

COUNTRY: Please indicate the country you are providing data for:

CONSENT

This survey is conducted by the MS International Federation (MSIF). The purpose of the survey is to collect information for the <u>Atlas of Multiple Sclerosis (MS)</u>. The Atlas is a key tool for organisations, health professionals and individuals when advocating for better access to diagnosis, treatment, care and support, and has been widely cited in the research literature. We thank you in advance for your support and collaboration in providing data for the country to ensure we have a complete picture of MS across the globe.

Your participation is voluntary, and refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled, and you may discontinue participation at any time.

Your personal data may be used by MSIF in relation to the Atlas project (for example for validation purposes, invitations to participate in future updates, advice or reporting etc.).

MSIF take the duty to protect your personal information seriously. Any personal information you provide will be collected, transferred and/or stored in compliance with MSIF's privacy policy <u>https://www.msif.org/privacy-policy/</u>. We will retain this information for the duration of the Atlas project. The data that we collect from you may be transferred to, and stored at locations both inside or outside the European Economic Area ("EEA") or Switzerland, including the USA.

To agree to the above terms and conditions and proceed with the survey please select "I agree" below:

1. I agree

2. I do not agree

INTRODUCTION

Thank you for agreeing to contribute data to the Atlas of MS - you are part of a global movement to create this important data source that will be used to improve the situation for people with MS worldwide. We cannot do this without you!

When answering the questions in this survey, please focus on Multiple Sclerosis (MS) only. Please do not include other demyelinating conditions such as Neuromyelitis Optica (NMO).

It is important that the answers provided are as accurate as possible. To help with validation and interpretation some questions ask for sources of evidence for the data. However, we appreciate that you may not have evidence for all questions – please consult with others in the country to ensure confidence in the answers and that the answers represent the whole country (not just one person's opinion). To help with the collaboration we have provided a PDF version of the survey that you can use to share and discuss with colleagues or collect data from multiple sources before inputting the data into the online survey.

If you do not know the exact answer, please provide **your best estimate**. If you really cannot provide an estimate, then it is fine to leave that particular question blank.

CONTACT DETAILS: Please provide the contact information for **the lead person** completing this questionnaire and coordinating the response for the country. There is space to include additional collaborators at the end of the survey.

By providing this information, you are consenting for MSIF and their trusted partners to securely hold this data for the duration of the Atlas project and to contact you in connection with the project.

Full Name:	
Title (Dr, Prof, Mr, Ms. etc):	
Current Position/job title:	
Organisation:	
Email:	

Please select ONE option that best describes the role of the lead person completing this questionnaire and coordinating the response for the country.

- 1. Clinician/other health professional/Researcher
- 2. Employee or volunteer for an MS society
- 3. Another role



Diagnostic tests

The next few questions relate to the availability and use of specific tests used in the diagnostic evaluation of Multiple Sclerosis (MS), as well as any barriers to using these tests routinely for MS diagnosis in the country.

Q1a. Which of the following diagnostic tests are **available at all** in the country? *Please indicate all diagnostic tests* that are available in the country even if they are not used for the diagnosis of MS or only used rarely for a small number of people under the column labelled Q1a below. Please include tests that are you are able to send to a different country to process.

IF NONE OF THE LISTED DIAGNOSTIC TESTS ARE AVAILABLE IN YOUR COUNTRY, PLEASE SKIP TO Q1c. EVERYONE ELSE PLEASE CONTINUE WITH Q1b

Q1b. Which of the diagnostic tests available, are **routinely used** in the **diagnosis of MS** in the country? **By routinely we mean for all or most people undergoing MS diagnostic investigations.** Please indicate all that apply under the column labelled Q1b below. Please include tests that you routinely use for MS diagnosis even if they are sent to a different country to process.

	Q1a Available at all in the country	Q1b Routinely used in the diagnosis of MS
Imaging and procedures:		
Magnetic Resonance Imaging (MRI)		
Optical Coherence Tomography (OCT)		
Visual Evoked potentials (VEP)		
Other Evoked potentials		
Spinal tap/lumbar puncture		
Laboratory tests:		
Oligoclonal bands (OCBs)		
Kappa free light chain (KFLC)		
Intrathecal immunoglobulin G (IgG) index		
Aquaporin-4-immunoglobulin G (AQP4-IgG antibody)		
Myelin Oligodendrocyte Glycoprotein (MOG-IgG)		
None of the tests are available/routinely used for the		
diagnosis of MS		

IF NO DIAGNOSTIC TESTS AVAILABLE AT Q1a – ANSWER Q1c. OTHERWISE PLEASE SKIP TO INSTRUCTION ABOVE Q1d

Q.1c You mentioned that you have no MS diagnostic testing ability in the country. Please provide more detail to help us understand the context of your country.

