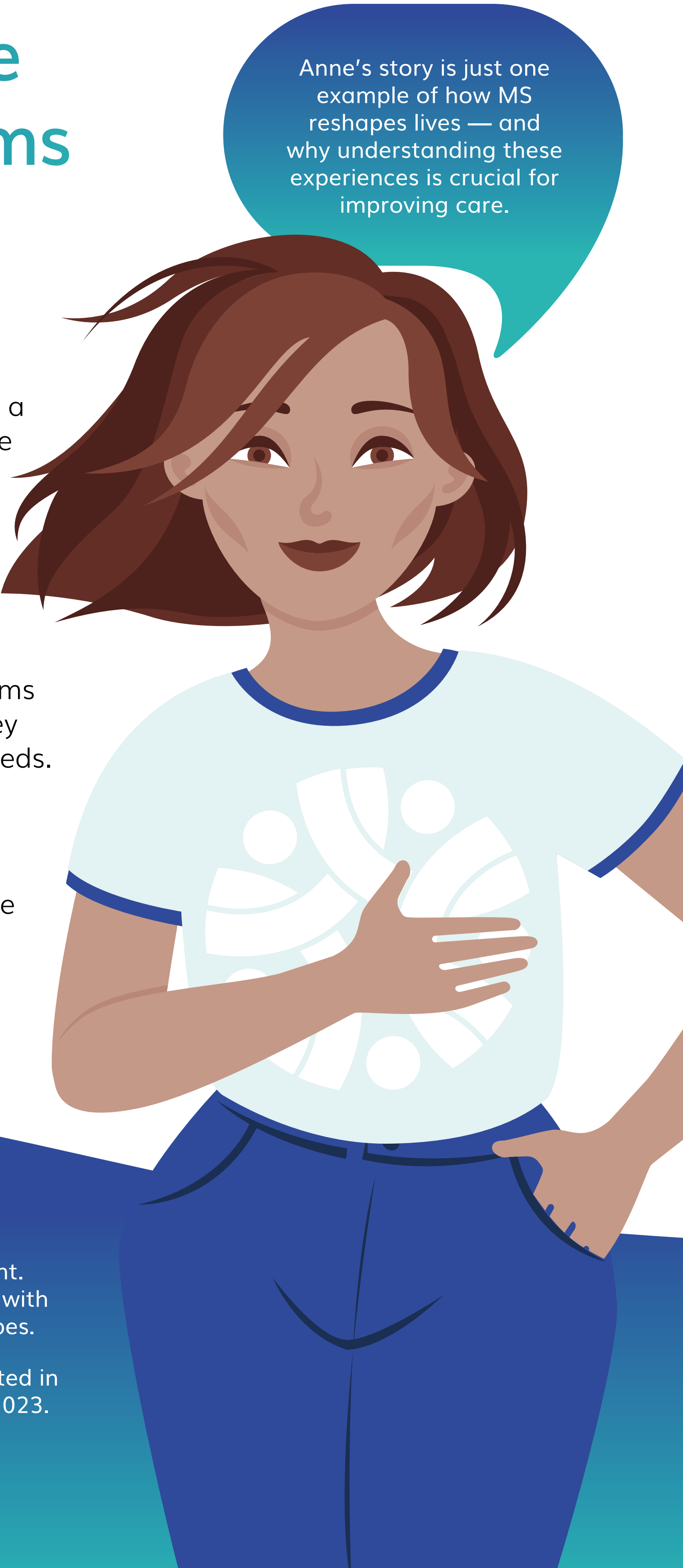
IMSS
ms forbundet
emsp EUROPEAN MULTIPLE SCLEROSIS PLATFORM

Impact of Multiple Sclerosis Symptoms (IMSS) in Norway

Despite progress in multiple sclerosis (*MS*) care, healthcare systems across Europe still lack a **coordinated and prioritised approach** to managing MS symptoms effectively. MS is a lifelong neurological condition affecting more than 1.2 million people in Europe, yet many continue to face gaps in care and support.

The European Multiple Sclerosis Platform (*EMSP*) is spearheading research to understand how people with MS experience and manage their symptoms across the continent. By **identifying disparities** EMSP aims to promote stronger collaboration among key stakeholders to effectively address unmet needs.

