

# Evolving approaches to measuring and managing disability in people with multiple sclerosis in Italy

**Multiple sclerosis (MS)** is a chronic neurological condition that predominantly affects adults, impacting approximately **144,000 individuals in Italy**.<sup>1</sup> Over the past 30 years, the prevalence of MS in Italy has risen by 53%, reflecting a growing public health concern.<sup>2</sup>

MS is the world's leading cause of progressive neurological disability among adults of working age and imposes a significant economic burden, driven mainly by the direct costs of medication and inpatient care, and the indirect costs of productivity loss due to unemployment, presenteeism, and absenteeism. Around one-third of people with MS in Italy face work-related challenges, with depression, physical fatigue, and cognitive impairments being key factors limiting productivity and employment.<sup>3,4</sup>






































Despite its rising prevalence and profound effects on daily life, critical gaps persist in how disability related to MS is recognised and managed.



Supported by **sanofi**

## Gaps in policy impact the delivery of multidisciplinary care for MS

While Italy does not have a dedicated national policy specifically for neurological diseases, the Italian National Chronicity Plan (NCP), launched in 2016, provides national guidelines for the management of neurodegenerative diseases within its strategic, patient-centred, multidisciplinary, and value-based approach to chronic conditions.<sup>5,6</sup> While MS is not explicitly mentioned in the NCP, national guidelines for MS management were published by the Italian Society of Neurology (Società Italiana di Neurologia-SIN) in 2022, and at least five regions have established Integrated Care Pathways (Percorsi Diagnostici Terapeutici Assistenziali-PDTA) for MS.<sup>7</sup> In addition, there is a nationwide network of over 190 specialised MS centres, which participate in a web-based registry established by the Italian MS Society's Foundation (Fondazione Italiana Sclerosi Multipla-FISM). Currently, the Italian register includes clinical data for about 40% of people with MS in the country.<sup>8</sup> Participating centres are expected to report disability scores for more than 80% of patients at least every six months, supporting improved recording and management of MS-related disabilities.<sup>9</sup>

			National policy for neurological disease management	National policy for chronic disease management	National registry for MS	Treatment guidelines for MS
<b>Italy</b>						
France						
Germany						
Spain						
Sweden						
United Kingdom						
United States						

Source for table data: MS Barometer 2020

To better understand views and experiences with measuring and managing MS-related disability in real-world clinical environments, we conducted a survey with 100 MS specialists and neurologists in Italy. To further capture the economic impact of MS-associated disability (including both direct and indirect costs), we also conducted a quantitative analysis. This infographic summarises the results for Italy.

“The list of symptoms is quite wide. It includes so many things that people with MS don’t think about. When you’re newly affected...you don’t necessarily relate one symptom to the condition, and that makes it even more tricky to understand and to make sure we address all the needs of the people.”

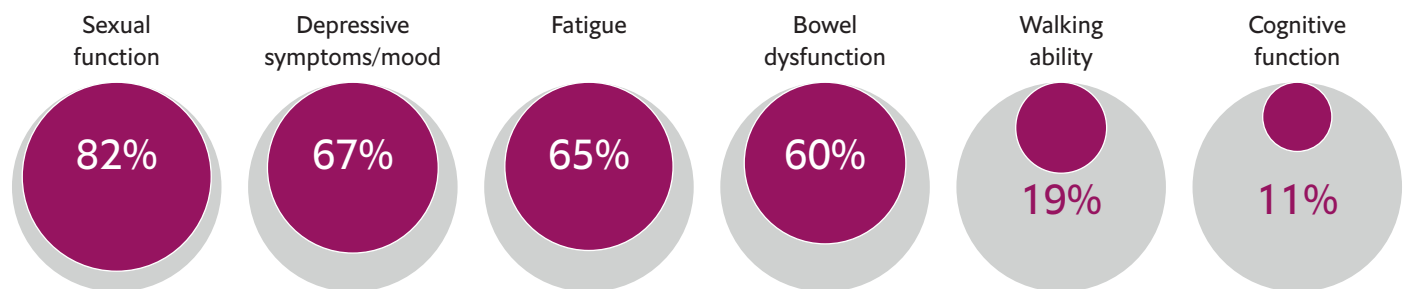
Lydia Makaroff, Chief Executive Officer, Multiple Sclerosis International Federation