IF AQUAPORIN-4-IMMUNOGLOBULIN G (AQP4-IGG) TESTING IS AVAILBLE AT Q1a, PLEASE ANSWER Q1d, OTHERWISE SKIP TO INSTRUCTION ABOVE Q1e

Q1d. Which types of **AQP4-IgG** (Aquaporin-4-immunoglobulin G) **testing methods are available** in the country? *Please indicate all that apply.*

1.	Cell based assay (CBA) - fixed or live
2.	Enzyme-linked immunosorbent assay (ELISA)
3.	Tissue based assay (TBA)
4.	Not sure

Page **2** of **14**



IF MYELIN OLIGODENDROCYTE GLYCOPROTEIN (MOG-IGG) TESTING IS AVAILBLE AT Q1a, PLEASE ANSWER Q1e AND Q1f OTHERWISE SKIP TO INSTRUCTION ABOVE Q1g

Q1e. Which MOG-IgG testing methods are available in the country? Please indicate all that apply.

- 1. Cell based assay (CBA) fixed or live
 - 2. Enzyme-linked immunosorbent assay (ELISA)
 - 3. Tissue based assay (TBA)
 - 4. Not sure

Q1f. Does the MOG-IgG testing in the country provide a titer (where positive results are ranked according to the strength of positivity)? *Please select one answer only.*

1.
2.

- 1. Yes
- 2. No only provides a positive or negative value
- 3. Not sure

EVERYONE ANSWERS HERE

Q1g. Please use this space to provide more detail and context regarding your answers about **the diagnostic tests available and used routinely for MS diagnosis in the country**. Please also include comments about any tests you process in a different country.

Q1h. Please include the types of source(s) you consulted to provide this information on the diagnostic tests available and used routinely to diagnose MS in the country.

If you have estimated this information or it is based on your opinion – please select the "Your personal opinion" code and indicate any assumptions or data, you used in the comment box below.

Please indicate **all** sources used.

- 1. Published academic paper or a poster/platform presentation at a scientific conference
- 2. Patient data (patient registry, government or health service statistics, electronic medical records, insurance claims data, patient surveys)
- 3. Advocacy Group Report e.g. from a MS organisation
- 4. Official Policy report from Government/Hospital
- 5. Opinion of medical professional
 - 6. Opinion of MS Society/patient organisation
 - 7. Your personal opinion (specify how you have estimated this:
 - 8. Other type of data source (specify_____

Please provide further details or links to any public academic papers or patient data that you have consulted or any further information about the source that is relevant.



IF NO DIAGNOSTIC TESTS AVAILABLE IN COUNTRY AT Q1a SKIP TO Q3.

IF MRI ROUTINELY USED IN THE COUNTRY AT Q1b ASK Q2a – OTHERWISE SKIP TO INSTRUCTION ABOVE Q2b

Q2a. Typically once an MRI scan is ordered, what is the average time taken for patients to receive both the scan and the results from the scan? *Please select one answer only. If the time varies depending on where people get their MRI (for example if people, are inpatients versus outpatients), please show the average across all settings or if that is not possible the average for the most common setting (i.e. for most people being diagnosed).*

- 1. Less than a week 2. 1 week 3. 2 weeks 4. 3 weeks 5. 1 month 6. 2-3 months 7. 4-5 months 8. 6 months 9. 7 or more months
 - 10. Not sure

Q2ai. Please use this space to provide more detail and context regarding your answers on **the average time taken after ordering an MRI scan, for patients to receiving the results** *Please also provide more detail on how the average time might vary in different settings such as outpatients versus inpatients.*

Q2aii. Please include the types of source(s) you consulted to provide this information regarding **the average time taken after ordering an MRI scan, for patients to receiving the results.**

If you have estimated this information or it is based on your opinion – please select the "Your personal opinion" code and indicate any assumptions or data, you used in the comment box below.

Please indicate all sources used.

- 1. Published academic paper or a poster/platform presentation at a scientific conference
- 2. Patient data (patient registry, government or health service statistics, electronic medical records, insurance claims data, patient surveys)
- 3. Advocacy Group Report e.g. from a MS organisation
- 4. Official Policy report from Government/Hospital
- 5. Opinion of medical professional
 - 6. Opinion of MS Society/patient organisation
 - 7. Your personal opinion (specify how you have estimated this:
 - 8. Other type of data source (specify____

Please provide further details or links to any public academic papers or patient data that you have consulted or any further information about the source that is relevant.



IF MRI AVAILABLE BUT NOT USED ROUTINELY AT Q1b PLEASE ANSWER Q2b. EVERYONE ELSE PLEASE GO TO INSTRUCTION ABOVE Q2c.

