

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

Multiple sclerosis (MS) is a chronic neurological condition affecting adults that can result in decreased longevity (especially with later diagnosis) and an increase in physical, cognitive and sensory disabilities, leading to a significant health and economic burden on both individuals and health systems.

280,000 people in Germany are living with MS, which is about 1 in 300 people. MS typically affects working-age adults, creating a significant impact on employment and quality of life – the average age at which someone receives an MS diagnosis in Germany is 33.<sup>1</sup>

The number of MS cases is on the rise. The number of cases in Germany is projected to increase 75-85% by 2040 compared to 2015 levels.<sup>2,3</sup>

The most common symptoms at the onset of MS are **sensory, visual and motor disturbances**<sup>4</sup>, and the most common symptoms reported by people living with MS are **pain, fatigue, reduced mobility and cognitive dysfunction**.<sup>5</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**

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

This project was commissioned, funded and reviewed by Sanofi. Economist Impact performed the research independently and retained full editorial control.

## Critical gaps in national MS policies hinder comprehensive disease management



National policies, guidelines and registries are crucial for managing chronic and neurological diseases like MS due to their wide-ranging impact on patient care, research and public health. However, these are lacking in many European countries; Germany has yet to develop national policies for neurological disease management and for chronic disease management.<sup>6</sup>

	National policy for neurological disease management	National policy for chronic disease management	National registry for MS	Treatment guidelines for MS
Germany	✗	✗	✓	✓
France	✓	✗	✓	✓
Italy	✗	✓	✓	✓
Spain	✓	✗	✗	✓
Sweden	✓	✗	✓	✓
United Kingdom	✗	✗	✓	✓
United States	✗	✗	✗	✓

Source for table data: MS Barometer 2020

**“It is absolutely necessary to have an MS registry...The registry in Germany gives us an overview of DMT use, symptom change and improvement. We are also in discussions about adding patient-reported outcome measures (PROMs) for fatigue and depression.”**

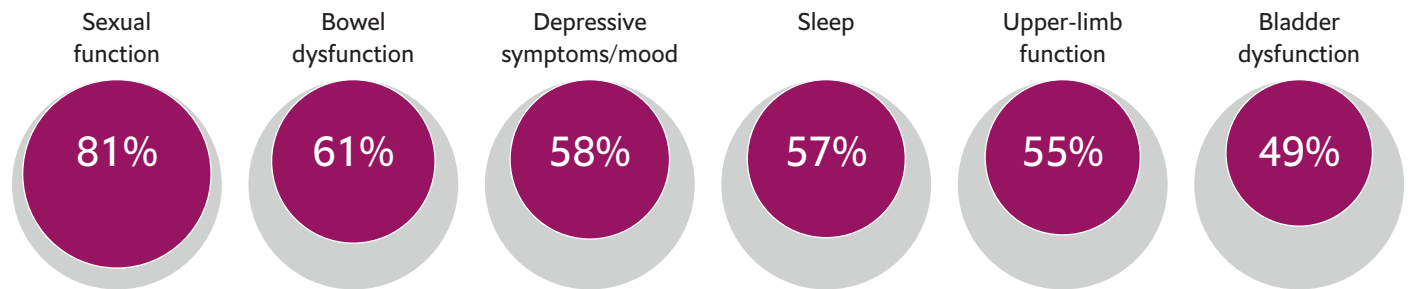
Herbert Temmes, Managing Director, German Multiple Sclerosis Society Federal Association

**Approximately 80% of people with MS experience fatigue, though our survey found that fewer than 60% of neurologists in Germany routinely assess it**

There is considerable variation in the symptoms experienced by people with MS, as well as in how frequently these symptoms are assessed across the country. Some symptoms, such as bowel dysfunction, can profoundly affect quality of life yet often remain unrecognised. Consequently, patients risk going untreated, allowing symptoms to worsen and further impact their wellbeing over time.

