



MS BAROMETER 2020

Assessing the gaps in care for people with multiple sclerosis across Europe

European Multiple Sclerosis Platform
The Health Policy Partnership



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About the European Multiple Sclerosis Platform

The European Multiple Sclerosis Platform (EMSP) represents more than 1 million people living with multiple sclerosis (MS) in Europe through its network of 43 member societies in 37 European countries. En route to its ultimate vision of a world without MS, EMSP works to ensure that people with MS have a real voice in determining their own objectives and priorities through advocacy, awareness raising, collecting data and supporting scientific research. EMSP's activities are directed at improving the quality of life of people with MS, as well as access to treatment, care, employment and adequate support.



About The Health Policy Partnership

The Health Policy Partnership (HPP) is an independent research organisation, working with partners across the health spectrum to drive the policy and system changes that will improve people's health.



About Quality Health

Quality Health, an IQVIA business, is a health and social care survey specialist, working for public, private and not-for-profit sectors, in the UK and overseas.

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Full data are available from: <http://msbarometer.com/>

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Foreword

The European Multiple Sclerosis Platform (EMSP) has been representing the voice of people with multiple sclerosis (MS) since its foundation in 1989. Our work seeks to drive improvements in the management of MS and in the lives of all Europeans with this challenging disease. In 2008, we released our first MS Barometer, with a view to fill data gaps and support international benchmarking. This initiative has continued to grow over the years, and this report marks our sixth edition. We hope that it will help to continue to highlight the unique experiences and perspectives of MS societies across Europe.

Our vision for care of MS was inspired by the World Health Organization's (WHO) framework for integrated care. We firmly believe in the aim for “all people [to] have equal access to quality health services that are co-produced in a way that meets their life course needs, are coordinated across the continuum of care, and are comprehensive, safe, effective, timely, efficient and acceptable; and all carers [to be] motivated, skilled and operate in a supportive environment”¹. This vision of integrated care will be key to implementing best practice in MS, which will in turn help people to maintain their quality of life and support more inclusive societies and economies. As the COVID-19 pandemic has so clearly demonstrated, our health systems are both inspirationally strong and desperately fragile.

The 2020 MS Barometer highlights the huge disparities in MS care in Europe. Particularly, we see issues in access to appropriate healthcare, health professionals and social support for people with MS and their carers across the continent. Countries that fail to provide quality care are failing their MS communities. To quantify and benchmark performance, results of the MS Barometer are scored, reinforcing the message that inadequate standards of care cannot and will not be accepted.

The complex nature of MS makes it an ideal case study for strengths and failures in health and social care. The 2020 MS Barometer shows that the entire MS community has work to do. Policymakers and decision-makers from the local to the European level must immediately secure sufficient and consistent funding for health and social care systems to provide people with MS with the clinical and practical support that meets their needs. We must facilitate access to employment, and secure disability benefits and social support for all people with MS. These services need to be available from the life-changing moment of diagnosis and be responsive to changing needs.

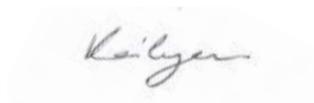
Intersectoral collaboration and understanding is key. The health, social, education and employment sectors must organise around people with MS, therefore communication between these typically separate entities should improve. We hope that innovation driven by the COVID-19 pandemic may help to ensure better access to care and opportunities for people with MS in the future. But MS advocates must continue highlighting and championing the policies that will improve the lives of people with MS. Our aim is that the findings from the 2020 MS Barometer will help with these efforts, supporting positive changes in health and social systems, and improving personalised care, social and financial protection, and quality of life for all people with MS in Europe.

Together, we will build a better Europe for people with MS, their carers and their communities. To support the European MS community in achieving these important goals, this year's report is complemented by country factsheets to explore national responses to MS and policy recommendations for our membership. We will also soon be launching our 2021–2025 Strategic Plan, which will focus on empowering the MS communities to drive change and be part of the solution for a better future.



Elisabeth Kasilingam

EMSP CEO



Key findings



The 2020 MS Barometer was developed with survey responses from 36 national multiple sclerosis (MS) societies representing 35 countries in Europe. The survey has identified that there are almost 1.2 million people with MS in Europe.

FROM
35
EU COUNTRIES

ALMOST
1.2M
PEOPLE HAVE MS IN EUROPE



The MS community is being left out of health policy

20

Countries do not include people with MS or MS patient groups in government consultation groups for MS policies.

24

Countries do not have a neurological or chronic disease policy which includes MS.

Availability of disease-modifying drugs (DMDs) has improved since 2015, but more progress is needed

57%

Among responding countries, just 57% of people with MS received DMDs in 2018.

▲ **90%**

▼ **10%**

Treatment rates vary enormously, ranging from as high as 90% in Lithuania, Malta and Switzerland to as low as 12% in Serbia and 10% in Bosnia and Herzegovina.

26%

People with progressive MS are being left behind as only about 26% among responding countries, received appropriate DMD treatment in 2018.



The symptoms of MS are not adequately managed:

There is lower availability and lower reimbursement of symptomatic treatments compared with DMDs across all surveyed countries.

48%

OF PEOPLE WITH MS
HAVE ACCESS TO PHYSICAL
REHABILITATION

Rehabilitation is a neglected cornerstone of care:

Among responding countries, only 48% of people with MS have access to physical rehabilitation. Access is even lower for psychological, cognitive and occupational rehabilitation.

Children and adolescents with paediatric MS and their carers need targeted support:

JUST
16

COUNTRIES PROVIDE
SPECIFIC SOCIAL
SUPPORT

Just 16 countries provide social support specific to carers of children and adolescents with MS.

People with MS face barriers to joining and staying in the workplace:

UNPROTECTED IN

7

COUNTRIES

In at least 7 countries, people with MS are not legally protected from dismissal due to their disease.

ONLY

48%

OF PEOPLE WITH MS ARE EMPLOYED

Among responding countries, only 48% of people with MS are in employment.

65%

NOT RECORDED IN NATIONAL MS
DISEASE REGISTRIES

Data collection is often inadequate:

65% of people with MS in Europe are not recorded in national MS disease registries.

Recommendations



The 2020 MS Barometer has highlighted many deficits in multiple sclerosis (MS) care across Europe. We call on all stakeholders to take action to reduce these gaps in care and champion evidence-based policies that will improve the lives of all people with MS.

European policymakers and decision-makers



Improve the social, economic and employment opportunities for all people with MS, with monitoring to ensure their rights are consistently and equally applied in all countries.



Expand employment and educational support to young people with disabilities, including MS, through existing European study and employment programmes.



Support all countries to improve access to appropriate MS therapies and programmes through expanded cross-border access to treatment, and improved use of regional funds and other EU financial mechanisms.



Reduce inequalities in access to specialised, multi-disciplinary healthcare by supporting professional societies and others to develop accredited MS specialist courses for healthcare professionals, and encouraging uptake in all countries.



Support the use of a common data set for MS data collection including patient-reported outcomes across all countries, and encourage trustworthy and transparent real-world data collection practices.

All national policymakers and decision-makers

Include people with MS and MS patient societies in government consultation groups for all policies relating to MS, and support these groups to monitor the implementation of frameworks for social, economic and employment rights.



National healthcare decision-makers

- Ensure a national chronic or neurological disease policy includes a holistic MS care model and has dedicated funding for implementation.
- Eliminate delays in national licensing and reimbursement of disease-modifying drugs and symptomatic treatments after European Medicines Agency (EMA) approval.
- Increase specialist training opportunities for MS among neurologists, nurses, rehabilitation specialists and other healthcare professionals.
- Integrate rehabilitation therapists and other specialists, such as neuropsychologists, pain specialists and social care specialists, into all MS multi-disciplinary teams as standard and secure reimbursement for these roles.
- Expand MS disease registries to cover all people with MS and mandate data collection encompassing clinical, occupational and patient-reported data.



National social care decision-makers

- Ensure long-term and consistent funding for social care to expand provision of quality services and secure financial protection.
- Expand the social care workforce and integrate new models of care which better support people with MS and their carers.



National education and employment decision-makers

- Enact employment legislation to protect people with MS and their carers from workplace discrimination and unfair dismissal.
- Expand and standardise distance learning and flexible working options to enable people with MS and carers to take up and maintain education and employment.

Neurologists and other MS professionals



Develop guidance on the use of symptomatic therapies to ensure a harmonised approach to symptom management for people with MS in all countries.

Expand access to physical, psychological, cognitive and occupational rehabilitation and overcome geographical barriers to access.

Integrate digital tools and e-health into daily clinical practice to help people with MS receive care.

The research community



Invest in research on treatment and care options for MS, especially progressive forms.

Eliminate delays in national licensing of disease-modifying drugs and symptomatic treatments after EMA approval.

Collect robust data on the impact of the COVID-19 pandemic on people with MS to understand its epidemiological, physical, psychosocial and personal effects.

Patient advocates and societies



Develop and provide educational information, including self-management courses, for people with MS, including children and adolescents with paediatric MS and their carers.

Organise a cross-sectoral and coordinated response to MS by collaborating with key stakeholder groups including policymakers, healthcare, social care and employment specialists, researchers and industry.

Introduction

Multiple sclerosis (MS) is a chronic, neurodegenerative disease in which a person's immune system targets healthy nerves. It is most frequently diagnosed in people aged 20–40 years.² It is an unpredictable disease that each person will experience differently, but common symptoms often include pain, fatigue, reduced mobility and cognitive dysfunction.³ The cause of MS is not known and there is currently no cure; however, timely diagnosis, treatment and support have a significant effect on disease progression and quality of life, regardless of the type of MS (Box 1). Following diagnosis, management of MS focuses on reducing progression with disease-modifying drugs (DMDs), symptom management and rehabilitation to maintain quality of life and neurological function.



COGNITIVE
DYSFUNCTION



FATIGUE



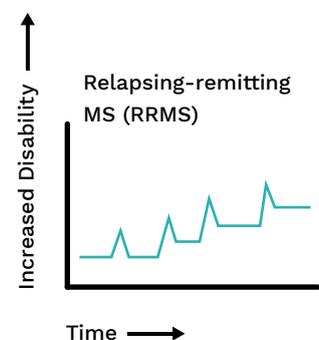
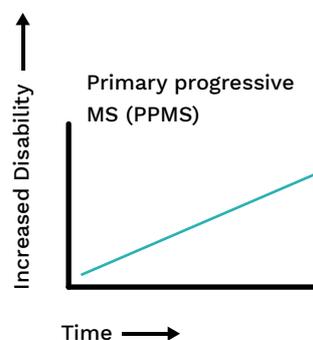
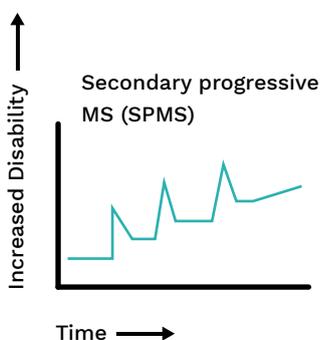
REDUCED
MOBILITY



PAIN

Box 1. There are four types of MS

MS occurs when the immune system attacks the protective layer around healthy nerve cells, causing damage to the pathways that transmit signals throughout the brain and body.² It is classified by disease stage and permanence of symptoms. Most MS begins as Clinically Isolated Syndrome and then manifests as either Relapsing-Remitting MS (RRMS), which features alternating periods of disease activity and remission, or Primary Progressive MS (PPMS), which has increasing disease activity without periods of remission. After years or decades, most RRMS cases will advance to Secondary Progressive MS (SPMS), which presents similarly to PPMS.²



The MS Barometer survey has been analysing MS management and care in Europe periodically since 2008. It provides an important framework for identifying the most persistent and challenging gaps in care, and understanding how MS management has changed over time (Box 2). By highlighting the experiences of Europe’s national MS societies, it offers a unique perspective on MS care and aims to support evidence-based decision making on MS in each country.

The 2020 MS Barometer has identified that there are more than 1,188,000 people with MS in Europe. We surveyed MS societies in 35 European countries and found that MS prevalence ranges from 299 per 100,000 people in Germany to 37 per 100,000 in Moldova. In the 27 countries reporting incidence for 2018, there were approximately 37,000 new diagnoses of MS. Of these, an estimated 10–15% of people will have been diagnosed with primary progressive MS, the most aggressive form of the disease.⁴ Another 2–10% may be children under the age of 18 who have developed paediatric MS^{5 6} – with their own unique set of needs.



Europe must prioritise better management of MS. MS is the number-one cause of non-traumatic disability in young and middle-aged Europeans.⁷ The average age at onset means that people are affected during the formative years of their life, when they may be looking to complete their education, establish a career or start a family. Beyond the personal impact, these challenges will have a direct and indirect impact on economic participation, employment, and health and social care systems.^{8 9} Furthermore, MS places a unique burden on women, who make up almost 70% of those diagnosed globally.⁹

Box 2. About the MS Barometer

Each iteration of the *MS Barometer* builds upon the previous version, refining and updating the questionnaire based on feedback from the prior report and new insights and developments in MS care.