Q2b. Please indicate why **Magnetic Resonance Imaging (MRI)** is <u>not</u>routinely used for the diagnosis of MS in the country? *Please indicate all that apply.*

- 1. Lack of awareness of the importance of this test in the diagnosis of MS
- 2. Health professionals (lab assistants, radiographers, neurologists, ophthalmologists etc.) with specialist knowledge to perform or analyse this test not readily available
- 3. Concern about the accuracy or reliability of this test (due to lack of laboratory expertise, or lack of quality equipment)
- 4. Cost of this diagnostic test is too expensive for the government, health provider or insurance provider
- 5. Cost of this diagnostic test is too expensive for the people suspected as having MS (e.g. lack of health insurance, or tests not covered/fully covered by health insurance, etc.)
- 6. People are not able to travel to access this diagnostic test (e.g. live too far away, cannot afford transport costs, not physically able to travel etc.)
- 7. People are worried about the social stigma related to having a confirmed diagnosis of MS
- 8. People are scared or worried about this diagnostic procedures/test (e.g. cultural superstition/myths, concern over side effects / pain / claustrophobia)
- 9. This diagnostic test is not recommended in the national guidelines for MS diagnosis
- 10. This diagnostic test is only used for differential diagnosis e.g: ruling out other demyelinating disorders
- 11. Other (specify_
- 12. Not sure

Please use this comment box to explain the barriers to using **MRI** routinely in the diagnosis of MS in more detail to provide more context about the situation in your country. *Please provide as much detail as possible.*

IF OCT AVAILABLE BUT NOT USED ROUTINELY AT Q1b PLEASE ANSWER Q2c. EVERYONE ELSE PLEASE GO TO INSTRUCTION ABOVE Q2d.

Q2c. Please indicate why **Optical Coherence Tomography (OCT)** is <u>not</u> routinely used for the diagnosis of MS in the country. *Please indicate all that apply.*

- 1. Lack of awareness of the importance of this test in the diagnosis of MS
- 2. Health professionals (lab assistants, radiographers, neurologists, ophthalmologists etc.) with specialist knowledge to perform or analyse this test not readily available
- 3. Concern about the accuracy or reliability of this test (due to lack of laboratory expertise, or lack of quality equipment)
- 4. Cost of this diagnostic test is too expensive for the government, health provider or insurance provider
- 5. Cost of this diagnostic test is too expensive for the people suspected as having MS (e.g. lack of health insurance, or tests not covered/fully covered by health insurance, etc.)
- 6. People are not able to travel to access this diagnostic test (e.g. live too far away, cannot afford transport costs, not physically able to travel etc.)
- 7. People are worried about the social stigma related to having a confirmed diagnosis of MS
- 8. People are scared or worried about this diagnostic procedures/test (e.g. cultural superstition/myths, concern over side effects / pain / claustrophobia)
- 9. This diagnostic test is not recommended in the national guidelines for MS diagnosis
- 10. This diagnostic test is only used for differential diagnosis e.g: ruling out other demyelinating disorders
- 11. Other (specify
- 12. Not sure

Please use this comment box to explain the barriers to using **OCT** routinely in the diagnosis of MS in more detail to provide more context about the situation in your country.



IF VISUAL EVOKED POTENTIALS AVAILABLE BUT NOT USED ROUTINELY AT Q1b PLEASE ANSWER Q2d. EVERYONE ELSE PLEASE GO TO INSTRUCTION ABOVE Q2e.

Q2d. Please indicate why **Visual Evoked Potentials (VEP)** is <u>not</u> routinely used for the diagnosis of MS in the country. *Please indicate all that apply.*

- 1. Lack of awareness of the importance of this test in the diagnosis of MS
- 2. Health professionals (lab assistants, radiographers, neurologists, ophthalmologists etc.) with specialist knowledge to perform or analyse this test not readily available
- 3. Concern about the accuracy or reliability of this test (due to lack of laboratory expertise, or lack of quality equipment)
- 4. Cost of this diagnostic test is too expensive for the government, health provider or insurance provider
- 5. Cost of this diagnostic test is too expensive for the people suspected as having MS (e.g. lack of health insurance, or tests not covered/fully covered by health insurance, etc.)
- 6. People are not able to travel to access this diagnostic test (e.g. live too far away, cannot afford transport costs, not physically able to travel etc.)
- 7. People are worried about the social stigma related to having a confirmed diagnosis of MS
- 8. People are scared or worried about this diagnostic procedures/test (e.g. cultural superstition/myths, concern over side effects / pain / claustrophobia)
 - 9. This diagnostic test is not recommended in the national guidelines for MS diagnosis
- 10. This diagnostic test is only used for differential diagnosis e.g: ruling out other demyelinating disorders
- 11. Other (specify_
- 12. Not sure

Please use this comment box to explain the barriers to using **Visual Evoked Potentials (VEP)** routinely in the diagnosis of MS in more detail to provide more context about the situation in your country.