The Impact of Multiple Sclerosis Symptoms (*IMSS*) initiative seeks to drive policy change, improve care pathways, and enhance rehabilitation outcomes, ensuring that people with MS receive the **comprehensive support** they deserve.



Anne's story is just one example of how MS reshapes lives — and why understanding these experiences is crucial for improving care.

EMSP and **24** national MS societies across **22** European countries collected real-life evidence on MS symptoms and management. Behind these findings are real people, each with their own challenges, uncertainties, and hopes.

In Norway, **1,073**[1] people with MS participated in the IMSS survey from May 5 to August 31, 2023.

A Life Changed by MS

Anne had always been full of energy — a nurse and passionate skiier in her free time. But at 30, her life took an unexpected turn. She started noticing strange sensations in her legs, followed by bouts of overwhelming fatigue. Over time, these symptoms grew harder to ignore. Tasks she once did effortlessly became a struggle. Her doctor ran tests, but the results were inconclusive. For four and a half years, Anne lived with uncertainty, her daily life becoming a patchwork of pain, confusion, and questions without answers.

Participant demographics

44.9 THE MEAN AGE OF PEOPLE WITH MS

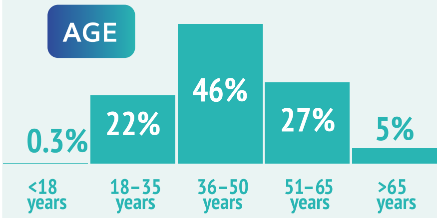
46% ARE 36–50 YEARS OLD

DUE TO MS **2 in 5** ARE NOT WORKING

65% HAVE HIGH-LEVEL EDUCATION

74% LIVE WITH THEIR FAMILY

AGE



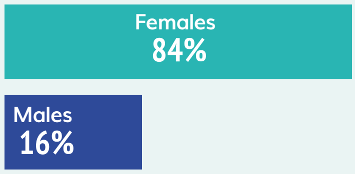
People between **18–35** reported the most anxiety but report the least of other symptoms.

Individuals aged **36–50** experienced the highest sensory and cognitive impairments but less muscle weakness, bowel problems, and mobility impairment.

Between **51-65**, low dizziness, vision, speech, and tremor issues but high pain, spasticity, sexual problems, and trouble swallowing.

Over 65, balance problems, muscle weakness, bowel/ bladder problems, and mobility impairment peak, while anxiety, depression, and cognitive impairment are the least.

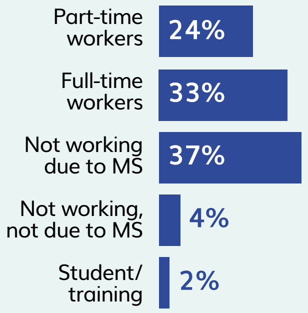
GENDER ‡



Females reported significantly *fewer* spasticity problems, mobility impairment, hand and arm problems, and tremors but *more* **cognitive impairment, dizziness,** and **trouble swallowing** compared to males.

Males reported significantly *fewer* fatigue, cognitive impairment, dizziness, and trouble swallowing, but *more* **spasticity problems, mobility impairment, hand and arm problems,** and **tremors** than females.

WORKING STATUS



Part-time workers experienced more fatigue.

Full-time workers reported significantly less presence of all symptoms.

People not working due to MS reported the most presence of symptoms.

Students and people in training reported high vision and hearing problems**.**

Understanding MS Across Europe

IMSS aims at uncovering the truths behind the symptoms, struggles, and stories of MS. How do people across Europe experience the condition? How do healthcare systems respond to their needs? And most importantly, where are they falling short?

For Anne, these questions resonate deeply. Her diagnosis eventually came at age 35, but the journey didn't end there. Her symptoms — fatigue, cognitive impairment, sensory problems, and balance problems — continued to affect her daily life. Navigating the healthcare system felt like an uphill battle, and she often wondered if there was more that could be done.

Anne's experience reflects a broader reality revealed through the IMSS survey. Thousands of respondents shared their stories, offering insight into the challenges of living with MS: delays in diagnosis, inconsistent care pathways, and limited support for symptom management. Despite these challenges, EMSP saw an opportunity to drive change. By amplifying these voices, EMSP could push for policies that prioritise comprehensive, equitable care for people like Anne across the continent.