The 2020 *MS Barometer* survey was developed in 2019 in close collaboration with an expert steering group, inspired by the World Health Organization's *Framework on integrated, people-centred health services*.¹ The survey was distributed to all EMSP member organisations and responses were collected from 35 countries. Throughout this report, responses refer to these 35 countries unless otherwise specified. Responses were analysed using a scoring framework developed to prioritise key aspects of MS management. The scoring framework reinforces the importance of data collection by treating all 'unknown' responses as equivalent to zero. For a full description of the project rationale, methodology and complete data set, please visit our project website: <https://msbarometer.com>

Countries in the survey: Austria, Belarus, Belgium, Bosnia and Herzegovina, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Moldova, the Netherlands, North Macedonia, Norway, Poland, Portugal, Romania, Russian Federation, Serbia, Slovenia, Spain, Sweden, Switzerland, Turkey and United Kingdom.

MS Barometer 2009



MS Barometer 2011



MS Barometer 2013



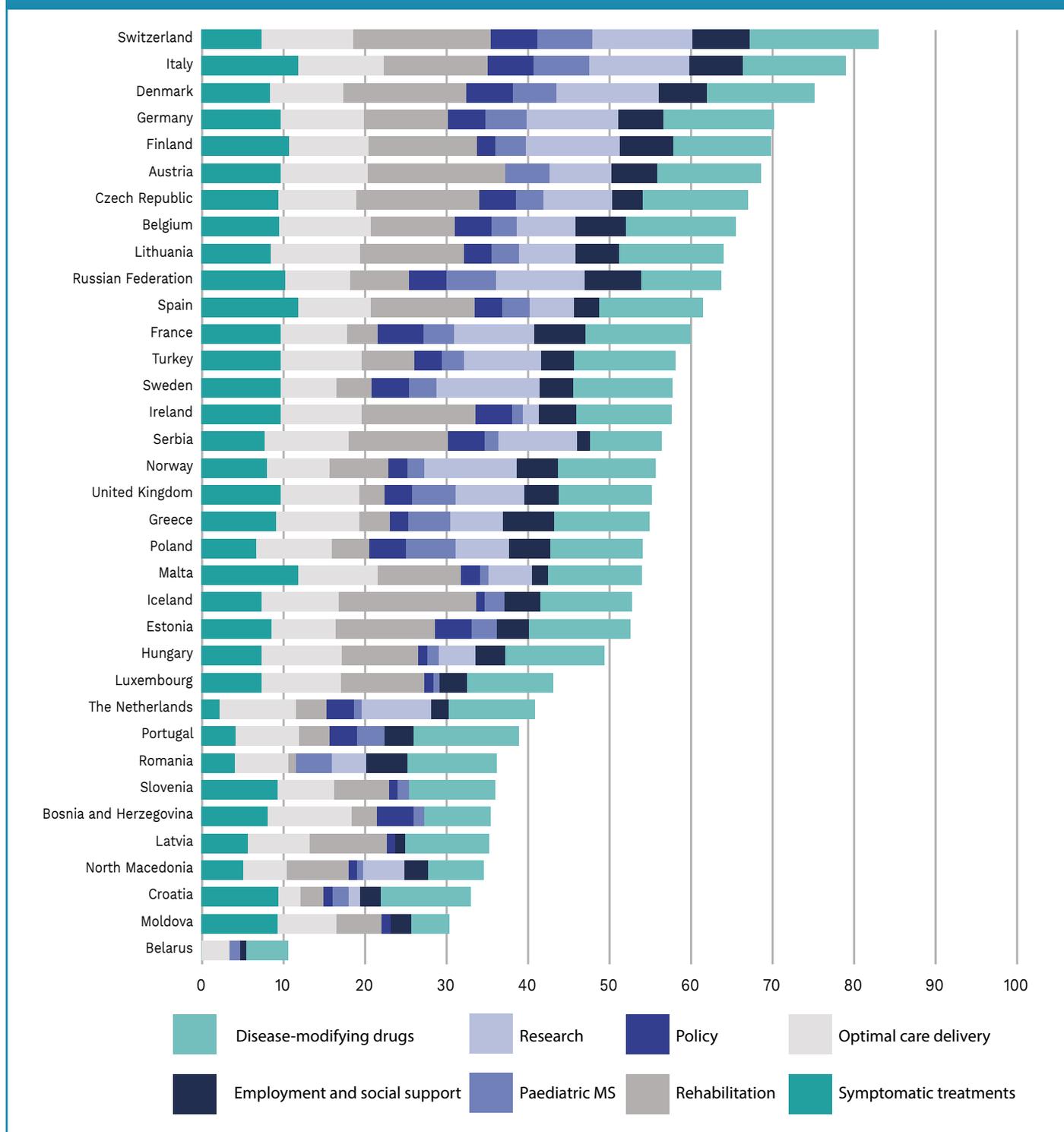
MS Barometer 2015



Survey findings

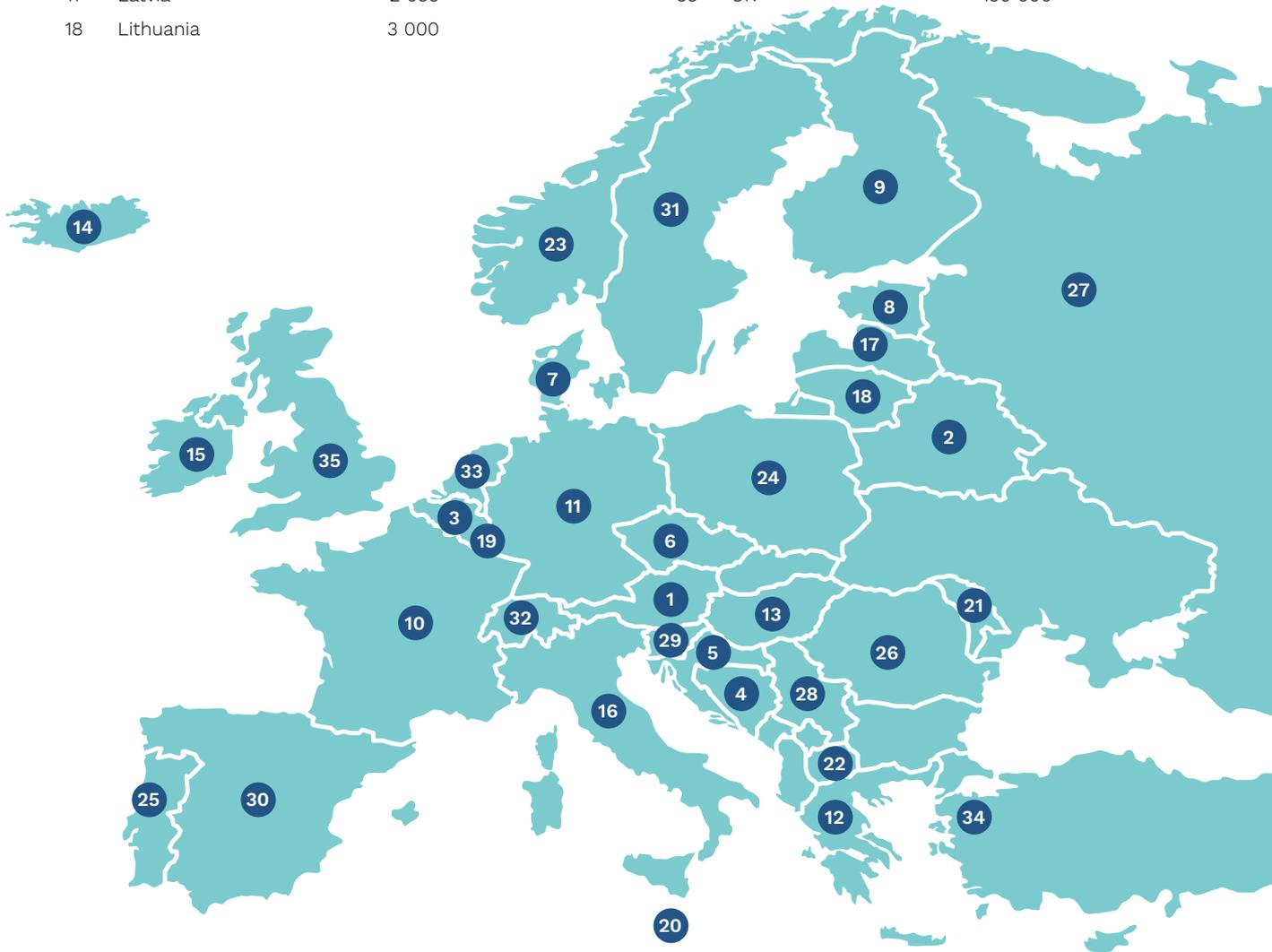
Each of the 35 countries participating in the 2020 MS Barometer survey shows strengths and weaknesses in MS care (Figure 1). This report presents key findings and important areas for change across the entire spectrum of MS care and support. We will explore these trends in the following sections.

Figure 1. Total scores for the 35 countries participating in the 2020 MS Barometer survey



People with MS around Europe

1	Austria	13 500	19	Luxembourg	700
2	Belarus	4 600	20	Malta	400
3	Belgium	13 500	21	Moldova	1 500
4	Bosnia and Herzegovina	3 557	22	North Macedonia	1 560
5	Croatia	6 000	23	Norway	13 000
6	Czech Republic	20 000	24	Poland	50 000
7	Denmark	16 169	25	Portugal	8 364
8	Estonia	1 000	26	Romania	9 000
9	Finland	12 080	27	Russian Federation	150 000
10	France	115 000	28	Serbia	9 000
11	Germany	250 000	29	Slovenia	3 500
12	Greece	20 000	30	Spain	55 000
13	Hungary	8 500	31	Sweden	21 500
14	Iceland	720	32	Switzerland	15 000
15	Ireland	9 000	33	The Netherlands	25 000
16	Italy	126 000	34	Turkey	70 000
17	Latvia	2 035	35	UK	130 000
18	Lithuania	3 000			



Policy

Key findings



24 countries have no chronic or neurological disease management policy; this includes eight of the 27 European Union Member States

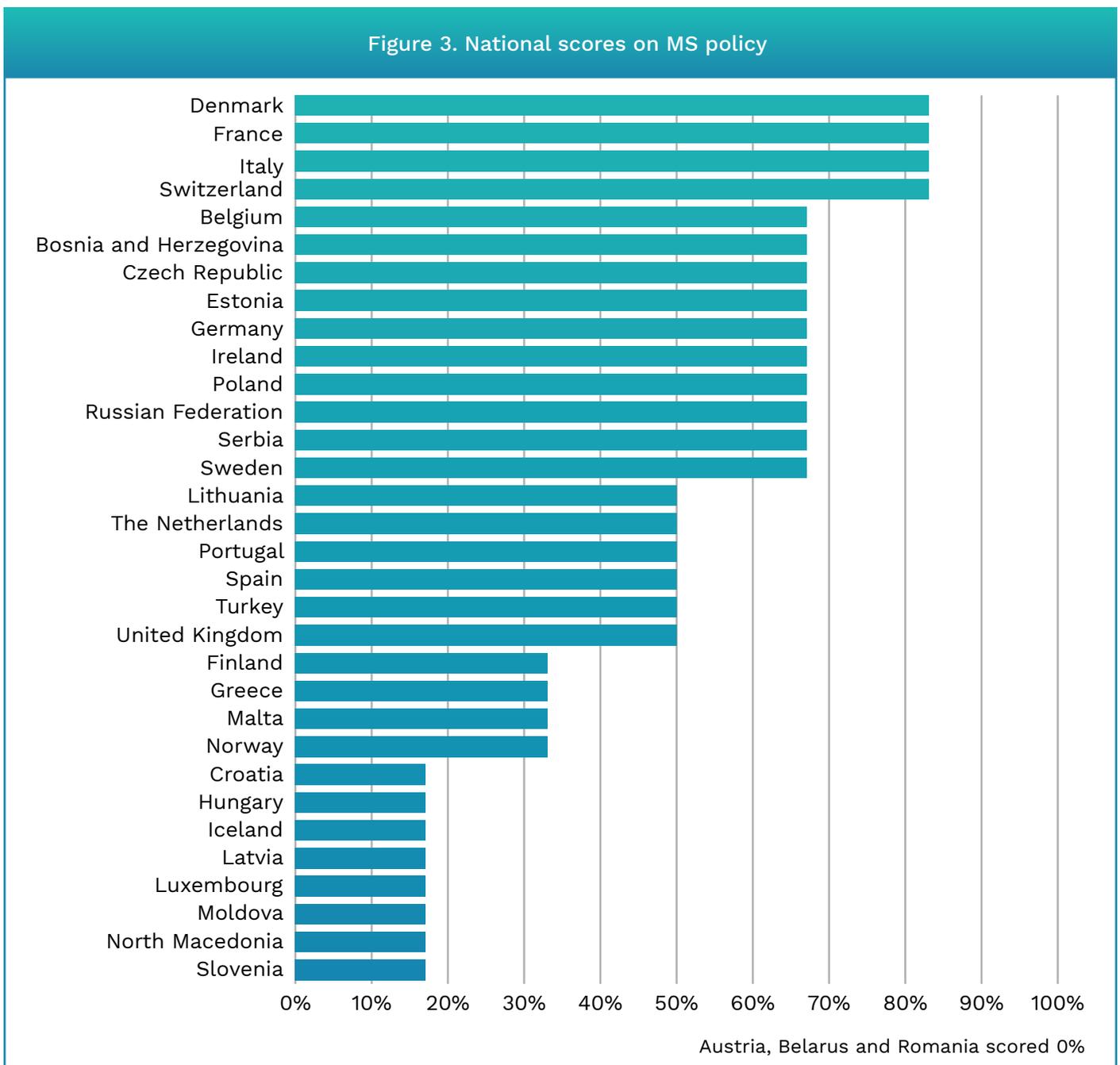


20 countries do not include people with MS or patient groups in government consultation groups for MS policies



Fewer than half of national MS societies are involved in decisions on reimbursing new MS therapies

Figure 3. National scores on MS policy



Why is policy important in MS?