IF OTHER EVOKED POTENTIALS AVAILABLE BUT NOT USED ROUTINELY AT Q1b PLEASE ANSWER Q2e. EVERYONE ELSE PLEASE GO TO INSTRUCTION ABOVE Q2f.

Q2e. Please indicate why **other evoked potentials** are <u>not</u> **routinely used** for the diagnosis of MS in the country. *Please indicate all that apply.*

1.	Lack of awareness of the importance of this test in the diagnosis of MS
2.	Health professionals (lab assistants, radiographers, neurologists, ophthalmologists etc.) with specialist knowledge to perform or analyse this test not readily available
3.	Concern about the accuracy or reliability of this test (due to lack of laboratory expertise, or lack of quality equipment)
4.	Cost of this diagnostic test is too expensive for the government, health provider or insurance provider
5.	Cost of this diagnostic test is too expensive for the people suspected as having MS (e.g. lack of health insurance, or tests not covered/fully covered by health insurance, etc.)
6.	People are not able to travel to access this diagnostic test (e.g. live too far away, cannot afford transport costs, not physically able to travel etc.)
7.	People are worried about the social stigma related to having a confirmed diagnosis of MS
8.	People are scared or worried about this diagnostic procedures/test (e.g. cultural superstition/myths, concern over side effects / pain / claustrophobia)
9.	This diagnostic test is not recommended in the national guidelines for MS diagnosis
10.	This diagnostic test is only used for differential diagnosis e.g. ruling out other demyelinating disorders
11.	Other (specify)
12.	Not sure

Please use this comment box to explain the barriers to using **other evoked potentials** routinely in the diagnosis of MS in more detail to provide more context about the situation in your country.



IF SPINAL TAP/LUMBAR PUNCTURE AVAILABLE BUT NOT USED ROUTINELY AT Q1b PLEASE ANSWER Q2f. EVERYONE ELSE PLEASE GO TO INSTRUCTION ABOVE Q2g.

Q2f. Please indicate why **spinal tap/lumbar puncture** is <u>**not</u> routinely used** for the diagnosis of MS in the country. *Please indicate all that apply.*</u>

- 1. Lack of awareness of the importance of this test in the diagnosis of MS
- 2. Health professionals (lab assistants, radiographers, neurologists, ophthalmologists etc.) with specialist knowledge to perform or analyse this test not readily available
- 3. Concern about the accuracy or reliability of this test (due to lack of laboratory expertise, or lack of quality equipment)
- 4. Cost of this diagnostic test is too expensive for the government, health provider or insurance provider
- 5. Cost of this diagnostic test is too expensive for the people suspected as having MS (e.g. lack of health insurance, or tests not covered/fully covered by health insurance, etc.)
- 6. People are not able to travel to access this diagnostic test (e.g. live too far away, cannot afford transport costs, not physically able to travel etc.)
- 7. People are worried about the social stigma related to having a confirmed diagnosis of MS
- 8. People are scared or worried about this diagnostic procedures/test (e.g. cultural superstition/myths, concern over side effects / pain / claustrophobia)
 - 9. This diagnostic test is not recommended in the national guidelines for MS diagnosis
- 10. This diagnostic test is only used for differential diagnosis e.g. ruling out other demyelinating disorders
- 11. Other (specify_
- 12. Not sure

Please use this comment box to explain the barriers to using **spinal tap/lumbar puncture** routinely in the diagnosis of MS in more detail to provide more context about the situation in your country.

IF LABORATORY TESTING FOR OLIGOCLONAL BANDS (OCBs) AVAILABLE BUT NOT USED ROUTINELY AT Q1b PLEASE ANSWER Q2g. EVERYONE ELSE PLEASE GO TO INSTRUCTION ABOVE Q2h.

