EMSP Barometer 2026 Survey

Name
- -

Email
ab@cifs.dk

Society Name
-

Country
-

Which conditions does your society / organisation work with?
MS and NMOSD and MOGAD

Consent

✔ I have read the information below and agree to participate in this survey.

This survey is conducted by the European Multiple Sclerosis Platform (EMSP) in collaboration with the Copenhagen Institute for Futures Studies (CIFS) as part of the MS Barometer project. The aim is to collect country-level information on policies, services, and systems related to MS, as well as selected aspects of NMOSD and MOGAD care. Participation is voluntary. Responses will be analysed and reported in aggregated form at the country level and will not be attributed to individuals. The information provided will be used solely for the purposes of the MS Barometer project. By proceeding with the survey, you confirm that you have read this information and consent to the use of your responses for analysis and reporting.

The MS Barometer project is co-funded by Alexion, Amgen, Juvisé Pharmaceuticals, Merck, Novartis, Roche, Sanofi.

MS Module

Welcome to the MS Module of the Survey --- Epidemiology

1. What is the estimated total number of people currently living with MS in your country?

1a. If available, please also provide the estimated number of people diagnosed with MS in each of the following diagnostic categories: 1. Primary-progressive MS*, 2. Secondary-progressive MS*, 3. Relapsing-remitting MS*

2. What was the estimated number of people newly diagnosed (incidence*) with MS in your country in 2025?

3. What are the most common comorbidities* present among people diagnosed with MS in your country?

3a. If you chose other comorbidites, please specify which:

3b. Please provide the source of information and, if available, indicate the number of people with MS living with the comorbidity/comorbidities you selected, where available.

MS Module

Part 1: Policy

1. Which of the following national health policy frameworks exist in your country, and does MS fall within their scope?

1a. If you chose other, please specify:

1b. If yes, please cite the documents below:

2. Are there any national policies or programmes addressing rare diseases*, including paediatric MS, NMOSD and MOGAD?

2a. If you chose yes, please specify:

3. In what ways are people with MS and MS societies involved in national policy making on MS?

3a. If you chose other, please specify:

4. Does your National MS Society's (/Societies' if more exist) governing body include people with MS?

5. Is the National MS Society (Societies if more exist) involved in the decision-making process of reimbursement of MS therapies/treatments?

6. To what extent is patient-reported outcomes data used in national policy, planning or reimbursement decisions?

7. To what extent is MS registry data used in national policy, planning or reimbursement decisions?

MS Module

Part 2: Care delivery section

1. What is the number of practising neurologists in your country? If known, specify the number of neurologists specialised in MS.

2. What is the number of nurses who care for people with MS in your country? Including nurses formally designated as MS nurses or nurses working primarily in MS specialist services.

3. Which of the following best describe the role of MS nurses in your country?

3a. Please specify aspects of care:

4. What is the number of centres providing care for people with MS in your country? If available, please provide 1. the number of dedicated MS centres and 2. the number of general neurology centres providing MS care

5. Are there population groups who systematically/consistently face barriers in accessing MS care in your country?

5a. If you chose other, please specify:

6. Is there a defined national or regional referral pathway for suspected MS from primary care to specialist neurology services? Or can patients directly seek specialist care without primary care referral?

6a. If you chose other, please specify:

7. What is the typical waiting time at the national level for a person with suspected MS to be seen by an official neurologist after referral?

7a. Please cite the source of reference, if available:

8. Does your country use national or international clinical treatment guidelines* to treat people diagnosed with MS?

8a. If yes, please cite the guidelines in the field below:

9. Can a person with MS access a multidisciplinary team as part of their routine disease management?

10. Are specific care pathways in place for people with progressive MS?

11. To what extent does your country's MS care system support a life-course approach*, ensuring continuity of care from diagnosis through ageing and advanced disease?

12. What types of patient education or self-management support are available for people with MS in your country?

12a. If you chose other, please specify:

13. To what extent are people with MS supported to participate in shared decision-making about their treatment?

MS Module

Part 3: Disease-modifying drugs (DMDs) section

1. What % of people diagnosed with MS in your country were receiving disease-modifying drug (DMD) treatment in 2025?

2. What % of the total population of people diagnosed with MS have started DMD treatment within 21 days from diagnosis?

3. What % of the total population of people diagnosed with progressive MS (PPMS, SPMS) have been prescribed appropriate DMD treatment in 2025? DMD treatments for progressive MS include: ocrelizumab, siponimod and cladribine.

4. Among people with MS who are currently not using an appropriate DMD, what is the main reason?

4a. If you chose other, please specify:

5. What are the most significant barriers that limit access to DMD treatment in your country?

5a. If you chose other, please specify:

6. Which DMDs are available in your country (include those that are licensed for MS as well as those available for off-label use e.g. Rituximab, Azathioprine)?

