ECONOMIST IMPACT

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

**Multiple sclerosis (MS)** is a chronic neurological condition that causes progressive physical, cognitive and sensory disability, often resulting in decreased longevity (especially with later diagnosis) for individuals and considerable health and economic burden for countries. More than **22,000 people in Sweden are living with MS**, equivalent to about one in every 500 individuals.[1] The disease primarily affects adults of working age, with the average age of diagnosis being 30, creating significant challenges for employment, independence, and quality of life.[2]

As the **leading cause of progressive neurological disability in working-age adults**, MS imposes wide-ranging health and financial pressures. Disease progression is directly associated with rising costs, including the costs of greater reliance on informal care, as well as productivity losses from reduced employment and premature exit from the workforce.

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

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To better understand views and experiences with measuring and managing disability in real-world clinical environments, we conducted a survey with 100 neurologists in Sweden (26% of study sample are general neurologists, 58% are neurologists specialising in MS, and 16% are neurologists specialising in an area other than MS).* 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 Sweden.

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

National policies, guidelines, and registries play a vital role in managing chronic and neurological diseases like MS because they significantly influence patient care, research, and public health. However, these are lacking in many European countries. Sweden stands out for its national MS registry and its policy for neurological disease management, placing it ahead of many peers. Nevertheless, Sweden has yet to implement a dedicated national policy for chronic disease management.[3]

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

Source for table data: MS Barometer 2020

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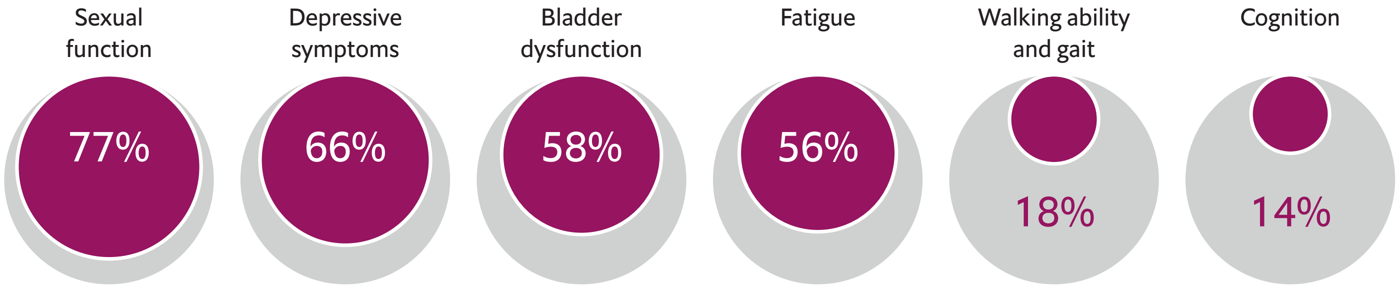
* The survey response rate among Swedish neurologists was approximately 26%. A total of 385 invitations were distributed, resulting in 100 completed surveys. Of the remaining participants, 170 did not respond, provided no answer, or were screened out, and 115 actively declined to participate.

> "Occupational therapists try to teach people how to do the problem-solving themselves, to see their everyday tasks and activities in a new light, to be able to do the problem-solving also when we're not there…I think if we meet people quite early, then we're able to talk about problem-solving and thinking about their life in a different manner."
>
> **Eva Månsson Lexell,** Registered Occupational Therapist, Associate Professor and Senior Lecturer, Department of Health Sciences, Lund University

## Approximately 80% of people with MS experience fatigue, but our survey found that less than 50% of neurologists in Sweden routinely assess it

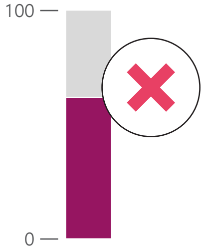
MS is a condition characterised by a broad range of symptoms, which vary widely from person to person. Our survey found that neurologists most often assess symptoms affecting mobility and cognitive health, such as walking ability, balance, and cognition. Meanwhile, bladder dysfunction, fatigue, endurance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

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

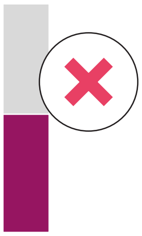


### Significant gaps exist in multidisciplinary support for people with MS

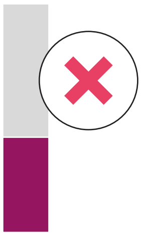
Our survey found that:



**More than 60%** of multidisciplinary teams lack access to MS specialised nursing, sexual and reproductive care, and support with diet and nutrition



**More than 50%** of multidisciplinary teams lack access to continence care



**More than 40%** of multidisciplinary teams lack access to mental healthcare and occupational therapy

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

Our survey found that even the most common clinician-led assessment, the Expanded Disability Status Scale (**EDSS**), is used by only 69% of clinicians, and nine other assessments are in use (by 11-46% of clinicians) in the country. Many clinician-led assessments are also time-consuming to administer, making them impractical for regular clinical practice.

For patient-reported outcome measures (PROMs), the most widely used in Sweden is the Multiple Sclerosis Impact Scale (**MSIS-29**), used by 71% of neurologists, though six other PROMs are also regularly used. The most frequently used performance scale is the **Timed 25-foot walk**, used by 73% of neurologists in Sweden.