Q2g. Please indicate why laboratory testing for Oligoclonal bands (OCBs) is <u>not</u> routinely used for the diagnosis of MS in the country. *Please indicate all that apply.*

- 1. Lack of awareness of the importance of this test in the diagnosis of MS
- 2. Health professionals (lab assistants, radiographers, neurologists, ophthalmologists etc.) with specialist knowledge to perform or analyse this test not readily available
- 3. Concern about the accuracy or reliability of this test (due to lack of laboratory expertise, or lack of quality equipment)
 - 4. Cost of this diagnostic test is too expensive for the government, health provider or insurance provider
- 5. Cost of this diagnostic test is too expensive for the people suspected as having MS (e.g. lack of health insurance, or tests not covered/fully covered by health insurance, etc.)
- 6. People are not able to travel to access this diagnostic test (e.g. live too far away, cannot afford transport costs, not physically able to travel etc.)
- 7. People are worried about the social stigma related to having a confirmed diagnosis of MS
- 8. People are scared or worried about this diagnostic procedures/test (e.g. cultural superstition/myths, concern over side effects / pain / claustrophobia)
- 9. This diagnostic test is not recommended in the national guidelines for MS diagnosis
- 10. This diagnostic test is only used for differential diagnosis e.g: ruling out other demyelinating disorders
- 11. Other (specify_
- 12. Not sure

Please use this comment box to explain the barriers to using laboratory testing for **Oligoclonal bands (OCBs)** routinely in the diagnosis of MS in more detail to provide more context about the situation in your country.



IF LABORATORY TESTING FOR KAPPA FREE LIGHT CHAIN (KFLC) AVAILABLE BUT NOT USED ROUTINELY AT Q1b PLEASE ANSWER Q2h. EVERYONE ELSE PLEASE GO TO INSTRUCTION ABOVE Q2i.

Q2h. Please indicate why **laboratory testing for Kappa free light chain (KFLC)** is <u>not</u> **routinely used** for the diagnosis of MS in the country. *Please indicate all that apply.*

- 1. Lack of awareness of the importance of this test in the diagnosis of MS
- 2. Health professionals (lab assistants, radiographers, neurologists, ophthalmologists etc.) with specialist knowledge to perform or analyse this test not readily available
- 3. Concern about the accuracy or reliability of this test (due to lack of laboratory expertise, or lack of quality equipment)
- 4. Cost of this diagnostic test is too expensive for the government, health provider or insurance provider
- 5. Cost of this diagnostic test is too expensive for the people suspected as having MS (e.g. lack of health insurance, or tests not covered/fully covered by health insurance, etc.)
- 6. People are not able to travel to access this diagnostic test (e.g. live too far away, cannot afford transport costs, not physically able to travel etc.)
- 7. People are worried about the social stigma related to having a confirmed diagnosis of MS
- 8. People are scared or worried about this diagnostic procedures/test (e.g. cultural superstition/myths, concern over side effects / pain / claustrophobia)
 - 9. This diagnostic test is not recommended in the national guidelines for MS diagnosis
- 10. This diagnostic test is only used for differential diagnosis e.g: ruling out other demyelinating disorders
- 11. Other (specify_
- 12. Not sure

Please use this comment box to explain the barriers to using **laboratory testing for Kappa free light chain (KFLC)** routinely in the diagnosis of MS in more detail to provide more context about the situation in your country.

IF LABORATORY TESTING FOR INTRATHECAL IMMUNOGLOBULIN G (IgG) INDEX AVAILABLE BUT NOT USED ROUTINELY AT Q1b PLEASE ANSWER Q2i. EVERYONE ELSE PLEASE GO TO INSTRUCTION ABOVE Q2j.

Q2i. Please indicate why **laboratory testing for Intrathecal immunoglobulin G (IgG) index** is <u>not</u> **routinely used** for the diagnosis of MS in the country. *Please indicate all that apply.*

- 1. Lack of awareness of the importance of this test in the diagnosis of MS
- 2. Health professionals (lab assistants, radiographers, neurologists, ophthalmologists etc.) with specialist knowledge to perform or analyse this test not readily available
- 3. Concern about the accuracy or reliability of this test (due to lack of laboratory expertise, or lack of quality equipment)
- 4. Cost of this diagnostic test is too expensive for the government, health provider or insurance provider
- 5. Cost of this diagnostic test is too expensive for the people suspected as having MS (e.g. lack of health insurance, or tests not covered/fully covered by health insurance, etc.)
- 6. People are not able to travel to access this diagnostic test (e.g. live too far away, cannot afford transport costs, not physically able to travel etc.)
- 7. People are worried about the social stigma related to having a confirmed diagnosis of MS
- 8. People are scared or worried about this diagnostic procedures/test (e.g. cultural superstition/myths, concern over side effects / pain / claustrophobia)
- 9. This diagnostic test is not recommended in the national guidelines for MS diagnosis
- 10. This diagnostic test is only used for differential diagnosis e.g: ruling out other demyelinating disorders
- 11. Other (specify_
- 12. Not sure

Please use this comment box to explain the barriers to using **laboratory testing for Intrathecal immunoglobulin G (IgG) index** routinely in the diagnosis of MS in more detail to provide more context about the situation in your country.