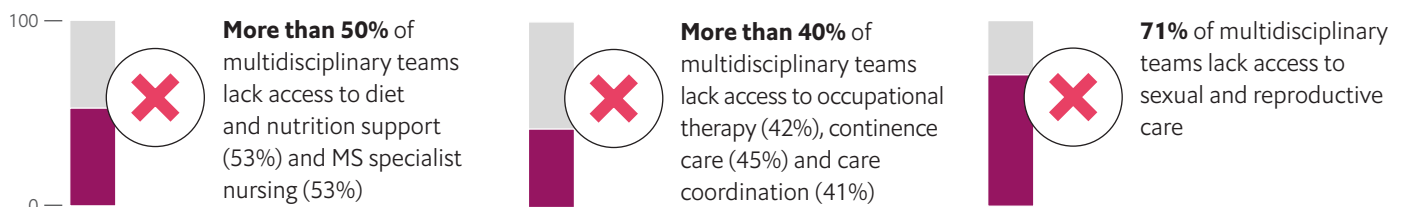


**Percentage of neurologists that do not routinely assess the following symptoms of MS:**



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

Our survey found that:



**“It changes life, not only of the patients, but also of the relatives... What stays the same? Nothing. Everything is different from work to private life, everything physical, cognitive, spiritual, social, it can go through all the aspects of life. Quality of life sometimes is worse for relatives than for patients. So, everything changes.”**

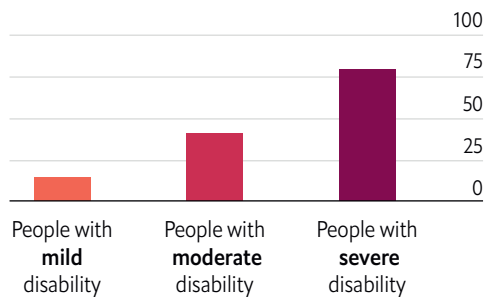
Raymond Voltz, Director of the Centre for Palliative Medicine, University Hospital Cologne

## Multiple tools are used to assess disability in MS across Germany, but not consistently. This inconsistency leads to wide variation in how disability is recorded

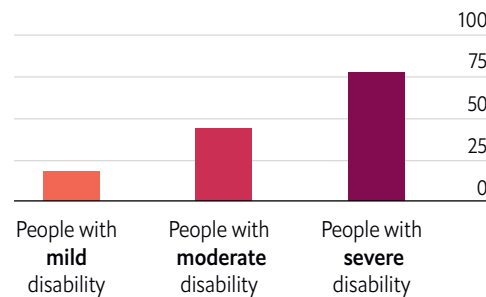
The Expanded Disability Status Scale (EDSS), the most widely used global tool for measuring MS disability, is applied routinely by just 36% of neurologists, while its patient-reported version is used slightly more often (42%). The Multiple Sclerosis Clinical Outcome Assessment (MSCOA) is the most frequently used overall tool, employed by 45% of neurologists. No performance scale is used universally across the country; the most frequent is the **Timed 25-foot walk**, used by 79% of neurologists in Germany.

### Almost 80% of people with MS with severe disability are unable to work and require support from an informal caregiver.

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



% of people with MS who require support from an informal caregiver



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






**“A lot of the symptoms like fatigue, cognitive fog and stress are invisible and unseen so those are very difficult to measure, and so they're often unsupported. And then there's a lack of consensus even on how to measure disability – that's quite challenging.”**

Lydia Makaroff, Chief Executive, Multiple Sclerosis International Federation

## Most neurologists in Germany report that a more comprehensive approach is needed to measure MS-associated disability

### Neurologists in Germany want better and simpler tools.

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

-  **56%** report **insufficient time during appointments** to administer standardised measures of disability
-  **54%** report **difficulty integrating measures into workflows or electronic health records**
-  **54%** report concerns about existing measures' **ability to detect disability progression**

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

- 1** **Simplifying disability assessment tools** so that they can be completed easily by a clinician in a short period of time
- 2** **Developing better patient self-monitoring and reporting options** for disability
- 3** **Improving options for remote assessment** of disability (eg, telemedicine)