MS requires a whole-systems approach. MS presents many complex policy challenges: a progressive neurodegenerative disease course, young age at onset and diverse symptoms which differ from person to person and day to day.^{10 11} Policies must therefore extend beyond healthcare, to education, social care and employment. Without a deliberate strategy linking these domains, responses to MS may be fragmented, causing people to fall through the gaps in care. Moreover, MS affects not only the person diagnosed but also their family and carers. Policies must address the needs of all people impacted by this disease.

A strong policy response requires a chronic or neurological disease strategy that includes a holistic approach to MS. These major government strategies are essential to facilitate clear and effective communication between the often-disconnected sectors of health and social care, and the professionals within them, as well as wider sectors such as education and employment.

The MS community should be able to participate in the policy and decision-making that impacts them. People with MS, their carers and MS patient groups are uniquely experienced in the realities of living with the disease. Their personal understanding of gaps in care and support means that they need to be consulted on the development of all new MS-related policies and programmes, in addition to care and reimbursement decisions.



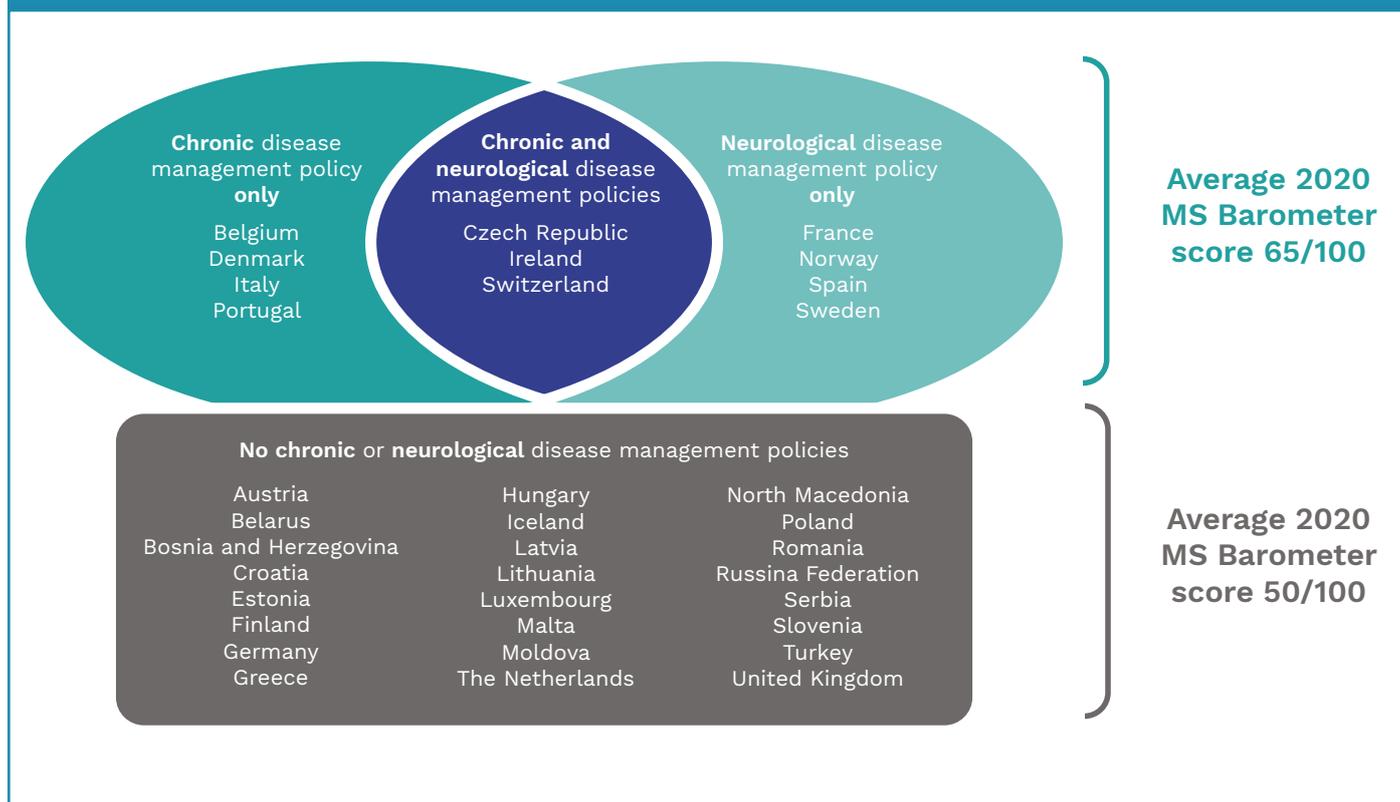
What did the Barometer find?

Countries that include MS in their chronic or neurological disease strategies have a stronger overall response to MS. Figure 3 shows the different policies adopted by countries in Europe, which were associated with better performance in MS care:

- The average score for countries where MS is included in chronic disease policy and/or a neurological disease policy was 65 out of 100.
- Countries with no chronic or neurological disease plan had an average score of 50 out of 100.

In practice, these differences may result in disparities in many aspects of MS management, such as the availability of therapies and specialist care, legislative support to allow flexible working conditions, and provision of support for carers. But these elements and more may be guided by 'top-down' government leadership.

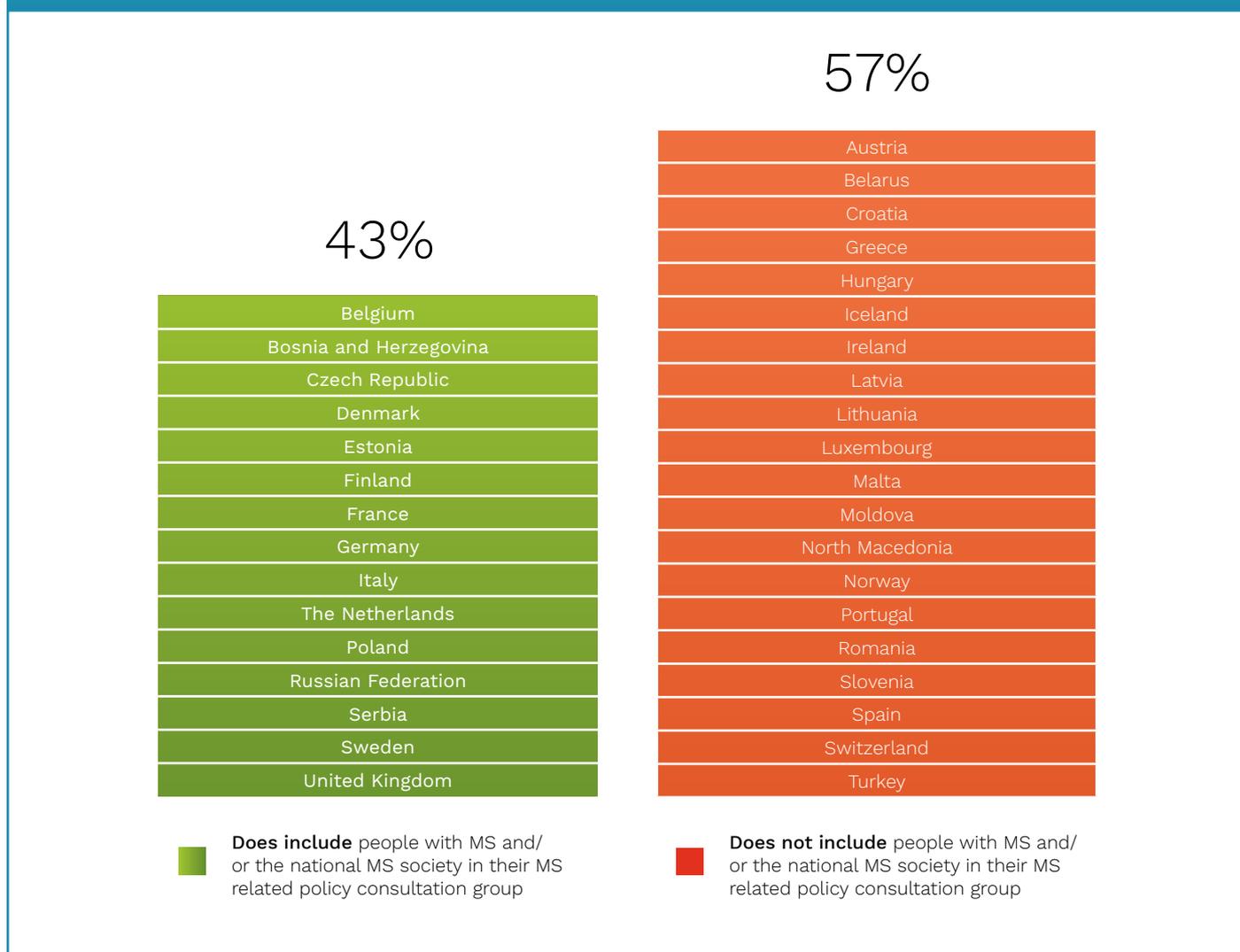
Figure 3. Existence reported for a chronic disease policy or neurological disease policy that includes MS



The participation of people with MS, carers and patient societies in policymaking varies substantially across Europe. This translates to significant differences in the abilities of people with MS to represent their interests and self-advocate. For example, of the 35 responding countries, only:

- 14 countries involve their national MS society in decisions on the reimbursement of new MS therapies
- 15 countries include people with MS and/or the national MS society in their MS-related policy consultation group (Figure 4).

Figure 4. Countries which include people with MS and/or the national MS society in their MS related policy consultation group



The countries which scored highest in the 2020 MS Barometer – Switzerland, Italy and Denmark – encourage the MS community to participate in MS policymaking. Other countries must follow suit and take advantage of the wealth of expertise that these individuals and organisations can offer.