IF LABORATORY TESTING FOR AQUAPORIN-4-IMMUNOGLOBULIN G (AQP4-IGG ANTIBODY) AVAILABLE BUT NOT USED ROUTINELY AT Q1b PLEASE ANSWER Q2j. EVERYONE ELSE PLEASE GO TO INSTRUCTION ABOVE Q2k.

Q2j. Please indicate why **laboratory testing for Aquaporin-4-immunoglobulin G (AQP4-IgG antibody)** is <u>not</u> **routinely used** for the diagnosis of MS in the country. *Please indicate all that apply.*

- 1. Lack of awareness of the importance of this test in the diagnosis of MS
- 2. Health professionals (lab assistants, radiographers, neurologists, ophthalmologists etc.) with specialist knowledge to perform or analyse this test not readily available
- 3. Concern about the accuracy or reliability of this test (due to lack of laboratory expertise, or lack of quality equipment)
- 4. Cost of this diagnostic test is too expensive for the government, health provider or insurance provider
- 5. Cost of this diagnostic test is too expensive for the people suspected as having MS (e.g. lack of health insurance, or tests not covered/fully covered by health insurance, etc.)
- 6. People are not able to travel to access this diagnostic test (e.g. live too far away, cannot afford transport costs, not physically able to travel etc.)
- 7. People are worried about the social stigma related to having a confirmed diagnosis of MS
- 8. People are scared or worried about this diagnostic procedures/test (e.g. cultural superstition/myths, concern over side effects / pain / claustrophobia)
- 9. This diagnostic test is not recommended in the national guidelines for MS diagnosis
- 10. This diagnostic test is only used for differential diagnosis e.g: ruling out other demyelinating disorders
- 11. Other (specify_
- 12. Not sure

Please use this comment box to explain the barriers to using **laboratory testing for Aquaporin-4immunoglobulin G (AQP4-IgG antibody)** routinely in the diagnosis of MS in more detail to provide more context about the situation in your country.

IF LABORATORY TESTING FOR MYELIN OLIGODENDROCYTE GLYCOPROTEIN (MOG-IgG) AVAILABLE BUT NOT USED ROUTINELY AT Q1b PLEASE ANSWER Q2k. EVERYONE ELSE PLEASE GO TO INSTRUCTION ABOVE Q2I.

Q2k. Please indicate why **laboratory testing for Myelin Oligodendrocyte Glycoprotein (MOG-lgG)** is <u>not</u> **routinely used** for the diagnosis of MS in the country. *Please indicate all that apply.*

- 1. Lack of awareness of the importance of this test in the diagnosis of MS
- 2. Health professionals (lab assistants, radiographers, neurologists, ophthalmologists etc.) with specialist knowledge to perform or analyse this test not readily available
- 3. Concern about the accuracy or reliability of this test (due to lack of laboratory expertise, or lack of quality equipment)
 - 4. Cost of this diagnostic test is too expensive for the government, health provider or insurance provider
- 5. Cost of this diagnostic test is too expensive for the people suspected as having MS (e.g. lack of health insurance, or tests not covered/fully covered by health insurance, etc.)
- 6. People are not able to travel to access this diagnostic test (e.g. live too far away, cannot afford transport costs, not physically able to travel etc.)
- 7. People are worried about the social stigma related to having a confirmed diagnosis of MS
- 8. People are scared or worried about this diagnostic procedures/test (e.g. cultural superstition/myths, concern over side effects / pain / claustrophobia)
- 9. This diagnostic test is not recommended in the national guidelines for MS diagnosis
- 10. This diagnostic test is only used for differential diagnosis e.g: ruling out other demyelinating disorders
- 11. Other (specify_
- 12. Not sure

Please use this comment box to explain the barriers to using **laboratory testing for Myelin Oligodendrocyte Glycoprotein (MOG-IgG)** routinely in the diagnosis of MS in more detail to provide more context about the situation in your country.



IF ANY TEST IS AVAILABLE BUT IT IS NOT USED, PLEASE ANSWER Q2I. OTHERWISE GO TO Q3.

Q2I. Please include the types of source(s) you consulted to provide this information regarding **the barriers to using the diagnostic tests.**

If you have estimated this information or it is based on your opinion – please select the "Your personal opinion" code and indicate any assumptions or data, you used in the comment box below.

Please indicate **all** sources used.

- 1. Published academic paper or a poster/platform presentation at a scientific conference
- 2. Patient data (patient registry, government or health service statistics, electronic medical records, insurance claims data, patient surveys)
- 3. Advocacy Group Report e.g. from a MS organisation
- 4. Official Policy report from Government/Hospital
- 5. Opinion of medical professional
 - 6. Opinion of MS Society/patient organisation
 - 7. Your personal opinion (specify how you have estimated this:
 - 8. Other type of data source (specify____

Please provide further details or links to any public academic papers or patient data that you have consulted or any further information about the source that is relevant.