## Over 95% of people with MS in Italy experience fatigue,<sup>10</sup> but our survey found that only about a third of neurologists assess this

MS is a condition that can lead to a broad range of symptoms, which vary widely from person to person. Our survey found that neurologists most often assess symptoms affecting mobility, safety, and cognitive health, such as walking ability, balance, and cognition. Meanwhile, fatigue and sexual function are reviewed less routinely, despite their significant impact on quality of life.



### Percentage of neurologists that do not routinely assess the following symptoms of MS:



### Significant gaps exist in multidisciplinary support for people with MS

Our survey found that:



### There is no universally adopted standard for assessing disability in MS




The Expanded Disability Status Scale (**EDSS**), the most widely used global tool for measuring MS-related disability, is applied routinely by just 45% of neurologists, while the next most routinely used, the Multiple Sclerosis Performance Test (**MSPT**), is utilised by 38% of neurologists. They are time-consuming to administer, making them impractical for regular clinical practice.

For patient-reported outcome measures (PROMs), the most common are the Multiple Sclerosis Impact Scale (**MSIS-29**) and the MS Quality of Life-54 item instrument (**MSQoL-54**), each of which are routinely used by 68% of neurologists. No performance scale is used universally across the country; the most frequently administered is the **Timed 25-foot walk**, used by 62% of neurologists in Italy.

# Most neurologists in Italy (72%) report that a more comprehensive approach is needed to measure MS-associated disability

## Neurologists in Italy want better and simpler tools.

Our survey found that many barriers exist to assessing disability in people with MS:

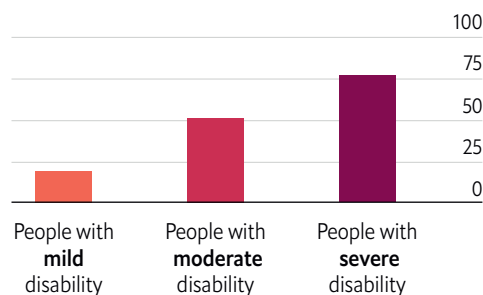
-  **54%** report concerns about existing measures' **ability to detect disability progression**
-  **54%** report a **misalignment between assessments and what matters most to patients**
-  **52%** report **insufficient time** during appointments to administer standardised measures of disability

When asked what would most improve assessment of disability in people with MS, respondents identified the following actions as the most promising:

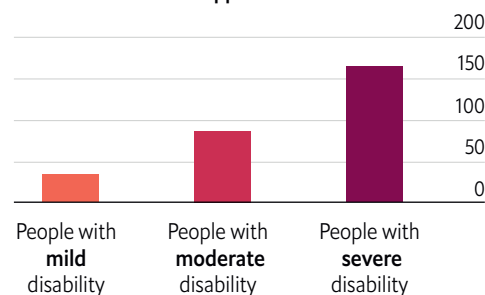
- 1** **Augmenting the EDSS** to include supplementary assessments related to cognitive function and upper limb function
- 2** Improving options for **remote assessment of disability**
- 3** Developing **better patient self-monitoring tools** for assessment of disability

### Over three-quarters of people with MS with severe disabilities are unable to work. Those who do work, take an average of 165 days of leave per year.

% of people with MS who are currently unemployed due to MS



Number of days per year that people with MS take as leave of absence from work due to MS-associated sick leave or medical appointments



Mild disability: EDSS 0-3.5; moderate disability: EDSS 4-6.5; severe disability: EDSS 7-9.5



**“Motor and cognitive fatigue severely impede patients’ ability to work, making it challenging for them to perform effectively in any professional field, regardless of the job’s physical or intellectual demands.”**