Clinical situation

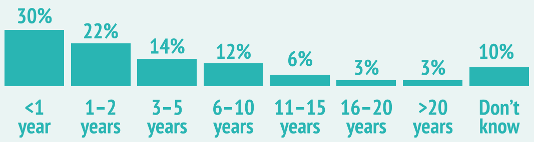
DIAGNOSIS AND SYMPTOM ONSET

51%
diagnosed between 18–35 yrs

10.2 YEARS
average disease duration

3 in 4
have at least 1 additional illnesses

Delay from symptom onset to diagnosis



30.1
symptom onset age

AVERAGE DELAY OF 4.2 YEARS

34.7
average diagnosis age

TYPES OF MS

59%
RRMS,
Relapsing Remitting MS

13%
PPMS,
Primary Progressive MS

11%
SPMS,
Secondary Progressive MS

17%
Unsure of their MS type

DISABILITY LEVELS

23% of the respondents had mild disability while 44% had moderate disability and 9% had severe disability. People living with PPMS reported similar moderate disability (45%) as people living with RRMS, but more severe disability (25%) than both RRMS and PPMS.

QUALITY OF LIFE

The majority of respondents had no or slight problems, while 4.8% were experiencing moderate or severe problems affecting their quality of life. The quality of life deteriorated more among people with PPMS (9%) and people with SPMS (10%) compared to RRMS[3].

USE OF DMDs

89% of respondents have used **Disease Modifying Drugs** (DMDs), with 71% currently using them. 69% reported *less* than a 1-year delay to start DMDs, while 10% experienced delays of 6 years or more. Among non-users, the main reasons were:

- 14% concerns about use
- 59% never being offered
- 11% physicians advising against them.

ON AVERAGE
1.7
YEARS DELAY BETWEEN DIAGNOSIS AND DMD START

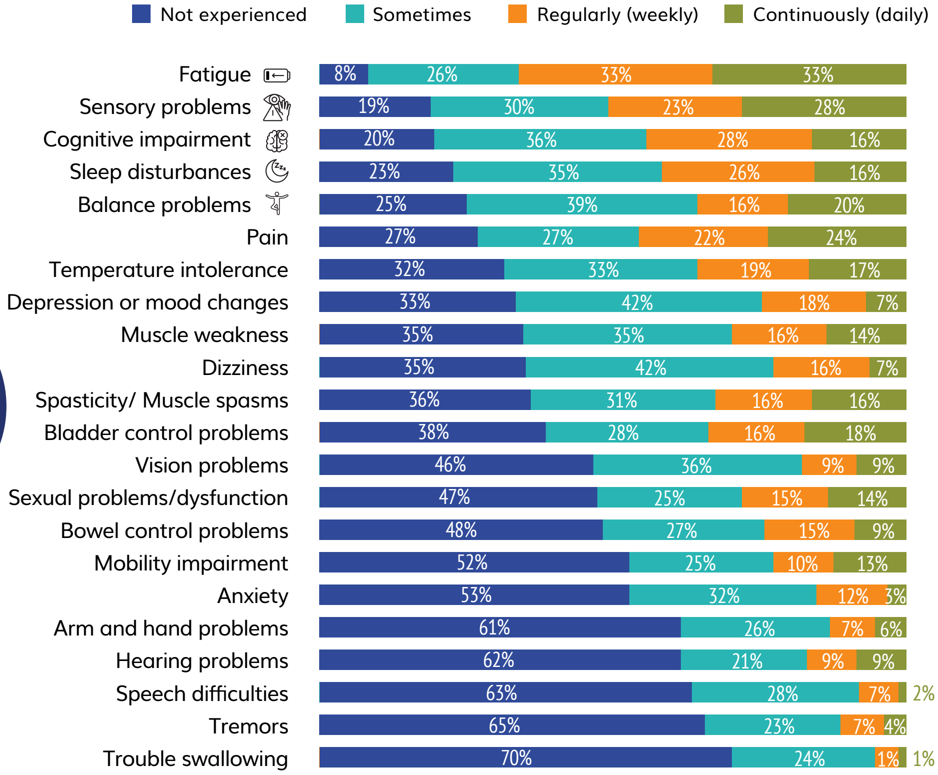
Symptoms

PRESENCE AND PREVALENCE

The symptoms reported the *most* were **fatigue, sensory problems, cognitive impairment, sleep disturbances,** and **balance problems.**