6a. If you chose other, please specify:

6b. For each of the DMDs listed, please indicate reimbursement level:

	Fully reimbursed	Partly reimbursed (Some out-of pocket payments apply	No reimbursement	Unknown
Alemtuzumab, ATC: L04AA34	○	○	○	○
Cladribine, ATC: L04AA40	○	○	○	○
Dimethyl fumarate, ATC: N07XX09	○	○	○	○
Diroximel fumarate	○	○	○	○
Fingolimod, ATC: L04AA27	○	○	○	○
Glatiramer acetate (more than one brand name), ATC: L03AX13	○	○	○	○
Haematopoietic stem cell transplantation (HSCT)	○	○	○	○
Interferon-beta 1a (more than one brand name), ATC: L03AB07	○	○	○	○
Interferon-beta 1b (more than one brand name), ATC: L03AB08	○	○	○	○
Natalizumab (more than one brand name), ATC: L04AA23	○	○	○	○
Ocrelizumab, ATC: L04AA36	○	○	○	○
Ofatumumab	○	○	○	○
Ozanlimod	○	○	○	○
Peginterferon beta 1a (more than one brand name), ATC: L03AB13	○	○	○	○
Ponesimod	○	○	○	○
Siponimod, ATC: L04AA42	○	○	○	○
Teriflunomide, ATC: L04AA31	○	○	○	○
Ublituximab	○	○	○	○

7. What types of reimbursement apply to DMDs in your country?

7a. If you chose other, please specify:

8. On average, how long does it take for a DMD recently approved by the EMA or relevant regulatory approval body in your country to become routinely reimbursed and accessible in your country?

9. Once a newly approved MS medication is reimbursed in your country, to what extent is it effectively accessible to people with MS in routine clinical practice?

We know that the survey is time consuming, remember to take a break! What is your drink of choice? :)

MS Module

Part 4: Symptomatic treatments

1. Does your country use national and/or international consensus statements or clinical guidelines for the symptomatic treatment* of MS?

1a. If yes, please cite the guidelines in the field below:

2. For the following MS-related symptoms, please indicate whether evidence-based symptomatic treatments are available

2a. For each of the MS symptoms listed, please indicate reimbursement level

	Fully reimbursed	Partly reimbursed (Out-of-pocket payments apply)	No reimbursement	Unknown
Spasticity treatments (e.g. baclofen, tizanidine)	○	○	○	○
Pain management (neuropathic pain medications)	○	○	○	○
Fatigue management (pharmacological)	○	○	○	○
Bladder dysfunction treatments	○	○	○	○
Sexual dysfunction treatments	○	○	○	○
Cognitive symptom management	○	○	○	○
Mobility aids/rehabilitation therapies (if in scope)	○	○	○	○

3. Is there a specialised early palliative care* service for people with MS that can be accessed early in the disease course (not limited to end-of-life care)?

MS Module

Part 5: Rehabilitation

1. Is access to rehabilitation* services for people with MS in your country formally aligned with EMSP rehabilitation recommendations (e.g. through national guidelines, standards, or policies)?

2. Which types of rehabilitation services are available to people with MS in your country?

2a. If you chose other, please specify:

2b. For each of the rehabilitation services listed, please indicate reimbursement level

	Fully reimbursed	Partly reimbursed (Out-of-pocket payments apply)	No reimbursement	Unknown
Spasticity treatments (e.g. baclofen, tizanidine)	○	○	○	○
Pain management (neuropathic pain medications)	○	○	○	○
Fatigue management (pharmacological)	○	○	○	○
Bladder dysfunction treatments	○	○	○	○
Sexual dysfunction treatments	○	○	○	○
Cognitive symptom management	○	○	○	○
Mobility aids/rehabilitation therapies (if in scope)	○	○	○	○

3. What are the most significant barriers to accessing rehabilitation services for people with MS in your country?

3a. If you chose other, please specify:

4. How is rehabilitation for people with MS typically organised in your country?

MS Module

Part 6: Paediatric MS

1. What is the estimated number of paediatric MS cases (children and adolescents up to 18 years old) in your country?

2. Do pediatric patients with MS have access to approved disease-modifying drugs (DMDs) in your country?

3. Does your country use clinical treatment guidelines* for paediatric MS?

3a. If yes, please cite the guidelines in the field below:

4. Is there a specialised clinic for paediatric MS in your country?

5. Are there programmes or services specifically aimed at supporting children and adolescents with MS and their families or carers?

6. Are there structured measures in place to support the transition from paediatric to adult MS care?

7. Is there a registry or structured data collection system specifically covering paediatric MS in your country?

7a. If you chose yes or other, please specify the name of registry/database and the type of funding:

MS Module

Part 7: Participation in society

1. Is there any support* available to help young people with MS complete their education?

2. What % of people with MS are employed? Please provide the estimated percentage breakdown of people with MS by employment status in your country (e.g. full-time, part-time, other arrangements), using the box below.

3. Are people with MS legally protected against dismissal or discrimination in employment due to their condition?

4. Are there incentives* to recruit or retain people with disabilities in general or with MS in employment?

4a. If you chose yes or other, please specify the name of the incentive and who finances it:

5. Are there measures in place to support people with MS in retaining employment as their condition progresses?

5a. If you chose other, please specify:

6. Is there an MS (or other chronic conditions) awareness-raising programme for the workplace?

7. What types of financial support* are available for early retirement due to disability, including MS, in your country?

7a. If you chose other, please specify:

8. Are home adaptation costs for people with MS covered or reimbursed*? If yes, please specify the level of reimbursement if data are available.