Managing MS - Care delivery

Key findings



33 countries reported a total of 61,002 neurologists, a median of one for every 23 people with MS, but there are significant geographical disparities

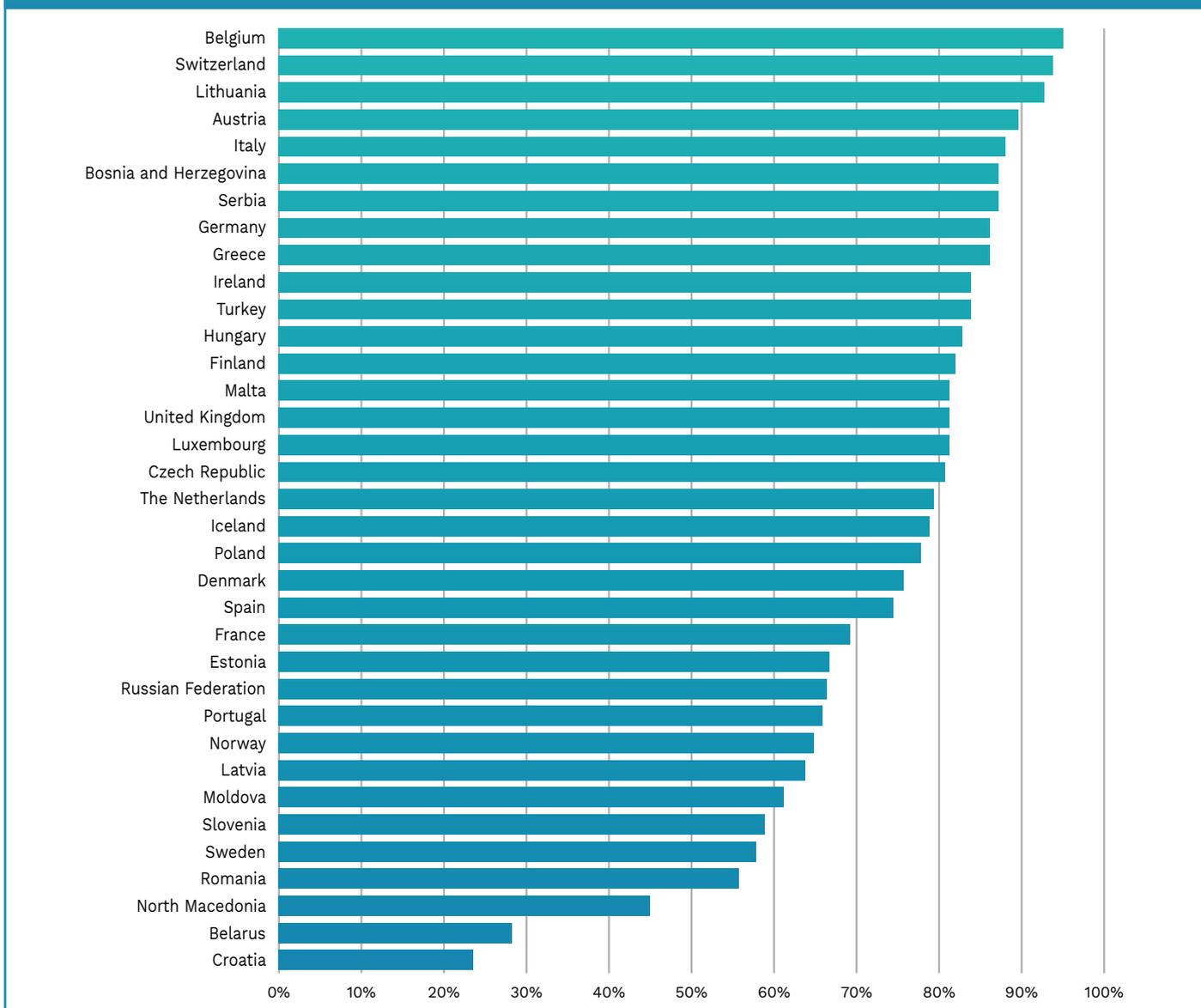


Only 26% of people with progressive MS received appropriate DMD treatment



Financial concerns remain a significant barrier to accessing and maintaining treatment in many countries

Figure 5. National scores on care delivery



Why is care delivery important in MS?

Optimal management of MS begins with a specialist, multi-disciplinary MS care team. These teams should consist of healthcare professionals such as a neurologist, nurse, rehabilitation specialists and other healthcare and allied health professionals as required.¹² These teams can provide prompt diagnosis, personalised treatment and rehabilitation, adapting plans over time to meet the changing needs of the person with MS.¹² Best-practice interventions will help to reduce the frequency and severity of relapses, as well as slowing the onset of irreversible disability. Without appropriate and accessible multi-disciplinary and specialist care, people with MS may be less likely to initiate or remain on their DMD treatments, which may exacerbate the progression of their disease.⁹ When many people with MS may be suffering from comorbidities, access to a range of specialists becomes even more urgent.



Whether standalone or within a larger medical centre, a dedicated and specialist MS team is a cornerstone of optimal MS care. A specialist MS centre is able to support a full multi-disciplinary MS team, and may ensure that all people with MS have access to high-quality care at every stage of their treatment.¹² MS centres should offer expertise from a range of relevant fields without geographical barriers, which may mean ensuring transportation options and supplemental telemedicine in order to reach every person with MS.

What did the Barometer find?

The availability and delivery of specialist MS centres varies considerably across Europe.

Some countries have dedicated MS centres, while others may have multi-disciplinary care integrated into larger neurological units, hospitals and universities. For example:

- Italy has 240 non-exclusive MS centres located in hospitals and neurological departments
- France has 23 MS resource and skills centres based in universities
- Finland has 12 neurological clinics in the central hospitals of the public health system.

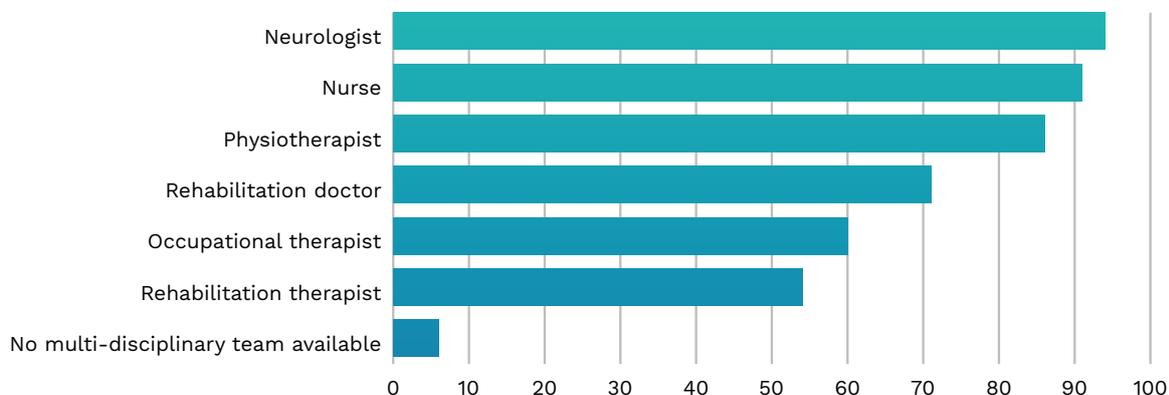
Whether exclusive or not, MS centres may be quite different in terms of the services offered: in Germany, MS centres may focus on diagnostics, while Ireland's one exclusive MS centre is a respite facility.

Nearly every country offers access to a neurologist and nurse for people with MS, but the availability of rehabilitation specialists is inconsistent.

Figure 6 shows the rates of countries reporting availability of different specialists for people with MS. Neurologists and nurses are included in almost all multi-disciplinary MS teams, but availability of other specialists is poorer. Access to specialist care could be improved by increasing the numbers of these professionals in MS care teams and by ensuring that they have access to MS specialist training. People with MS would benefit from reimbursement policies that facilitate access to the full range of specialists they may require.



Figure 6. Percentage of countries reporting different healthcare professionals in their multi-disciplinary MS teams



Approximately 61,000 neurologists work across 33 countries in Europe, though not all may be practising. However, the distribution of general neurologists varies substantially between countries:

- + A small number of countries including Latvia and Lithuania report having more than one neurologist per 10 people with MS
- Two countries have less than one neurologist for more than 100 people with MS:
 - Ireland has one neurologist for every 281 people with MS
 - The UK has one neurologist for every 148 people with MS.



General neurologists may divide their time across all neurology areas, and therefore have limited time not only to treat people with MS but also to stay informed of the latest developments in the field. Where possible, MS specialist neurologists are preferable over general neurologists because they may be more familiar with the complexities and nuances of MS. However, any neurologist is preferable to none, because challenges in accessing general or specialist neurologists may delay diagnosis, create barriers to initiating or changing treatments, and limit time for consultations. If a person with MS only sees their neurologist on an annual basis, a single visit may not be sufficient time to provide adequate symptom assessment and referrals to appropriate specialists. Without having a chance to build a rapport with their care provider, the person with MS may find it difficult to initiate conversations on subjects like sexual dysfunction, incontinence, or mood and anxiety disorders, all of which are crucial concerns for quality of life. Increased uptake of telemedicine may enable more frequent consultations to better monitor each person's wellbeing.



MS nurses may also help to alleviate pressures on neurologists while providing high-quality care and support for people with MS. At least 1,500 nurses were reported to care for people with MS across 19 countries in Europe. This is likely to be an underestimate as not all countries reported data and, of those that did, many specified that they only had figures for MS specialist nurses. Nurses have a key role within the healthcare team and for the person with MS and their family.¹³ They may serve as a main point of contact for the person with MS, and can be a source of informational and emotional support that helps the person adhere to their treatment and optimise management of their disease in a holistic manner.¹³ Increasing the numbers of MS specialist nurses across Europe may help to improve the quality of care for people with MS. [The MS Nurse PROfessional](#) course is one e-learning training curriculum for nurses to receive certification in the field.¹⁴ Initiatives such as this may be particularly efficient areas for further investment to optimise care and availability of expertise for MS.

Underlying all clinical support, people with MS can learn to self-manage their disease. Once a person is diagnosed with MS, they should be offered a self-management course. Such initiatives, often offered by the national patient association, may help to empower the person and help them to live with MS. Yet despite the importance of self-management for people with MS, 11 countries do not offer any courses.

Disease-modifying drugs

Key findings



Just 57% of people with MS received DMD treatment in 2018

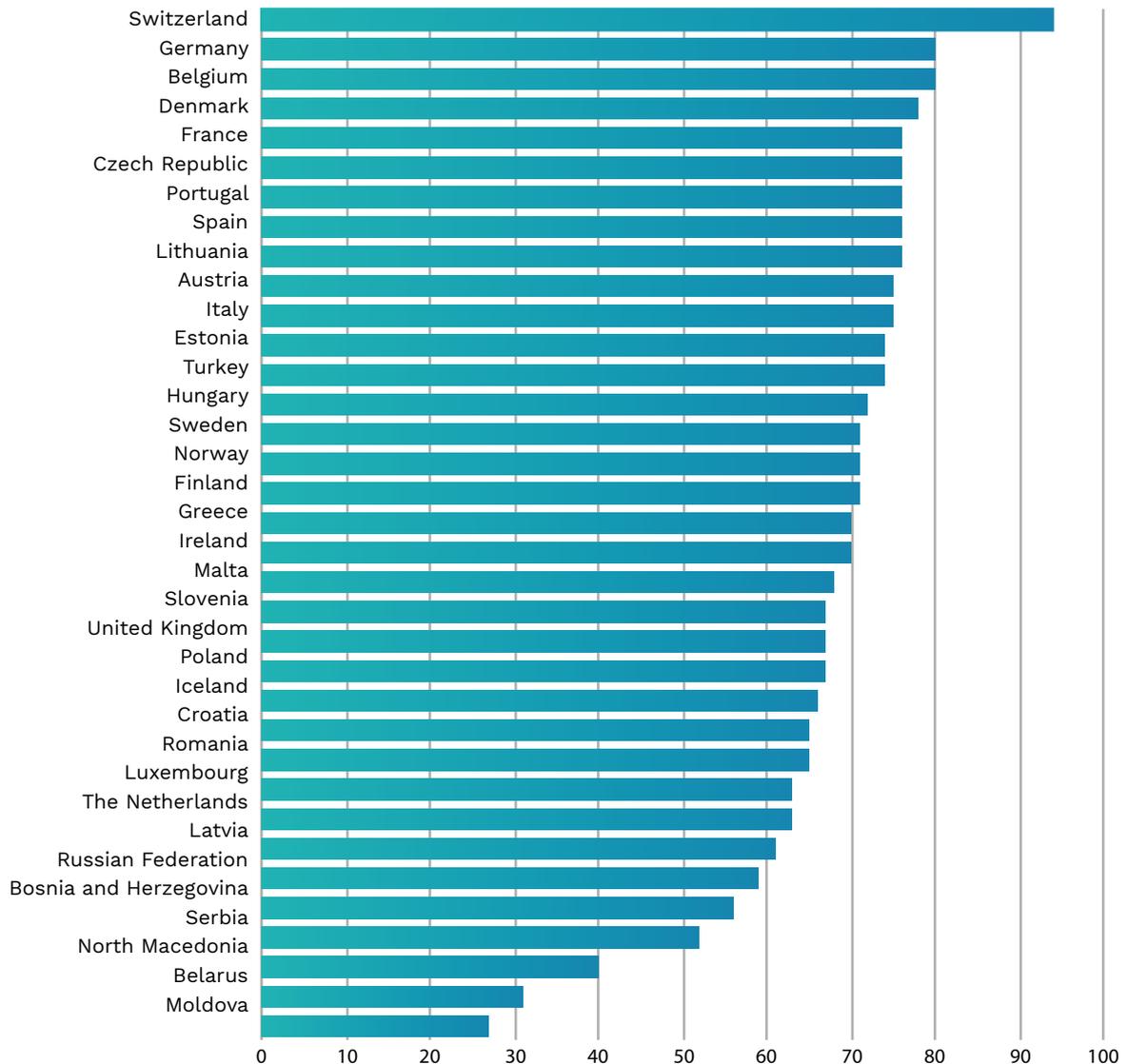


Only 26% of people with progressive MS received appropriate DMD treatment



Financial concerns remain a significant barrier to accessing and maintaining treatment in many countries

Figure 7. National scores on disease-modifying drugs



Why are DMDs important in MS?