99%
EXPERIENCED AT LEAST ONE SYMPTOM

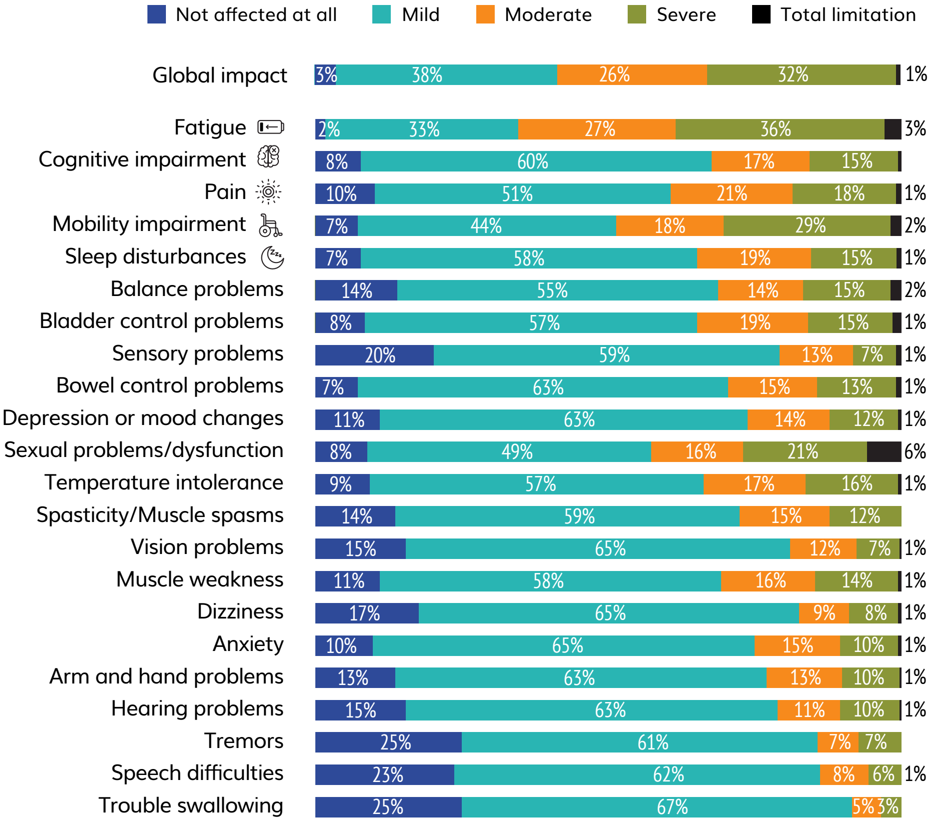
ON AVERAGE
13
SYMPTOMS EXPERIENCED TOGETHER



SEVERITY AND IMPACT

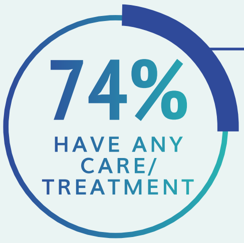
The symptoms that were affecting the daily lives of people with MS were **fatigue, mobility impairment, sleep disturbances, bowel control problems,** and **sexual problems**[4].

The top 3 *most* debilitating symptoms were **fatigue, cognitive impairment,** and **pain**[5]**.**