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

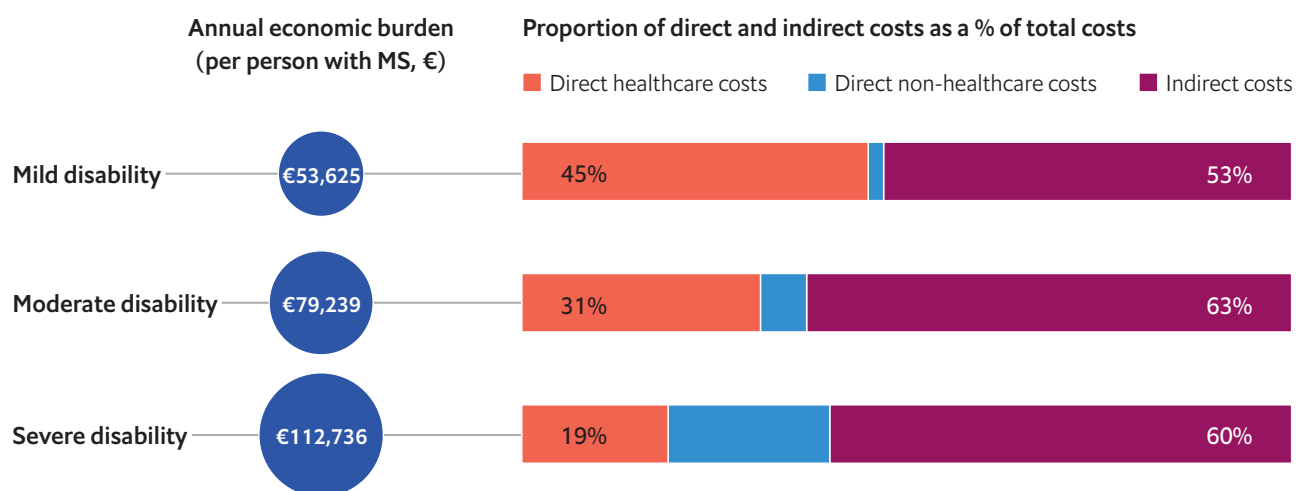
Our economic model found that as MS advances, costs incurred by people with MS dramatically go up, most notably the direct non-healthcare costs.

Direct healthcare costs include medicines, consultations and inpatient admission expenses, 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 in 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 **€112,000**, more than double the annual cost of someone with mild disability.



### Our model estimates the annual economic burden of MS in Germany to be over €7 billion.



## Where to from here?



**Make 'invisible symptoms' more visible:** symptoms such as fatigue, bowel- and bladder dysfunction, and depression are common in MS but are often missed in Germany. Neurologists should ask about these symptoms and their impacts more routinely to ensure that patients receive timely support or treatment adjustments.



**Modernise disability assessment:** neurologists in Germany 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.



**Expand and standardise multidisciplinary coverage:** Germany's MS centres offer strong support in physiotherapy and cognitive rehabilitation, but access to other key services—such as occupational therapy—is limited, and nurse-led care remains underdeveloped. Expanding and standardising multidisciplinary services, while formalising the role of MS nurses in disability monitoring and care coordination, would help reduce fragmentation, improve holistic disability management, and enhance patients' quality of life.



**Leverage digital and remote monitoring tools:** the greatest barriers to measuring disability are the limited time and resources available to clinicians in Germany. Wider use of digital solutions—such as tele-assessments, wearables and smartphone apps—would enable more consistent and holistic patient follow-up, while reducing travel demands for patients and easing workloads for healthcare professionals. Self-monitoring between clinic visits could also support earlier identification of symptom progression, timely adjustments to therapy, and greater patient empowerment.

**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 diagnosis and intervention, as well as 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 overall impact 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. Atlas of MS. Germany. MS International Federation. [Internet]. Available at: <https://atlasofms.org/fact-sheet/germany>.
2. Holstiege J, Akmatov MK, Klimke K, et al. Trends in administrative prevalence of multiple sclerosis and utilization patterns of disease modifying drugs in Germany. *Mult Scler Relat Disord*. 2022 Mar;59:103534.
3. Baginski K, Voeltz D, Hoyer A. Projected number of people with multiple sclerosis in Germany between 2015 and 2040. *Mult Scler Relat Disord*. 2024 Sep;89:105774.
4. DMSG. Sensory, visual and motor disorders are the most common symptoms at the onset of multiple sclerosis. German Multiple Sclerosis Society. [Internet]. Available at: <https://www.dmsg.de/multiple-sklerose/ms-erforschen/grafiken-des-quartals/monats/berichte-zu-grafiken-des-quartals/monats/sensibilitaets-seh-und-motorische-stoerungen>.
5. MS Barometer. MS in Germany. European Multiple Sclerosis Platform. [Internet]. Available at: <https://www.healthpolicypartnership.com/app/uploads/MS-Barometer-factsheet-Germany.pdf>.
6. MS Barometer 2020. Assessing the gaps in care for people with multiple sclerosis across Europe. European Multiple Sclerosis Platform. [Internet]. Available at: <https://www.healthpolicypartnership.com/app/uploads/MS-Barometer-2020.pdf>.

---

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.