DMDs are the backbone of MS clinical care. These therapies modulate the immune response which causes MS, thus reducing the severity and frequency of relapses, slowing the progression of disease and onset of disability.^{9,15} For most people with MS, DMDs should be initiated as soon as possible after diagnosis and treatment should be maintained as long as the person wishes.⁹

A range of DMDs are approved for MS in Europe, though access may be challenging in different countries. People with MS may change DMDs at some point over the course of their illness, often due to changing disease stage, new treatment goals or side effects.¹⁶ Because DMDs may be taken for decades, it is important that they be both tolerable and affordable for the person with MS. However, even when therapies are approved and made available nationally, some people may have difficulty in accessing the treatment.

Not every person with MS wishes to take DMDs. A person may opt to forgo DMD treatment for many reasons, including costs, side effects, changing life goals, or progression of disease.¹⁶ However, this puts them at risk of irreversible disease progression and increased future health and social care needs. Governments must ensure that all people with MS have timely access to a range of acceptable treatments, as well as neurologists to prescribe and switch DMDs to meet the needs of the person with MS.



What did the Barometer find?

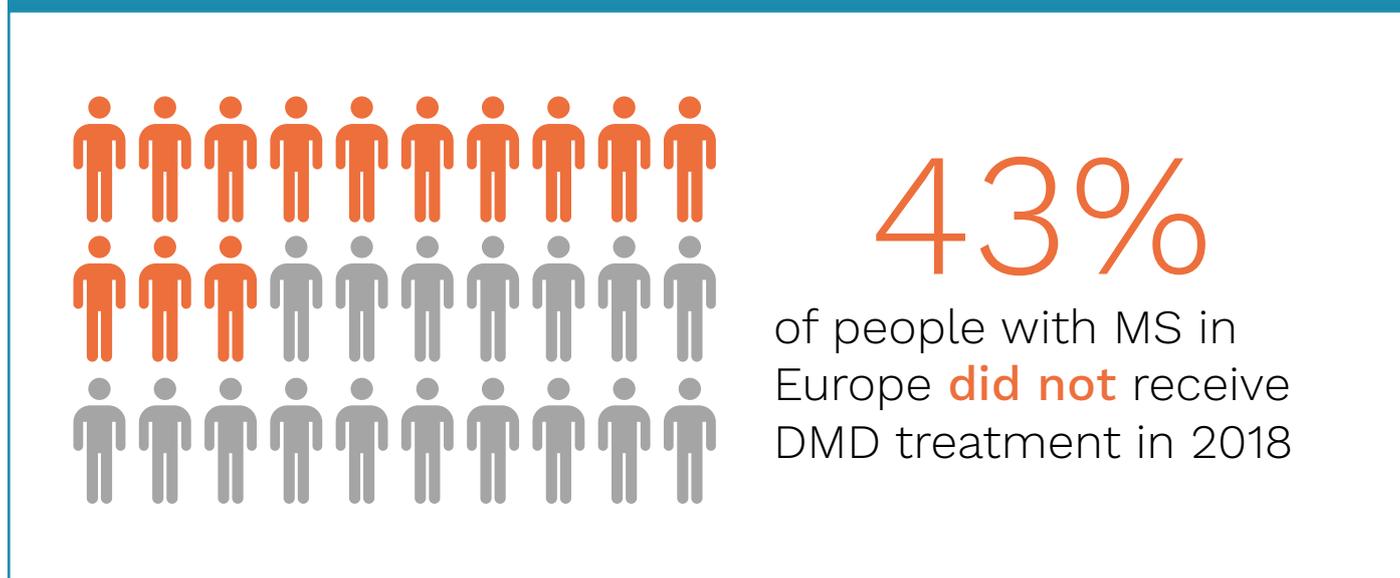
Availability of a range of fully reimbursed DMDs is generally good. For example:

- 32 countries offer at least one DMD with 100% reimbursement
- 30 countries make available at least 6 of the 12 DMDs surveyed.

Appendix I lists availability and reimbursement rates for the 12 DMDs surveyed in each country. Generally, access to DMDs has improved significantly since the previous MS Barometer survey in 2015¹⁷. However, gaps in access to a variety of DMDs persist. Eight countries require some out-of-pocket payments for DMDs, and most countries did not have full availability of the latest therapy approved by the European Medicines Agency (EMA).

Despite improvements in availability, too many people still do not have access to DMDs. In 2018, 43% of people with MS in Europe were not receiving DMD treatment (Figure 8). Barriers to use of DMDs noted by the respondents include unacceptably high co-payments, reluctance on the part of hospitals to approve changes to more expensive therapies, a shortage of neurologists to prescribe and oversee treatments, and geographical challenges in accessing treatment.

Figure 8. Percentage of people with MS in Europe who did not receive DMD treatment in 2018



The 5 countries that did not respond to this question are not included in this analysis.

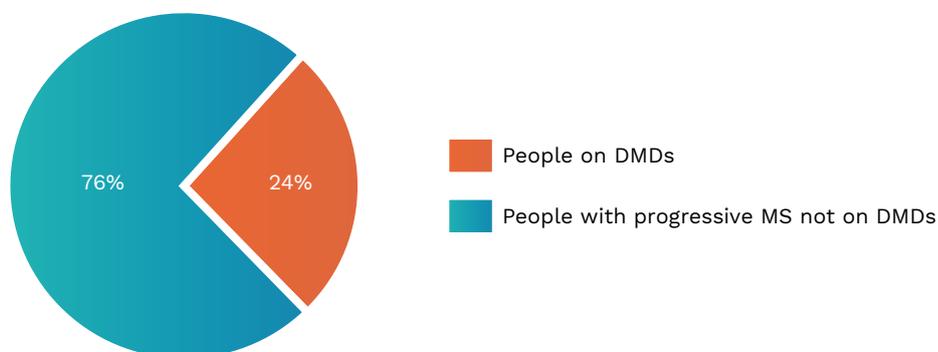
Use of DMDs varies considerably depending on the country. For example, treatment rates are as high as 90% in Lithuania, Malta and Switzerland, but far lower in countries such as Moldova (6%), Bosnia and Herzegovina (10%) and Serbia (12%).



National approval for use and reimbursement of DMDs often faces significant delays. In many countries, national approval of new therapies may come years after the EMA's approval. Reasons for this include delayed initiation by pharmaceutical companies of market access assessments, or slow regulatory processes and duplicative evidence requirements by the national authority.¹⁸

Treatment rates are worse for people with progressive MS than for those with RRMS. There are just four treatment options available, and only three approved in Europe, for progressive forms of MS.¹⁵⁻¹⁹⁻²¹ However, less than a quarter of people with progressive MS receive appropriate DMD treatment (Figure 9). Because of the limited options for people with progressive MS, it is all the more important to ensure that therapies are promptly approved and reimbursed once they have passed scientific and regulatory approval.

Figure 9. Percentage of people with progressive MS in Europe receiving appropriate DMD treatment



The 5 countries that did not respond to this question are not included in this analysis.

The 14 countries that did not respond to questions on the number of people with progressive MS and the percentage of people with progressive MS receiving appropriate DMD treatment are not included in this analysis.

Symptomatic treatments

Key findings



Across all surveyed countries, there is lower availability and lower reimbursement of symptomatic treatments than DMDs

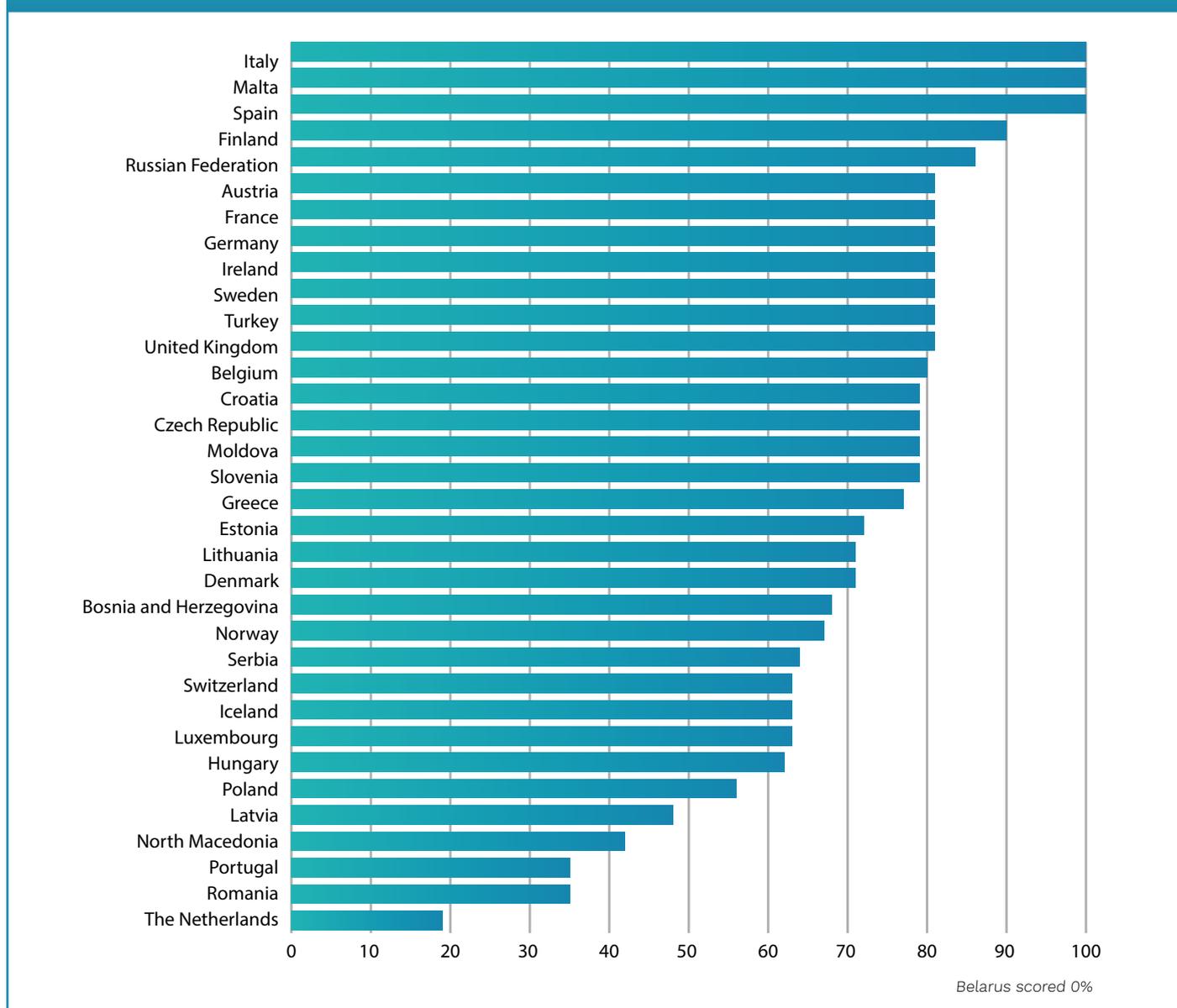


Only 20 countries use national or international guidance for symptomatic treatment of MS



Five countries report having no psychological or cognitive rehabilitation services for most people with MS

Figure 10. National scores on symptomatic treatments



Why are symptomatic therapies important in MS care?

Symptomatic treatments are an essential component of care. Because MS affects the nervous system, the range of possible symptoms is extensive.^{9,22} Many, such as pain, fatigue and incontinence, will have a significant effect on daily living.⁹ However, with appropriate support for symptom management, people with MS may more easily be able to maintain their lives, relationships, education and careers. But without it, many people may find that their quality of life is severely diminished.⁹

MS symptom management is not systematically structured. Many treatments used to manage MS symptoms are issued off-label, and formal investigations of clinical efficacy in MS populations is lacking.²³ There is no formal clinical guidance in Europe for MS symptomatic treatments, so people with MS may depend entirely on their individual neurologist's expertise in this area. Given the importance of symptom management,²³ inconsistencies and limits in availability and access to these therapies are unacceptable.

Palliative care can be seen as a specialised form of symptomatic treatment. Many people will have preconceived notions of palliative care as an end-of-life intervention. But for chronic neurodegenerative illnesses such as MS, palliative care may be initiated at any stage of disease in order to manage pain and other symptoms.²⁴ This approach complements standard care because treatment has the objective of making the person with MS comfortable and maintaining their quality of life, rather than focusing on the underlying disease.²⁴



What did the Barometer find?

Despite their importance, symptomatic treatments have not been prioritised by governments looking to manage MS. Though just eight major symptomatic treatments were surveyed, only 14 countries responded that all were available and fully reimbursed. Many other countries provide symptomatic therapies, but with out-of-pocket costs. These costs can force people with MS to limit treatment duration due to financial constraints. For all survey responses on symptomatic therapies, see Appendix II.

Europe does not prioritise early palliative care for people with MS. Just ten countries reported providing this for people with MS (Figure 11). These countries range from some of the wealthiest to some of the poorest in Europe; delivery of MS palliative care is not dependent on wealth or excellence in other areas of healthcare. Any country may choose to dedicate resources and prioritise this often-overlooked area of MS care.