EVERYONE ANSWERS HERE

Q3. Over the past few years, emerging research data has supported the inclusion of the visual system in the MS diagnostic criteria for fulfilment of a region of dissemination in space. If lesions on the optic nerve could be confirmed using Optical Coherence Tomography (OCT) or Visual Evoked Potential (VEP), what impact would this change have in the country? *Please indicate all that apply*

1.	No difference

- 2. Improve the **speed** of MS diagnosis
- 3. Improve the **accuracy** of MS diagnosis
- 4. Improve access to diagnostic tests for people with MS (because OCT and/or VEP are more widely available than MRI)
- 5. Improve access to diagnostic tests for people with MS (because OCT and/or VEP are more affordable than MRI for either patients or for the health care system)
 - 6. Potential for advocacy to improve access to OCT and/or VEP
 - Potential for advocacy to encourage the general public to schedule OCT scans as part of routine eye tests and for optometrists to refer relevant patients to neurology if neurological condition suspected
- 8. Other (specify___
- 9. Not sure

Please use this comment box to provide more detail to support your answer to help us understand why this change could make a difference in your country (or indeed why it would not).



Updates to MS Guidelines

The following questions are to establish how most neurologists in the country would prefer to learn about updates to MS guidelines. This could help guide communication strategies in the future.

Q4a. How do neurologists in the country prefer to learn about changes to diagnostic, treatment or management guidelines for MS (such as updates to the McDonald criteria)? *Please indicate the 3 most popular options.*

- 1. Attending conferences (national, regional or global)
- 2. Webinars
 - 3. Newsletters print format
 - 4. Electronic newsletters, blogs or email communication
- 5. Social media X/Twitter
- 6. Social media LinkedIn
- 7. Social media YouTube
- 8. Social media other
- 9. Research social networks and sharing platforms (e.g. ResearchGate, ORCID, Google Scholar, Academia.edu)
- 10. Journals multiple sclerosis specific: e.g. MS Journal (MSJ), MS And related Disorders, (MSARD)
- 11. Journals general neurology: e.g. Lancet Neurology, Neurology
- 12. Journals other
- 13. Specialist training/education/Continuing Professional Development (CPD)/Continuing Medical Education (CME)
- 14. Word of mouth
- 15. Other (specify____
- 16. Not sure

Q4b. From which types of organisations or people do neurologists in the country prefer to learn about changes to diagnostic, treatment or management guidelines for MS (such as updates to the McDonald criteria)? *Please indicate the 3 most popular options.*

1.	
	ECTRIMS, ACTRIMS, PACTRIMS, MENACTRIMS etc.
2.	World Federation of Neurology
3.	Regional Neurology Professional Organisations (such as the African Academy of Neurology and the European Federation of Neurological Associations)
4.	National Neurology Professional Organisations (such as American Academy of Neurology, Japanese Society of Neurologists, Brazilian Academy of Neurology)
5.	Continuing Professional Development/Medical Education providers/Learning Platforms
6.	MS organisations
7.	Healthcare professionals (neurologists, MS nurses etc.), researchers or decision makers
8.	Patients
9.	Other (specify)
10.	Not sure
 _	



Diagnosis appointment

The next couple of questions are about the duration of the appointment when a patient receives a diagnosis of MS. We understand that the appointment duration can differ based on the hospital or region (or whether it is in the public or private setting). Please try to estimate the average number of minutes for such appointments across the entire country and for the majority of people undergoing diagnosis.

Q5a. Approximately what is the average duration of the appointment in which a patient receives their MS diagnosis in the country?

INSERT TIME		
IN MINUTES:		

Not sure

Q5b. Do neurologists in the country generally feel this appointment duration (in which people receive their MS diagnosis) is too long, just right or not long enough to explain the diagnosis, next steps and answer patient questions and concerns?

1.	Much too long
2.	Slightly too long
3.	Just right
4.	Not quite long e
_	

- Not quite long enough
- Not nearly long enough 5.
- 6. Not sure

Q5c. Please use this space to provide more detail and context regarding your answers on the appointment duration (including any information on how this might vary for people accessing an MS diagnosis in different parts of the healthcare system or regions or hospitals).

Q5d. Please include the types of source(s) you consulted to provide this information regarding the appointment duration.

If you have estimated this information or it is based on your opinion - please select the "Your personal opinion" code and indicate any assumptions or data, you used in the comment box below.

Please indicate all sources used.

