagnosis.

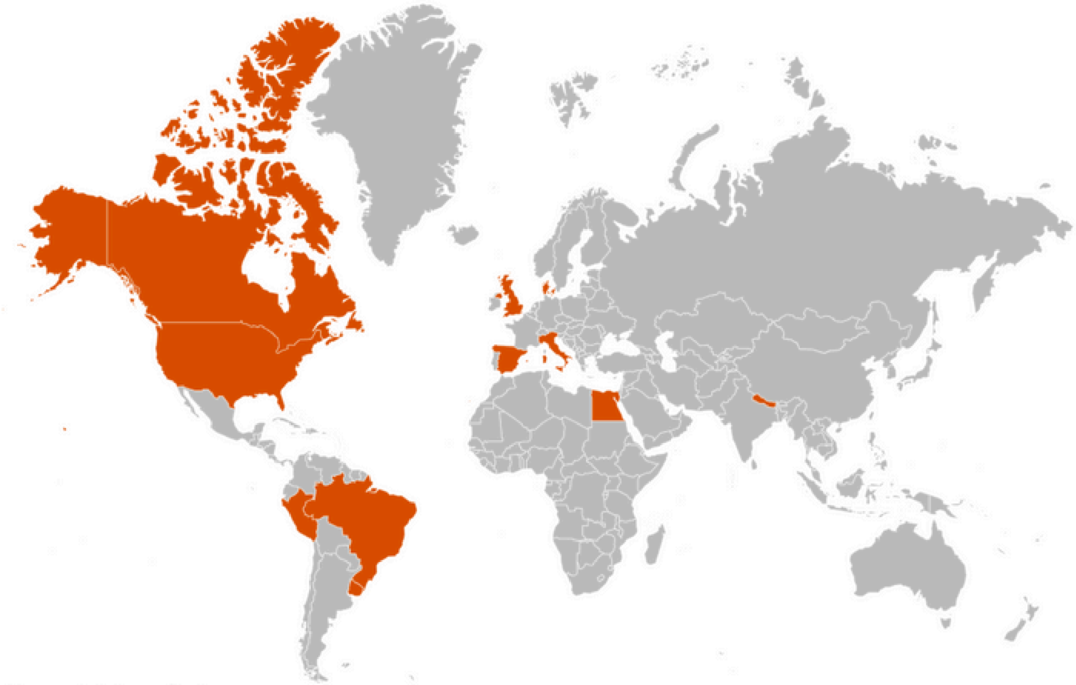
- Global Barriers to the Diagnosis of Multiple Sclerosis
- Brain health – time matters: 2024 report

Additional sources are also referenced to provide context, evidence and useful resources.

Facilitated discussions

Nick Rijke, with support from Anne Helme, facilitated structured discussions with the following MSIF stakeholder groupings.

- MSIF Board & CEOs, in person
- International Medical and Scientific Board, MSIF
- International Working Group on Access to Healthcare, MSIF
- People Affected by MS Expert Group, MSIF
- MSIF Staff (who also edited the report, particularly Anne Helme and Rachel King)



Structured interviews with selected MSIF member organisations

Nick Rijke, with support from Anne Helme, conducted a series of structured interviews with staff and/or Board members from the following MSIF Members.

- Brazil
- Canada
- Denmark
- Egypt
- Italy
- Nepal
- Peru
- Spain
- United Kingdom
- United States
- Uruguay

Summary of Recommendations

There are many recommendations, though most overlap. It is anticipated that these could be implemented over a period of years, depending on the resources available. In the short term there is an obvious opportunity to make a difference, through implementation of the 2024 McDonald Criteria, due to be published soon. This should be seen as an opportunity not only to communicate what has changed since 2017, but to communicate (and press the case for) how MS should now be diagnosed, including addressing barriers to implementation. That is a complex challenge, though the work is contained within the recommendations described below.

The recommendations were first considered in relation to each of the identified barriers and are described in the main body of the report under these headings. In this summary they are grouped under the lead agents and whether they reflect ongoing work or additional activity. The lead agents are grouped as MSIF, national MS (patient) organisations and professional bodies (such as the Committees for Treatment and Research in MS (TRIMS), neurology organisations, and other healthcare professional societies for ophthalmology, radiology, general practice etc). Where MSIF is presented as leading, often this will be as the convener of others. With regard to what is additional, note that some organisations may already be doing (or planning to do) the recommended work, while others are not. We indicate what additional resource will be needed to undertake additional activity.

Ongoing activity

A MSIF as the lead agent, having a supporting and coordinating role

1.Continue to convene MS organisations to share their experiences and insights of approaches that can improve diagnosis. Case studies should have sufficient detail to function as learning and adaptation opportunities for others. National CEOs are encouraged to consider who from their organisations are most relevant in sharing and learning. Topics may especially have focus on:

- Supporting people to navigate the healthcare system.
- Understanding and meeting the information needs of people going through the diagnostic pathway, but who are not yet formally diagnosed as having MS.
- Reaching and informing the variety of professionals now important to diagnosis
- Peer support groups specifically for people who are newly diagnosed.
- Meeting emotional support needs of people newly diagnosed or going through the diagnostic pathway.