Figure 11. Availability of specialised early palliative care services



Rehabilitation

Key findings



16 countries provide access to rehabilitation as outlined in the EMSP consensus paper Recommendations on Rehabilitation Services for Persons with Multiple Sclerosis in Europe

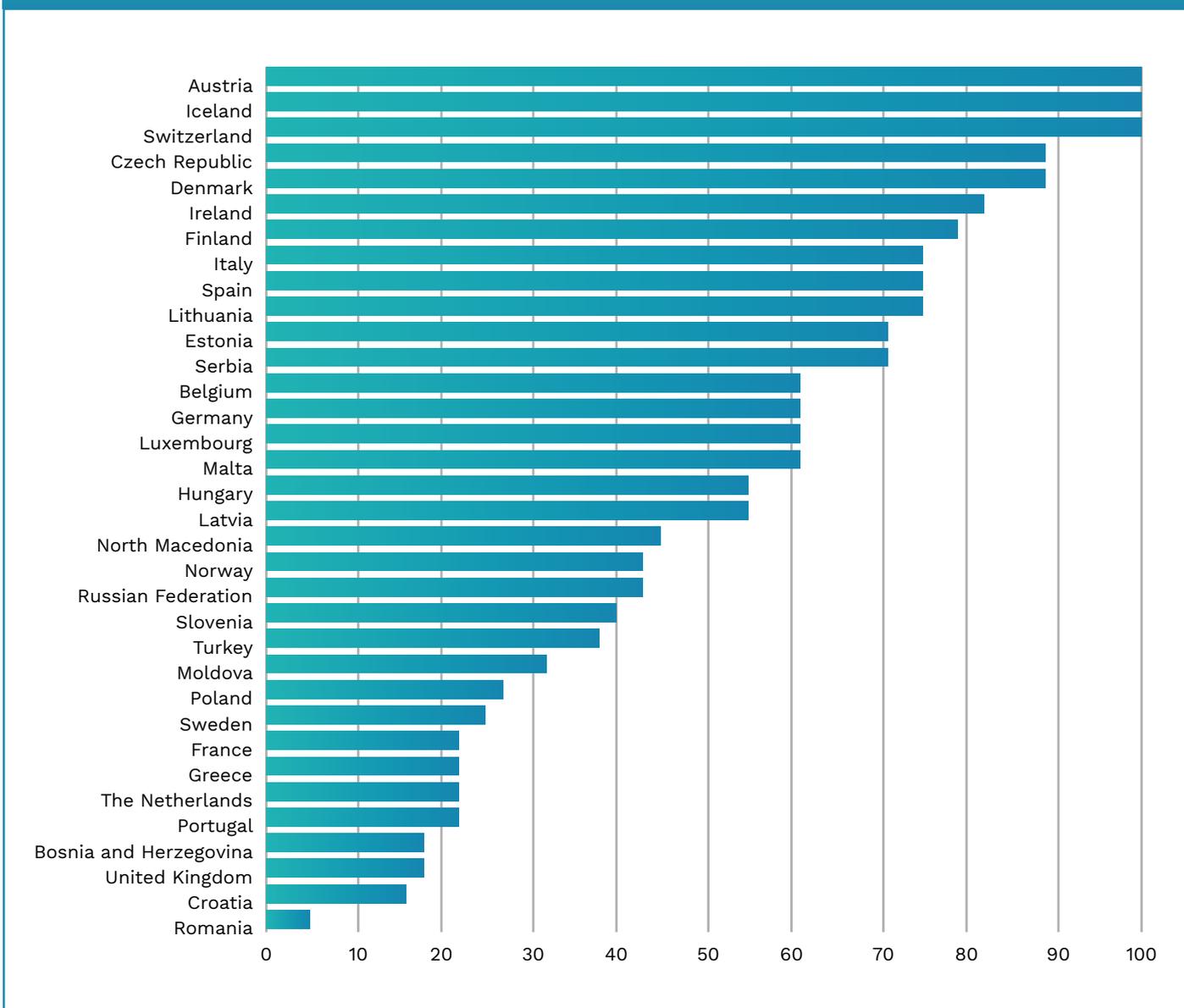


Approximately 52% of people with MS in Europe may not have full access to physical rehabilitation, and these figures are even worse for psychological, cognitive and occupational rehabilitation



Five countries report having no psychological or cognitive rehabilitation services for most people with MS

Figure 12. National scores on rehabilitation



Why is rehabilitation important in MS?

Rehabilitation is a key area of MS management that is often deprioritised and sometimes neglected. Rehabilitation may be key to restoring function after a relapse and maintaining function as MS progresses. Specialised MS rehabilitation addresses physical symptoms of MS, such as difficulties with gait.²⁵ But it also supports the invisible symptoms of MS, such as depression and cognitive changes, through psychological, cognitive and occupational rehabilitation.²⁵

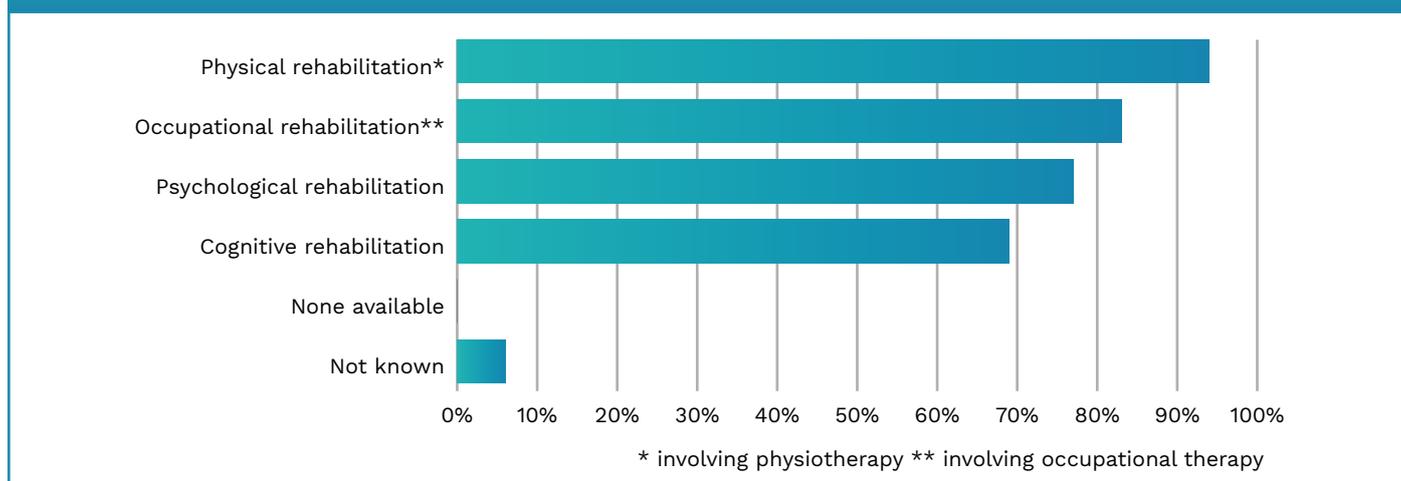
The differences between good and poor access to rehabilitation for MS may be stark. Without appropriate rehabilitation and adaptations, a person with MS may struggle with daily tasks or leave the workforce prematurely.²⁵⁻²⁷ Without psychological and cognitive rehabilitation, a person's emotional wellbeing and cognitive capacity may be severely affected.²⁵ Ultimately, limited access to or use of rehabilitation will require greater support from both health and social care.^{25 27} In terms of enabling a person with MS to enjoy a high quality of life, rehabilitation may be as impactful as symptomatic treatments.²⁵



What did the Barometer find?

Sixteen European countries report providing access to rehabilitation services according to EMSP's Recommendations on Rehabilitation Services for Persons with Multiple Sclerosis in Europe.²⁵ However, disparities in types of care persist between countries (Figure 13). There seems to be relatively good availability of physical rehabilitation, whereas other types of rehabilitation are not as widely available. Worryingly, nearly 30% of countries report no availability of cognitive rehabilitation.

Figure 13. Availability of different types of rehabilitation among surveyed countries (percentage reporting service available)



Availability of rehabilitation does not indicate full, unlimited or affordable access. Government-provided entitlements to free rehabilitation sessions vary from country to country, and can be severely limited. For example:

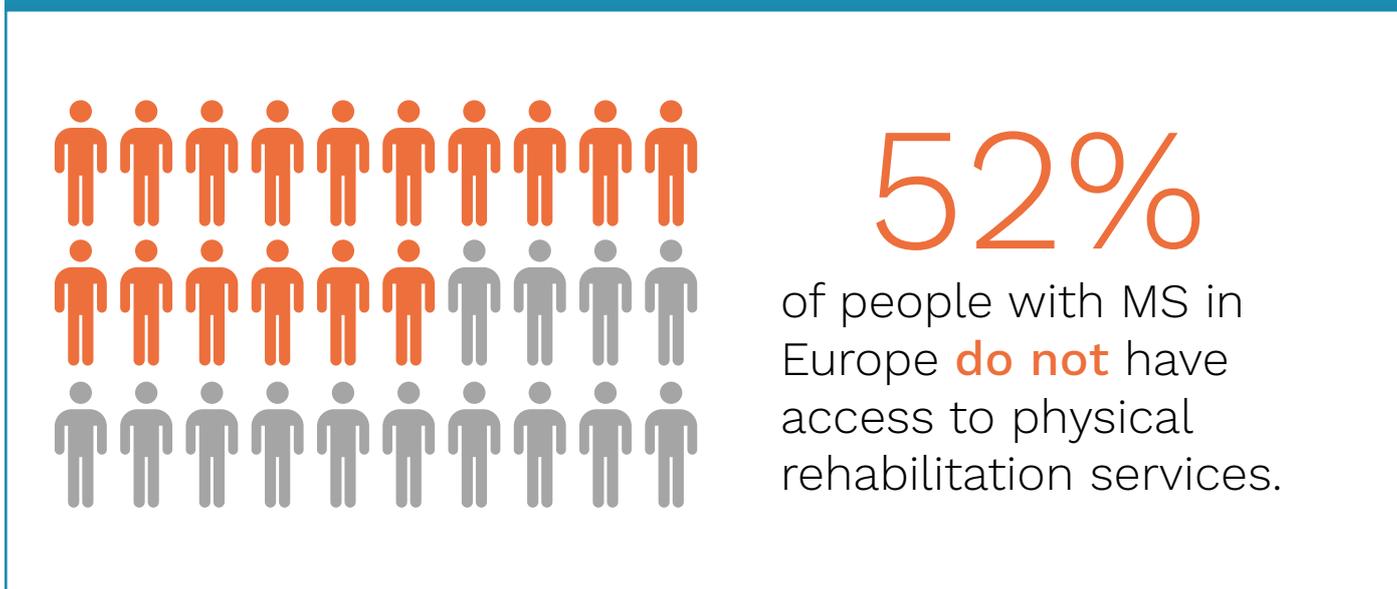
- In Sweden, people with MS are not guaranteed to receive physical rehabilitation each year
- In Portugal, they may be limited to 10 sessions annually
- In Greece, only about 10% of people with MS can access outpatient rehabilitation, the rest being inpatient

Across Europe:

- Physical rehabilitation was available to an average of 48% people with MS across 24 responding countries (Figure 14)
- Psychological rehabilitation was available to an average of 41% people with MS across 15 responding countries

- Cognitive rehabilitation was available to an average of 28% people with MS across 13 responding countries
- Occupational rehabilitation was available to an average of 19% people with MS across 16 responding countries
- Inpatient rehabilitation was available to an average of 18% of people with MS across 21 responding countries, and only nine countries confirmed offering access to inpatient rehabilitation as often as required, with no limitations.

Figure 14. Percentage of people with MS in Europe who do not have access to physical rehabilitation services



The 11 countries that did not respond to this question are not included in this analysis.

Significant barriers limit the use of rehabilitation services by people with MS. Challenges identified in the surveyed countries include:



Requiring referral from a neurologist



Long waiting times



Limits on the number of sessions reimbursed per year (for both inpatient and outpatient services)

There may also be difficulties accessing rehabilitation specialised to the needs of people with MS. Furthermore, given that many countries had no available data on access to rehabilitation, the true gap in service delivery is likely to be much larger.

Highlight

Paediatric MS

Paediatric MS is a rare disease

An estimated 2–10% of people with MS develop the disease before the age of 18, which is classified as paediatric MS.^{5 6} Historically, paediatric MS has been difficult to diagnose,²⁸ but advances in the past decade have improved both diagnosis and understanding of the disease.^{5 6}

The 2020 MS Barometer found that there are more than 30,000 cases of paediatric MS in the 22 countries responding to this question. Given estimates on the total population with MS in Europe and the estimated prevalence of paediatric MS, this is highly likely to be an underestimate.