- 1. Published academic paper or a poster/platform presentation at a scientific conference
- 2. Patient data (patient registry, government or health service statistics, electronic medical records, insurance claims data, patient surveys)
- 3. Advocacy Group Report e.g. from a MS organisation
- 4. Official Policy report from Government/Hospital
- 5. Opinion of medical professional
- 6. Opinion of MS Society/patient organisation
- 7. Your personal opinion (specify how you have estimated this:
- 8. Other type of data source (specify

Please provide further details or links to any public academic papers or patient data that you have consulted or any further information about the source that is relevant.



Diagnosis Guidelines

Q6. Which of the following aspects are included in any national guidelines related to MS diagnosis/care (if they are available) in the country? *Please indicate all that apply.*

- 1. Not applicable no guidelines for MS diagnosis/care in the country
- 2. Providing information about what MS is and the types of MS (RRMS, Progressive etc.)
- 3. Providing information and support for pregnancy or future desires to have children (family planning)
- 4. Disease modifying therapy (DMT) options
- 5. Symptomatic management and treatments/referrals to other specialist healthcare professionals (physiotherapists, rehabilitation specialists, speech and language therapists, psychologists, counsellors, dietitians, continence health professionals etc.)
- 6. Managing relapses and exacerbations
- 7. Providing information on national, local or online resources/support groups or MS organisations
- 8. Discussing legal requirements (social care, employment rights, benefits and driving license implications)
 - 9. Discussing any social care needs and if so, refer to these services
- 10. Financial planning
 - 11. Modifiable risk factors such as exercise, diet, vaccinations, smoking
 - 12. Providing information on monitoring and follow-up how often a patient is reviewed or assessed
 - 13. Providing information of shared decision making between patients and healthcare professionals.
 - 14. Other (specify
 - 15. Not sure

Please provide any other details on the guidelines and a link to them if publicly available:

Collaborators and Acknowledgments

Q7a. Please indicate who was consulted or collaborated with in order to provide the answers to these questions. *Please indicate all that apply*

1.	Clini
2.	Othe
	(Plea
3.	Didn
4.	Didn
5.	Didn
6.	Othe

- 1. Clinicians based in the country or with experience of working in the country
- 2. Other experts in the country (who are not clinicians)
 - (Please specify what their role/expertise is: _____
 - 3. Didn't consult anyone else no other experts with knowledge of MS diagnosis in the country
- 4. Didn't consult anyone else you lacked time to consult any other clinicians or experts in the country
- 5. Didn't consult anyone else you tried to approach other experts, but they lacked time to take part
- 6. Other (please specify) _

Q7b. Would you like your name to appear in the list of contributors to the Atlas of MS update?

We will not make public any personal information without your permission, and the information displayed will be limited to your name and country.

- 1. Yes (Please specify below)
 - 2. No (Please skip to QG)

Please specify how you would like your name to appear in the list of contributors, including any titles. *see website for examples* <u>https://www.atlasofms.org/collaborators-and-acknowledgements</u>).

Q7c. Is there anyone else who you have collaborated with to complete this survey who would like to appear in the list of named contributors to the Atlas of MS update and have agreed for their name to be passed to MSIF?

Please ensure that you have consent to provide us with their name and for us to publish this in our report (the information displayed will be limited to their name and country).

- 1. Yes (Please specify details below)
- 2. No (Please skip to the thank you)



Please specify the contact name (including any titles) and email address for each collaborator below.

Please ensure that you have consent to provide us with their name and for us to publish this in our report (the information displayed will be limited to their name and country)— see the website for examples - https://www.atlasofms.org/collaborators-and-acknowledgements).

	Name Format of name should be: Title (Dr. Prof. Ass. Prof), Forename, Surname: E.g.: Ass Prof. Diana King	Email address (this is so we can reach out for clarifications/queries as well as updates about the Atlas)	Clinician/other health 1. Clinician/other health professional/Researcher 2. Employee or volunteer for an MS society 3. Another role
1.			
2.			
3.			
4.			
5.			
6.			
7.			
8.			
9.			
10.			

Thank You

Thank you very much for completing this survey – we are very grateful for your help.

You can find out more about MSIF's work and how you can join in by:

- Signing up to our newsletters: <u>https://www.msif.org/get-involved/our-newsletters/</u>
- Visiting the Atlas of MS website: <u>www.atlasofms.org</u>
- Exploring our work to improve access to treatments and healthcare (and how the Atlas data supports this work): <u>https://www.msif.org/improving-access-to-ms-treatment-and-healthcare/</u>
- Reviewing the grants available for clinicians/researchers working in low or middle income countries: <u>https://www.msif.org/research/awards-grants-and-fellowships/</u>
- Exploring the World MS Day website https://worldmsday.org/about/. This important date for the MS calendar is officially marked on 30 May and brings the whole global MS community together to share stories, raise awareness and campaign. Make a difference and encourage everyone you know to join-in!
 The theme for the next two years is MS diagnosis