9. Are peer support groups for people with MS available in your country?

9a. If you chose other, please specify:

10. Who primarily organises or facilitates MS peer support groups in your country?

10a. If you chose other, please specify:

11. Does the disability assessment framework* in your country explicitly account for the fluctuating and progressive nature of MS when determining eligibility for disability-related support or work ability?

12. Is there an information programme* for informal caregivers of people with MS (family members, friends)?

12a. If you chose other body, please specify:

13. Which types of support are available for MS in your country?

13a. If you chose other, please specify:

14. What are the most significant barriers preventing caregivers from using available support services?	**14a. If you chose other, please specify:**

MS Module

Part 8: Research

1. Does your national MS Society (/Societies if more exist) provide grants or other types of financial support for MS research?	**1a. If you chose yes or other, please specify:**
2. Is there a national MS research agenda* in your country, or formally defined research priorities?	**2a. If you chose yes, please specify the focus areas:**
3. In your country, is there any on-going or planned research including clinical trials specifically addressing paediatric MS?	**3a. If you chose yes, please specify:**
4. Does your country have a national MS registry or structured MS data collection system?	**4a. If you chose yes or other, please specify the name of registry/database and the type of funding:**
5. How is the national MS registry funded?	
6. What % of the total population of people diagnosed with MS is recorded on the national registry?	
7. What are the aims/purpose of the registry/database?	**7a. If you chose other, please specify:**
8. What type of information is collected by the national MS registry?	**8a. If you chose other, please specify:**
9. If patient-reported outcome measures (PROMs) for MS are collected, which PROM domains are included?	**9a. If you chose other, please specify:**

NMOSD Module

Welcome to the NMOSD Module of the Survey

1. What is the estimated total number of people living with NMOSD in your country?

2. What comorbidities* are most commonly present among people diagnosed with NMOSD?

2a. Other comorbidities, please specify which:

2b. Please provide the source of information and, if available, indicate the number of people with NMOSD living with the comorbidity / comorbidities you selected where available.

3. Is there a national/local NMOSD patient organisation in your country?

3a. If you chose yes, please specify:

4. In which ways are people with NMOSD and/or NMOSD (or other relevant) patient organisations involved in NMOSD-related policy development at the national level?

4a. If you chose other, please specify:

5. Are NMOSD (MS or any other relevant) patient organisations involved in the decision-making process of reimbursement of NMOSD therapies/treatments?

6. Are there designated national or regional NMOSD expertise centres in your country?

7. Are there formally defined national or regional care pathways for NMOSD (from diagnosis to long-term care)?

8. Does your country use national or international clinical treatment guidelines to treat people diagnosed with NMOSD?

8a. If yes, please cite the guidelines in the field below:

9. Is testing for AQP4 antibodies routinely available in your country?

9a. Which laboratory methods are used for AQP4 antibody testing?

9b. If you chose other, please specify:

10. What are the main barriers that limit access to treatment/therapy for NMOSD in your country?

11. What types of patient education or self-management* support are available for people with NMOSD in your country?

11a. If you chose other, please specify:

12. Which of the following EMA-approved NMOSD treatments are available in your country?

12a. If you chose other, please specify:

12b. Please indicate the level of reimbursement for those available in your country in the box below.

13. Does your country have a national NMOSD registry* or structured data collection system?

14. In your country, is there any on-going or planned research including clinical trials specifically addressing NMOSD?

14a. Please specify the research:

MOGAD Module

Welcome to the MOGAD Module of the Survey

1. What is the estimated total number of people living with MOGAD in your country?

2. What comorbidities* are most commonly present among people diagnosed with MOGAD?

2a. If you chose other, please specify which:

2b. Please provide the source of information and, if available, indicate the number of people with MOGAD living with the comorbidity / comorbidities you selected where available.

3. Is there a national/local MOGAD patient organisation in your country?

3a. If you chose yes, please specify:

4. In which ways are people with MOGAD and/or MOGAD (or other relevant) patient organisations involved in MOGAD-related policy development at the national level?

4a. If you chose other, please specify:

5. Are MOGAD (MS or any other relevant) patient organisations involved in the decision-making process of reimbursement of MOGAD therapies/treatments?

6. Are there designated national or regional MOGAD expertise centres in your country?

7. Does your country use national or international clinical treatment guidelines* to treat people diagnosed with MOGAD?

7a. If yes, please cite the guidelines in the field below:

8. Is testing for MOG antibodies routinely available in your country?

8a. Which laboratory methods are used for AQP4 antibody testing?

8b. If you chose other, please specify:

9. What are the main barriers that limit access to treatment/therapy for MOGAD in your country?

10. What types of patient education or self-management support are available for people with MOGAD in your country?

10a. If you chose other, please specify:

11. Does your country have a national MOGAD registry* or structured data collection system?

12. In your country, is there any on-going or planned research including clinical trials specifically addressing MOGAD?

12a. Please specify the research:

Please upload any relevant files