Paediatric MS requires a specialised approach that supports the unique needs of this community

The clinical, emotional, educational and practical needs of young people with MS can be quite different to those of adults with MS:

- Most children and adolescents are diagnosed with relapsing-remitting MS, and will have slower disease progression than people who are diagnosed in adulthood.^{6 29}
- As a result of their young age at onset, people with paediatric MS may be relatively younger when their disability progresses than people who are diagnosed as adults.²⁹
- Children with MS may have poorer academic performance than their peers, and greater efforts are needed to ensure that they have equal opportunities to learn and develop.⁶



However, not all countries have appropriate provision of care for paediatric MS. For example, of 35 countries reporting to the survey:

- 25 countries reported that paediatric patients have full access to MS treatments approved in their country
- 19 countries have a specialised clinic for paediatric MS
- 12 countries have clinical guidelines for treatment of paediatric MS
- 7 countries have rare disease management programmes, policies or plans which include paediatric MS.

Carers of children and adolescents with MS also face unique challenges and require targeted support

Parents or other carers need emotional, informational and financial support to allow them to best support the child's wellbeing along with their own.³⁰ Yet across Europe there is a lack of initiatives for them:

- Just 16 countries provide any social support specific to paediatric MS carers
- Only 18 countries provide child disability allowances.

Some countries have specific initiatives in place for children and adolescents with MS and their carers

Services and events provide opportunities for young people with MS to connect with a community, learn more about their disease and enjoy time with their family and peers. Examples of such programmes are found in many countries:



The French foundation for MS research (Fondation d'Aide pour la Recherche sur la Sclérose En Plaques, ARSEP) has an annual day for people with MS under the age of 21.³¹



Romania's national MS patient society (Asociatia Pacientilor cu Afectiuni Neurodegenerative din Romania, APAN) has held an annual retreat for children with MS since 2017.³²

Employment and social support

Key findings



Among the 15 countries that reported data, only 48% of people with MS are in full-time or part-time employment

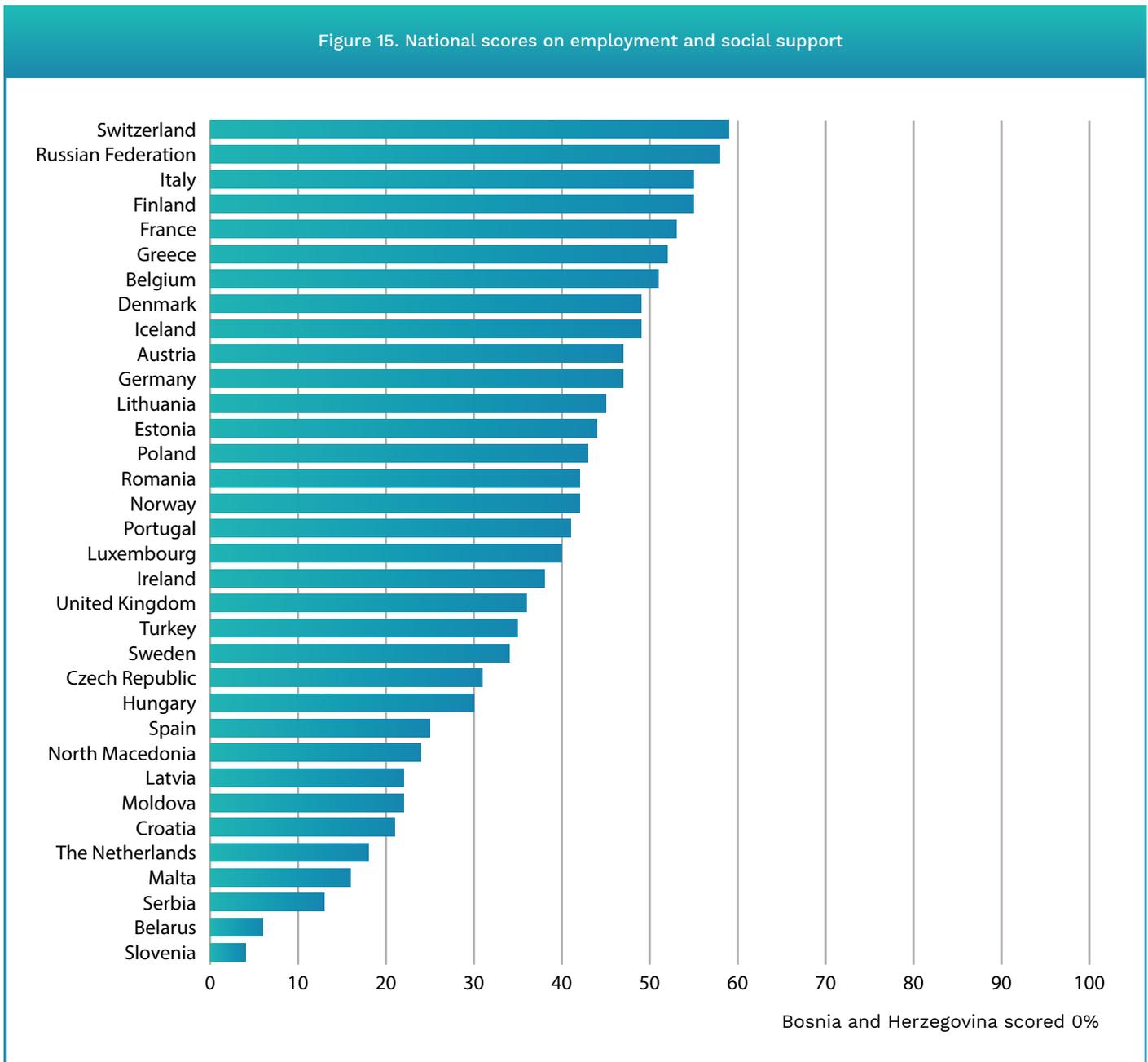


21 countries provide no support for young people with MS to complete their education



In at least 7 countries, people with MS are not legally protected from unfair dismissal from work

Figure 15. National scores on employment and social support



Why are employment and social support important in MS?

Optimal management of MS must extend beyond the health system to education, employment and social care. With most diagnoses occurring during a period when people are pursuing studies, establishing careers and starting families, an individual's entire course of life may be altered by the onset of MS. People with MS will require varying social support as their disease progresses, including support for social inclusion, financial support to supplement income, support with form-filling to receive benefits to which they are entitled, transportation support, or household adaptations such as wheelchair ramps and accessible showers.³³

With adequate support, many people with MS can complete their education and maintain employment. Flexible hours and the option of remote learning and working may be instrumental in allowing people with MS to meet their responsibilities. Adaptable schedules will also enable a person with MS to undergo treatments and manage the unpredictable and variable symptoms of their disease.³⁴

Legislation may help keep people with MS and their carers in the workforce. Anti-discrimination laws can protect people

from wrongful termination and secure appropriate accommodations needed for social inclusion.

Recognition of the invaluable role of informal MS

carers may provide the family with much-needed flexibility and support to balance their lives.³⁵ Because a person with MS may have a relapse of symptoms without warning, their carers need as much flexibility as possible to be able to support them.

Countries that fail to provide a robust response to the needs of people with MS and their carers will face economic and social costs. A lack of support contributes to people being

forced to leave the workforce.³⁴ In one 2016 global survey, more than 80% of people with MS who were not working reported that this was because of their disease.³⁴ Being out of work may result

in significant personal losses, including independence, emotional wellbeing and financial security. Lower workforce participation also brings societal losses with the reduced talent pool and increased burden

on disability and unemployment insurance.³⁶ While some level of social support

is available in most countries, it is not clear that this is sufficient to maintain quality of life or ability to stay in work for people with MS and their families.

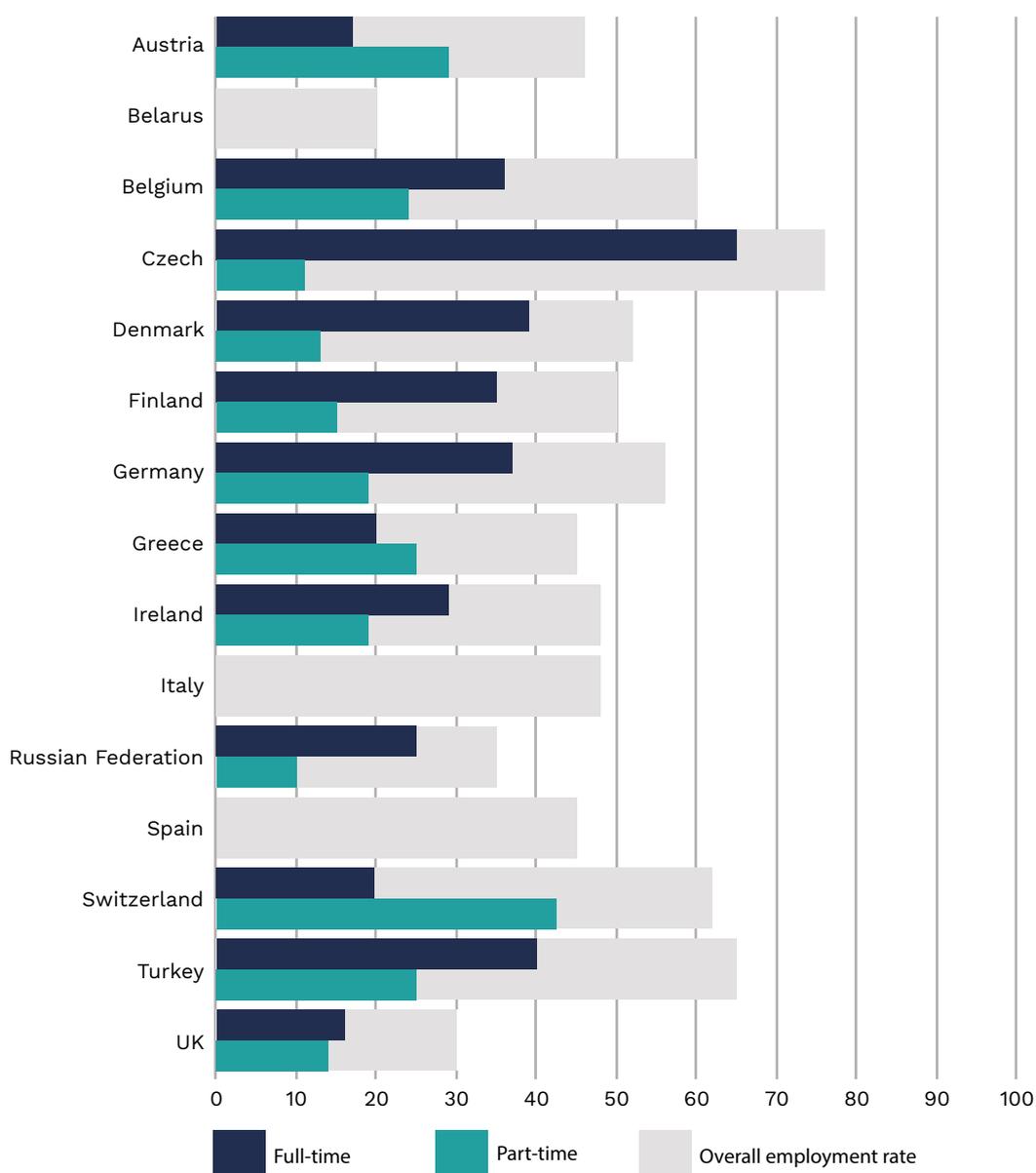


What did the Barometer find?

Gaps in employment and social support persist across Europe. Only 15 countries were able to report any employment data at all for people with MS. Figure 16 indicates the rates of full-time and part-time employment across these countries. Among respondents, employment rates varied significantly:

- There are only seven countries where at least 50% of people with MS are in employment: Belgium, Czech Republic, Denmark, Finland, Germany, Switzerland and Turkey.
- 20 countries reported no data on the employment rates of people with MS.

Figure 16. What percentage of people with MS are in full-time or part-time employment?



The 20 countries that did not respond to this question are not included in this analysis.

Employment legislation may not need to be disease-specific to provide some protections for people with MS. Many countries provide general support for all people with disabilities, for example:



Financial support for early retirement due to disability (28 countries)



Incentives to recruit or retain people with disabilities in employment (27 countries)



Legal protections against dismissal from employment due to a health condition (27 countries)



Flexible working practice legislation for people with disabilities (22 countries)

However, existing legislation may need adapting to recognise the complexities of MS and other neurodegenerative diseases. In many countries, disability status is assigned based on physical evaluations. For example, in Spain, a person with MS must reach a disability assessment of 33% lost functionality before qualifying for many of the social support provisions that exist.³⁷ A person's access to support may depend on receiving their scheduled evaluation at the same time as they are experiencing their most severe physical limitations. As some of the most debilitating MS symptoms may be 'invisible', such as pain and fatigue, standard physical disability assessments may not be sufficient to gauge the full extent of social support that the person with MS requires.

Governments and MS advocates must intervene early in a person's disease course to ensure that the person has sufficient support to pursue and maintain a career. Fewer than half of countries responding to the survey offer this crucial support. In the workplace, MS awareness-raising programmes for employers and employees may help to reduce stigma and improve understanding of any accommodations introduced for people with MS. Such informational support is currently offered in 18 out of 35 countries.