**Prof Gianvito Martino,**  
Director of the Division of Neuroscience,  
San Raffaele Hospital



## As MS advances, the financial burden faced by patients and their caregivers increase substantially

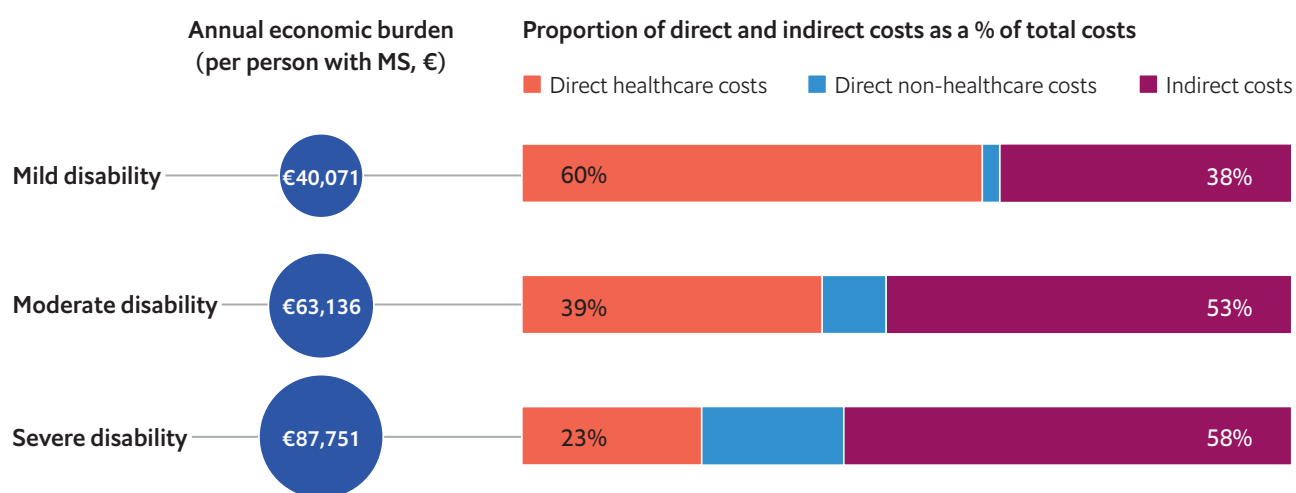
Our economic model found that as MS advances, costs incurred by people with MS, particularly direct non-healthcare and indirect costs, dramatically go up.

Direct healthcare costs include medicines, consultations and inpatient care, while direct non-healthcare costs include home and vehicle adaptations, transportation costs, and out-of-pocket expenses for paid assistance.

As disability increases, the largest cost to people with MS comes from indirect costs, such as absenteeism, loss of employment and early retirement, as well as the costs of informal caregiving. For people with severe disability, the total cost per year is over **€87,751**, more than double the annual cost of someone with mild disability.



### Our model estimates the annual economic burden of MS in Italy to be over €3.8 billion.



## Where to go from here?



**Augment the policy response to MS:** developing a focused national policy to address neurological conditions, such as MS, or explicitly including MS in the Italian National Chronicity Plan (NCP), will enhance disease management by improving multidisciplinary care coordination and expanding access to effective therapies. Government initiatives to facilitate the participation of additional MS centres in the Italian MS registry will enable more comprehensive data collection, thereby enabling more effective policy development.



**Improve linkages between specialised centres, regional centres and community centres to facilitate integrated care:** Italy is moving towards decentralising MS care to make it more accessible and holistic. However, there remain challenges in establishing strong collaborations between different levels of the healthcare system to enable smooth transitions and continuity of care.<sup>11</sup> Further expansion of current projects, like the Stay Home project, that aim to improve care coordination will be beneficial in establishing high-quality, integrated care to people living with MS.<sup>12</sup>



**Modernise disability assessment:** neurologists in Italy reported that disability assessment tools need to be simplified, and that a more comprehensive approach is needed to measure disability. More holistic approaches and assessments of disability would support better policymaking and optimise resource allocation within the health system.



**Leverage digital and remote monitoring tools:** neurologists in Italy emphasise the need to develop the capability for remote monitoring of disability status. Technology should be leveraged to improve MS-related disability self-assessments and remote monitoring, which can help track disease progression, facilitate comprehensive evaluations, and expand ongoing monitoring of symptom changes outside traditional clinical visits.