2.Continue to support development of advocacy skills among MS organisations, in the context of diagnosis. Both learning through sharing, as above, but also through practical training, facilitated peer learning, and through action learning facilitated by MSIF's programme supporting organisational development.

3.Working with the International Advisory Committee for Clinical Trials in MS (IACCTMS), disseminate revised McDonald criteria and associated publications through member organisations and the IMSB, via meetings, newsletters, shared platforms and other communications. The focus will be on supporting members to communicate these updates to relevant stakeholders in their own national and regional contexts.

4.Ensure that global health policy initiatives, such as IGAP, incorporate challenges and solutions regarding the diagnosis of MS.

B National MS Organisations as lead agents

1.Continue to use diagnosis as a theme for public relations activity, such as for World MS Day, (MSIF to continue support through sharing common messages and resources).

2.Update existing information around diagnosis to include revised criteria and newer tests (MSIF to continue support with shared resources).

3.Continue (where this is already core work) to make the case for healthcare system changes that could improve diagnosis.

C Professional organisations as lead agents

1.Regional TRiMS (Committees for Treatment and Research in MS) and regional/national neurology academies to continue to host diagnosis related sessions in conferences/meetings and webinars.

2.Relevant professional bodies continue to provide courses related to the diagnosis of MS, for professional development.

Additional activity

D MSIF as the lead agent, having a supporting and coordinating role

1.Develop shared messaging around early signs of MS that warrant neurological referral (convening professional and MS patient organisation representatives to co-create messaging on early signs and symptoms of MS that should trigger referral).

- Needs staff resource/time and commitment from professionals.
- Needs funds for publication costs and for design of materials such as infographics, including translations.
- Requires time, collaboration, and input from professional stakeholders.

2.Develop template webpages and information resources about the most up-to-date diagnostic pathway for member organisations to use. This should include Search Engine Optimisation for agreed early signs/symptoms (see: Google Search Essentials). Member organisations can tailor and publish these on their own platforms.

- Needs staff resource/time to coordinate, funds for web design & resources, including translations.
- Could be led or piloted by a member organisation.
- Some existing resources can be good models.
- Impact will mostly depend on use of resources by members.

C Professional organisations as lead agents

3.Convene TRiMS and other relevant international professional organisations to plan dissemination and implementation activity for 2024 McDonald Criteria. This could include targeted materials for neurologists, radiologists, ophthalmologists, or other specialties.

- Needs staff and health professional time to coordinate and potentially to assist with development of materials. Some existing materials/content could be translated and shared.
- Needs professional educational materials/resources for specific audiences, from neurologists through radiologists, ophthalmologists and others.
- Needs strong networking to project messaging through other disciplines' channels, such as conferences.
- May need improved evidence around budget impact, not only cost effectiveness.
- Must be done in partnership with the International Advisory Committee for Clinical Trials in MS (IACCTMS) – needs stakeholder mapping to plan effectively.

E National MS Organisations as lead agents

1.Expand public relations campaigns to include general practice doctors as a target audience. (See case study from Spain).

- Needs (a) materials suited to GPs and (b) relationships with professional bodies to reach them effectively.

2.As in (3) above, national MS organisations convene national professional organisations to plan implementation of 2024 McDonald Criteria.

- Include range of professionals, including, but beyond neurologists.
- Include health system representatives, to consider barriers to implementation and solutions over realistic timescales.
- Include lab facilities/testing companies.

3. Commission health economics studies to re-examine the economic case for enhanced neurology services, including early diagnosis and early treatment. Including immediate budget impact as well as longer-term cost effectiveness.

- Needs research funding and associated costs.
- Include health system users' evidence needs in designing studies.

4.Consider creating navigator programmes to support people through their diagnosis journey.

- Depending on the approach taken this may involve significant staff time, and/or volunteers, as well as funds for resources.

5.Consider the information and support needs of people in the diagnostic pathway, though not yet formally diagnosed. (For some this is an ongoing activity).

- Needs staff time for resources and making these available, such as through webpages, email channels etc

F Professional organisations as lead agents

For all the recommendations listed above, we assume that professional organisations will be key partners internationally and nationally. Much of this work cannot be done well without their input and active support.

- Their expertise is critical.
- Their influence and networks are also critical.
- They provide a channel to their professional discipline, but also influence beyond their discipline, such as to GPs, ophthalmologists and radiologists
- We need their time commitment and where possible, the information resources they can make available.

To read the full report click HERE or scan the QR code

ms international federation

X.COM
@MSIntFederation
FACEBOOK
MSInternationalFederation
LINKEDIN
multiple-sclerosis-international-federation
YOUTUBE
@MSInternationalFederation

www.msif.org