# Most neurologists in Sweden (73%) report that a more comprehensive approach is needed to measure MS-associated disability

## Neurologists in Sweden want better and simpler tools.

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

- **54%** report a **lack of staff/resources** to support comprehensive assessments
- **51%** report **difficulty integrating measures into workflows** or electronic health records
- **49%** report **insufficient time during appointments** to administer standardised measures of disability

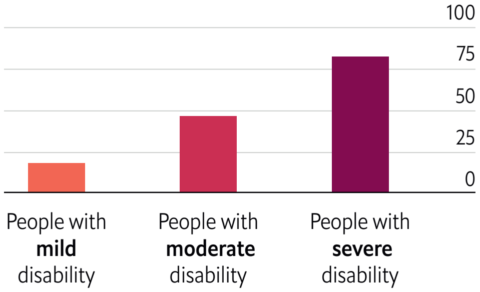
When asked what would most improve assessment of disability in people with MS, respondents identified the following actions as the most promising:

1. **Simplifying disability assessment tools** so that they can be completed easily by a clinician in a short period of time
2. **Developing automated templates** to input data that estimate disability scores, which can then be linked to electronic health records
3. **Improving options for remote assessment** of disability (eg, telemedicine)

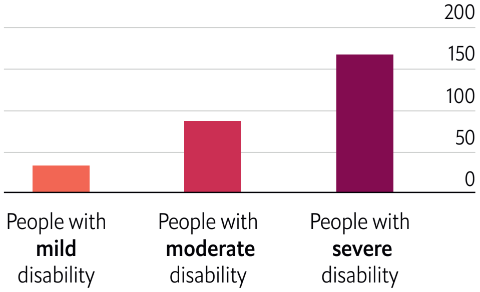
> "The EDSS is the sort of traditional 'gold standard'. But everyone knows it's less than perfect. Everyone knows that there is inter-rater variability and intra-rater variability. Everyone knows that it's maybe not optimally patient valid because it's based on examination, more or less, with addition of some questions we ask patients."
>
> **Jan Hillert,** Senior Professor in Neurology, The Karolinska Institute

### Over 80% 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

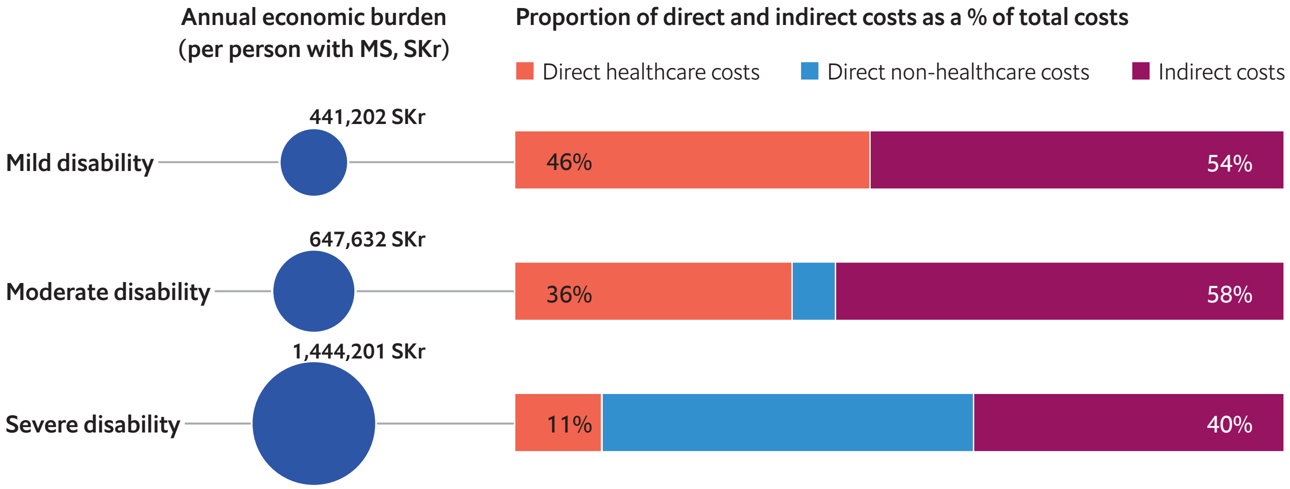
# As MS progresses, the financial burden faced by patients and their caregivers increases substantially

Our economic model found that as MS advances, costs incurred by people with MS, most notably 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 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 **1,444,201SKr**, more than three times the annual cost of someone with mild disability.

**Our model estimates the annual economic burden of MS in Sweden to be over 14.5SKr billion.**



## Where to go from here?

**Make "invisible symptoms" more visible**: symptoms such as fatigue, bladder dysfunction, and depression are common in MS, but are often not assessed by neurologists in Sweden. A more comprehensive assessment of all symptoms affecting quality of life should be routinely performed by neurologists, who should ask about these symptoms and their impacts more regularly to ensure that patients receive timely support or treatment adjustments.

**Expand multidisciplinary coverage**: Sweden'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. By broadening the availability of multidisciplinary services and formalising the role of MS nurses in disability monitoring and care coordination, Sweden can reduce fragmentation in care, promote more holistic disability management, and enhance patients' quality of life. These improvements would be further supported by sustained investment in chronic disease management frameworks and a cohesive national policy for the same.

**Modernise disability assessment**: neurologists in Sweden 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 not only improve care for individual patients, but also support better policymaking and optimise resource allocation within the health system.

**Leverage digital and remote monitoring tools**: barriers to measuring disability in Sweden include lack of staff and limited time and resources available to clinicians. 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 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. Swedish Neuro Registries: Multiple Sclerosis. Annual report 2022 aimed at patients. [Internet]. Available at: https://www.neuroreg.se/media/dw0jhqjk/sammanfattande-årsrapport-2022-riktad-till-patienter.pdf.

2. Swedish Neuro Registries. Multiple Sclerosis Annual Report for 2024. [Internet]. Available at: https://www.neuroreg.se/media/bryfepkb/ms-%C3%A5rsrapport-2024-justerad-2025-08-11.pdf.

3. 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.