Treatment and care

CARE FOR SYMPTOMS

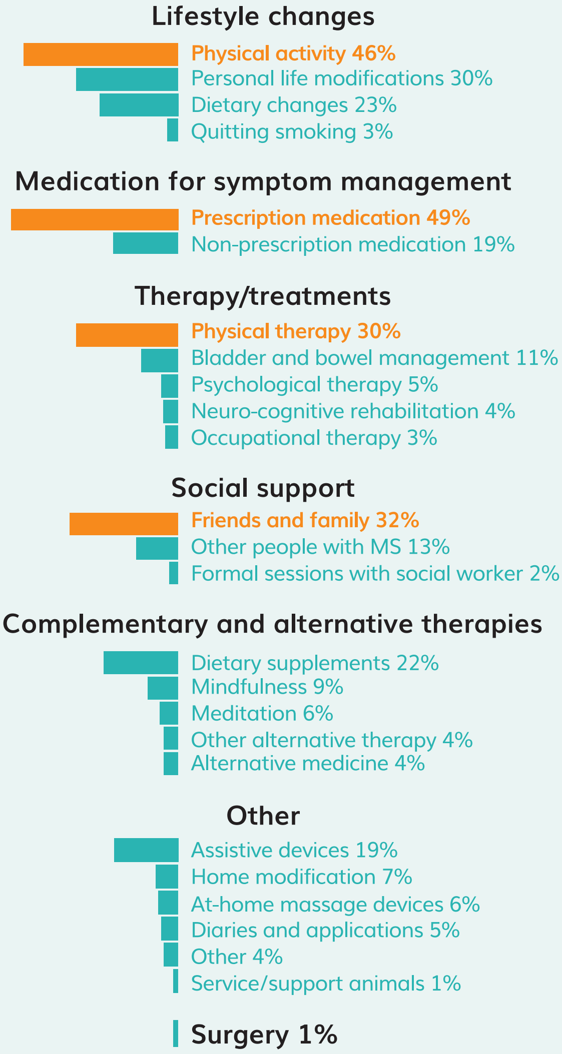


26% don't use any care /treatment. The *top reasons* for not using a specific treatment were having no need, treatment was not offered to them, or they cannot afford this treatment.

ON AVERAGE **4.8** TREATMENTS OR CARE

People with MS reported using 4.8 treatments or care on average for their symptoms.

The *most* used treatments were*: **prescription medication, physical actiivity, social support: friends and family,** and **physical therapy.**

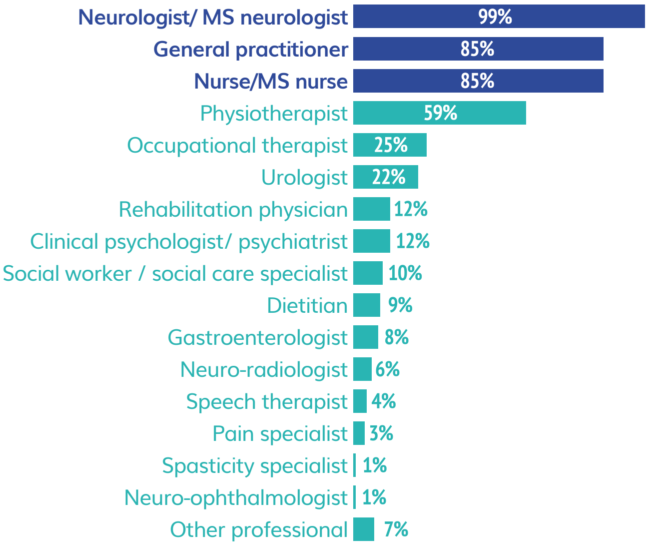


INVOLVEMENT OF PROFESSIONALS

ON AVERAGE **4.5** HEALTHCARE PROFESSIONALS

People with MS had 4.5 healthcare professionals on average taking care of their MS. 68% reported that their healthcare professionals are coordinating together.

The *most* involved professionals were **neurologist, general practitioner,** and **nurse/ MS nurse***.



CAREGIVER PRESENCE AND ASSISTANCE

88% have no need for assistance

8% do not have caregivers but need assistance

4% have caregivers

Of those caregivers, **69%** were a family, partner, or friend. **38%** were paid professionals*.

3 in 4 ARE A FAMILY, PARTNER OR FRIEND

ON AVERAGE **17.8** HOURS/ WEEK

The caregivers supported people with MS for 17.8 hours per week on average. **62%** of respondents mentioned that the carer was of **great or good** help to them.