**MS places a substantial health, economic and social burden on individuals in the prime of their life, with costs and disabilities escalating dramatically as disease severity increases.** The progression of MS amplifies the challenges of daily living, as well as the indirect costs from informal caregiving and lost productivity in prime working years, underscoring the critical importance of comprehensive, patient-centred care. Early intervention and improved multidisciplinary approaches could help slow disease progression, lower disability, and ultimately enhance outcomes for people living with MS. Investing in holistic care, symptom tracking, and modernised assessment tools is essential to reduce the overall impact of MS and support patient well-being.



A description of the methodology and sources for all insights in this infographic can be found in the white paper available via <https://impact.economist.com/health/measuring-what-matters>.

#### References:

1. Italian Multiple Sclerosis Register. MS Barometer 2025: 144,000 people with MS at risk of exclusion. [Internet]. Available from: <https://www.aism.it/barometro-sm-2025-144000-persone-con-sm-rischio-di-esclusione>.
2. Khan G, Hashim MJ. Epidemiology of Multiple Sclerosis: Global, Regional, National and Sub-National-Level Estimates and Future Projections. *Journal of Epidemiology and Global Health*. 2025;15(1):21.
3. Grange E, Di Giovanni R, Martinis L, et al. Identifying key determinants of work-related difficulties in multiple sclerosis: integrating clinical measures and socio-occupational factors. *Neurol Sci*. 2025;46(6):2747-57.
4. Ramagopalan SV, Dobson R, Meier UC, et al. Multiple sclerosis: risk factors, prodromes, and potential causal pathways. *Lancet Neurol*. 2010;9(7):727-39.
5. MS Barometer 2020. Assessing the gaps in care for people with multiple sclerosis across Europe. European Multiple Sclerosis Platform. [Internet]. Available from: <https://www.healthpolicypartnership.com/app/uploads/MS-Barometer-2020.pdf>.
6. Health Policy Partnership. Rethinking MS in Italy. A policy brief. [Internet]. Available at: <https://www.healthpolicypartnership.com/app/uploads/Rethinking-MS-in-Italy.pdf>.
7. The Italian Multiple Sclerosis Society (AISM). The guidelines for the diagnosis and treatment of MS in adults have been published on the ISS portal. [Internet]. Available at: [https://www.aism.it/istituto\\_superiore\\_sanita\\_linee\\_guida\\_diagnosi\\_e\\_terapia\\_sclerosi\\_multipla\\_adulto](https://www.aism.it/istituto_superiore_sanita_linee_guida_diagnosi_e_terapia_sclerosi_multipla_adulto).
8. Italian Multiple Sclerosis Registry. Italian Multiple Sclerosis Registry: Real-world data for increasingly precise medicine. [Internet]. Available at: <https://www.aism.it/registro-italiano-sclerosi-multipla-i-dati-real-world-una-medicina-sempre-piu-di-precisione#>.
9. Trojano M, Bergamaschi R, Amato MP, et al. The Italian multiple sclerosis register. *Neurol Sci*. 2019;40(1):155-65.
10. Battaglia M, Kobelt G, Ponzio M, et al. New insights into the burden and costs of multiple sclerosis in Europe: Results for Italy. *Mult Scler*. 2017;23(2\_suppl):104-16.
11. Manacorda T, Ponzio M, Terzuoli F, et al. Transforming multiple sclerosis care in Italy through Integrated Care Pathways and local networks of service providers. A survey on clinical centres. *Population Medicine*. 2023;5(Supplement).
12. Filippi M, Gallo P, Gasperini C, et al. Implementing proximity care for people with multiple sclerosis in Italy: the bottom-up approach of the StayHome project. *J Neurol*. 2025;272(1):96.

While every effort has been taken to verify the accuracy of this information, Economist Impact cannot accept any responsibility or liability for reliance by any person on this report or any of the information, opinions or conclusions set out in this report. The findings and views expressed in the report do not necessarily reflect the views of the sponsor.