Financial support for household adaptations is limited. Across the 20 countries that responded, only Denmark and Luxembourg offer full reimbursement of home adaptations. A further 13 countries reported an average of 50% reimbursement, and five countries reported no reimbursement for the costs of home adaptations.

Carers need more formal support to balance their personal, professional and caring commitments. Informational programmes are available in 28 countries for family members and friends, but more can be done, such as extending legal protections and financial support that already exists for people with MS.

Research

Key findings



Fewer than half of countries surveyed have a national MS disease registry, meaning 65% of people with MS in Europe may be unrecorded in official registries

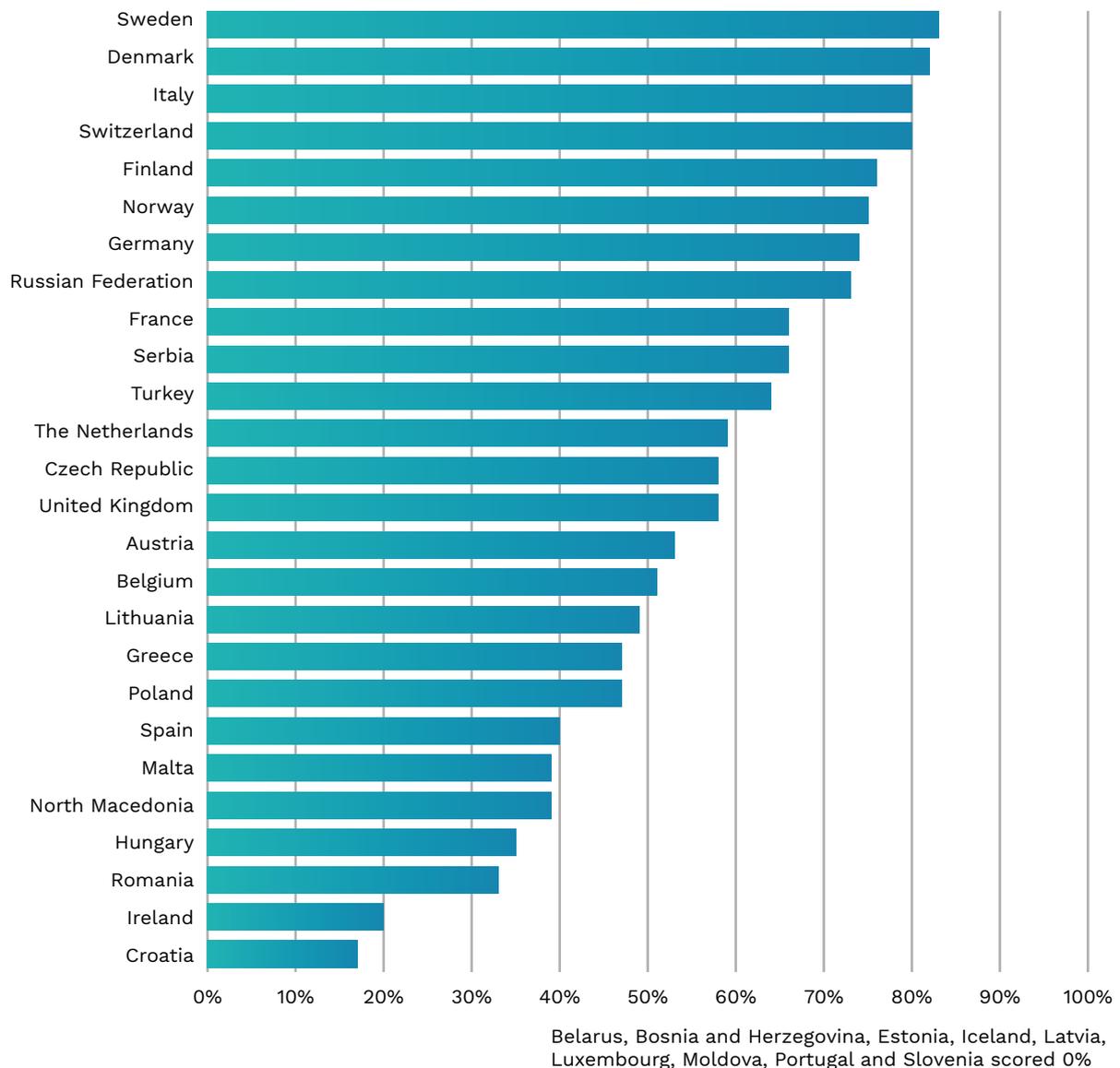


Only eight countries have a national research agenda for MS



17 national MS societies provide grants and other financial incentives to support research

Figure 17. National scores on research



Why is research important in MS?

Research strengthens our understanding of MS and the best ways to manage it. Investments in research have led to many improvements in MS diagnosis and management, including better imaging and treatments, and greater understanding of the risk factors for disease progression.³⁸⁻⁴⁴ MS registries allow observation of epidemiological trends as well as patterns in patient-reported outcomes, occupational data and other types of data. The information gained may inform decisions on service improvements, clinical research objectives and patient advocacy.

MS societies should play a role in driving MS research, but other sectors, including national governments, must also be involved. MS societies and people with MS will have unique insights on the most urgent priorities of those living with the disease. Collaboration among all stakeholders involved in MS and integration of the MS patient community can help to advance the research agenda and answer the many unknowns that remain in MS care. However, it is ultimately national governments that provide funding incentives to realise these priorities and support ambitious research.



What did the Barometer find?

Disease registries are an essential investment for better MS management. Countries with an MS disease registry (Figure 18) had a significantly better median Barometer score than those without:



Countries with an MS disease registry had a median score of 61



Countries without an MS disease registry had a median score of 37.

The existence of a disease registry will improve MS management by allowing clinicians, policymakers and people with MS to understand the scale of the disease burden and the effectiveness of existing services. In some countries, such as Sweden, people with MS may also be empowered to self-report data, which may be particularly useful to analyse information on patient-reported outcomes and experiences.

Figure 18. Countries with a national, local or regional, or no MS disease registry



Even in countries where registries exist, not all people with MS are included. As Figure 19 indicates, 65% of people with MS in Europe are not recorded in a national disease registry. This rate varies substantially between countries:



Denmark records 100% of people with MS on its national registry



Finland and Malta each record over 90% of their MS population on national registries



North Macedonia and the UK report that less than 20% of people with MS are recorded on their registries.

Survey respondents noted that improvements can be made if recording is mandated and healthcare practitioners are better supported to collect data.

Figure 19. Percentage of people with MS in Europe who are not recorded in national registries



The two countries that did not respond to this question are not included in this analysis.

Different sectors sometimes come together to support MS research. There are different models of running and funding MS registries: funding can come from public and private sources or a combination of both, and sometimes it is MS societies that actively maintain these registries. Patient associations are also a significant contributor to other branches of MS research:



17 national MS societies provide grants or other types of financial support for MS research



The Italian MS Society Foundation (FISM) invests €5 million – €6 million in MS research annually.

A national MS research agenda may provide an overarching direction for investigations in MS. Eight countries in Europe – 23% of the surveyed members – have a national MS research agenda: Croatia, France, Italy, Lithuania, Russian Federation, Spain, Switzerland and the UK. These countries may be better equipped to make strategic investments in ambitious, large-scale MS research projects.

Conclusions

Europe has seen progress in several domains of MS care since the previous MS Barometer. In the 2015 iteration, access to affordable DMDs was identified as a notable challenge for a significant portion of our member societies;¹⁷ the 2020 MS Barometer has shown that advocacy initiatives have helped drive major improvements in the cost and availability of DMD treatments.

However, the 2020 MS Barometer has demonstrated that significant disparities in access to quality care and support for MS persist. Despite advocacy efforts, policymakers have failed to address many of the most urgent priorities in MS. Deficits were particularly glaring in the provision of adequate rehabilitation and social support, as well as regarding specialised paediatric MS care. Furthermore, symptomatic treatment remains inadequately prioritised even though it may have an enormous bearing on quality of life and daily living.

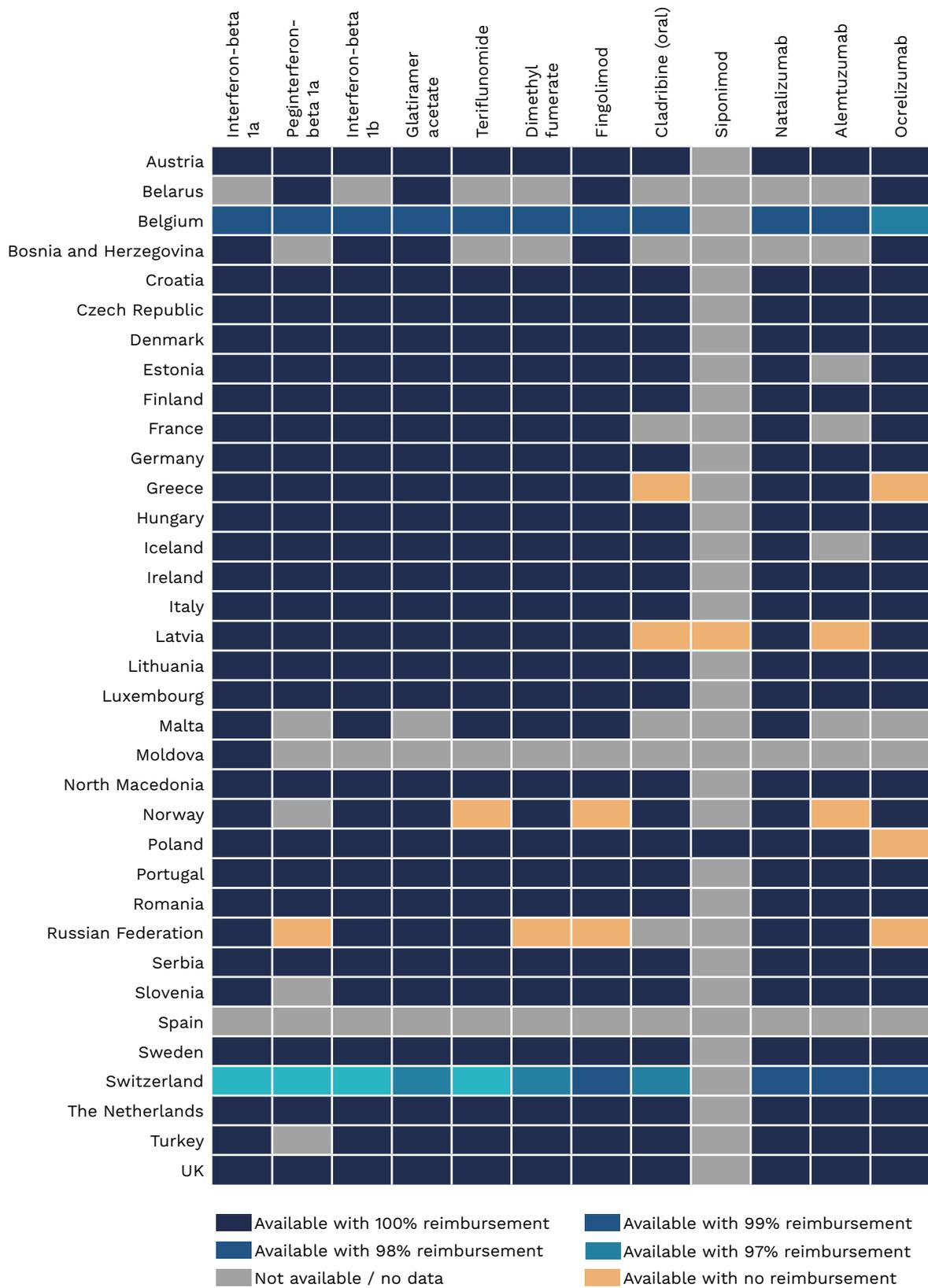
This survey of 35 European countries clearly illustrates that national wealth alone is not sufficient to ensure quality MS care. As the Barometer scores show, some countries with lower income statuses can outperform higher-income countries in specific domains as well as in the overall results. While aggregated scores tell only part of the story of MS care in a country, they may be considered a snapshot of the strengths and weaknesses of the MS systems. The MS Barometer is an advocacy tool which can help to keep MS and other neurodegenerative diseases on health and social care agendas. These findings should inspire policymakers and decision-makers from every country to look anew at their health and social care plans to improve MS management.

We need MS care to be improved today. The COVID-19 pandemic has placed new strains on our health and social systems. However, it provides an opportunity and political momentum to invest in and reorganise these systems. We must use this moment to re-confirm and re-energise the MS community's efforts, and drive policymakers and decision-makers to take evidence-based action to ensure a holistic approach to care for all people with MS.



Appendix I. Availability and reimbursement of disease-modifying drugs

Figure 20. Availability and reimbursement rates for disease-modifying drugs



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