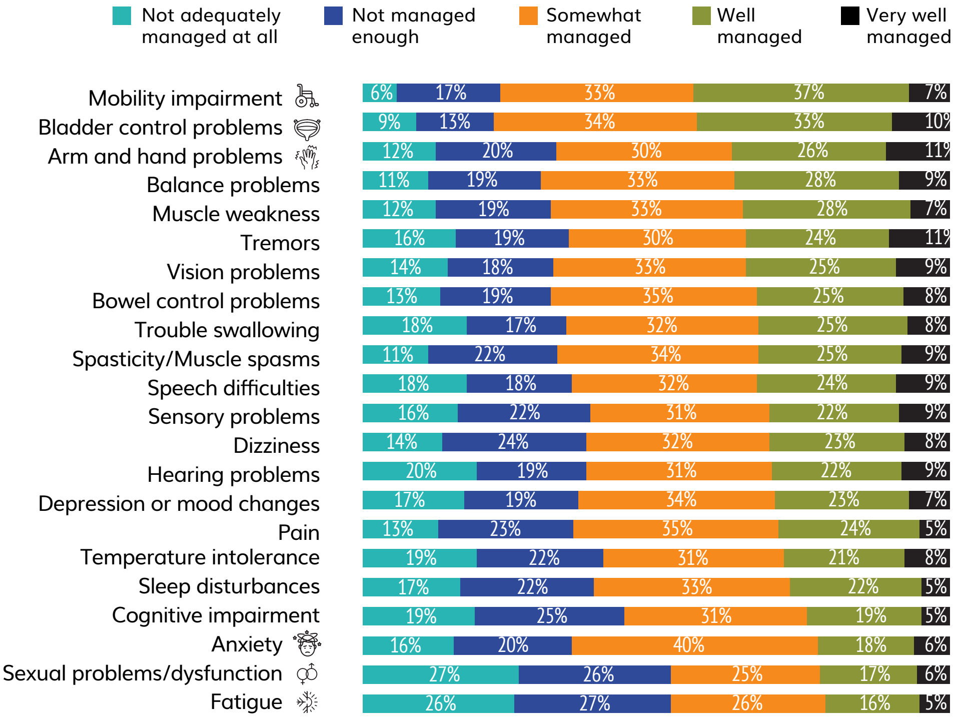
People living with PPMS and SPMS reported similar needs for a caregiver with 9-10% having a caregiver and 10-11% needing one while people with RRMS reported the most not having and not needing a caregiver (90%).

Satisfaction with management of symptoms

The *most* well managed symptoms were **mobility impairment, bladder control problems,** and **arm and hand problems.**

The *least* well managed symptoms were **fatigue, sexual problems/ dysfunction,** and **anxiety.**

2 in 5
NOT SATISFIED WITH THEIR CARE



The promise of change

As the IMSS initiative brings together people with MS, researchers, policymakers, and healthcare providers, we hope to have a future where no one has to face their symptoms alone. A future where MS care isn't just about managing symptoms but **empowering people to lead fulfilling lives.**

The story of MS isn't just about the condition; it's about the people living with it. And for Anne, it's a story that continues, now with **the promise of a brighter tomorrow.**

Note: Percentages are rounded for simplicity and may not sum to 100% or match exactly.

*Participants were allowed to give more than one answer (multiple choice), hence the total can be more than 100%.

‡Gender: Non-binary: 0.1%, prefer not to say: 0.1%

References: [1] Among respondents, 87.1% were MS society members, 6.7% were linked but not members, and 6.2% had no society affiliation. [2] Measured by the PDDS: Patient-Determined Disease Steps, provided for use by the NARCOMS Registry: www.narcoms.org/pdds. NARCOMS is supported in part by the Consortium of Multiple Sclerosis Centres (CMSC) and the CMSC Foundation. [3] Measured by EuroQOL Research Foundation: EQ-5D-5L. [4] The tool used to measure the severity of symptoms is SymptoMScreen: https://www.symptomscreen.org, categorised into 5 groups: Not affected at all (0); Mild (1 and 2), Moderate (3), Severe (4 and 5), Total limitation (6). [5] The 'Severity and Impact' chart is organized from the most to the least debilitating symptoms.

Acknowledgement: EMSP thanks people with MS and their caregivers across Europe for participating in this IMSS survey experience. EMSP thanks the Scientific Working Group which included MS experts and the national MS societies for their support. EMSP thanks the young people with MS who supported the development of the survey part of the Young People's Network, the MS International Federation, and GfK Spain (expert in Healthcare Market Research).

Funding: This project has been financially supported by Almirall, Biogen, Bristol Myers Squibb, Coloplast, Merck, Novartis, Roche, and Sanofi.