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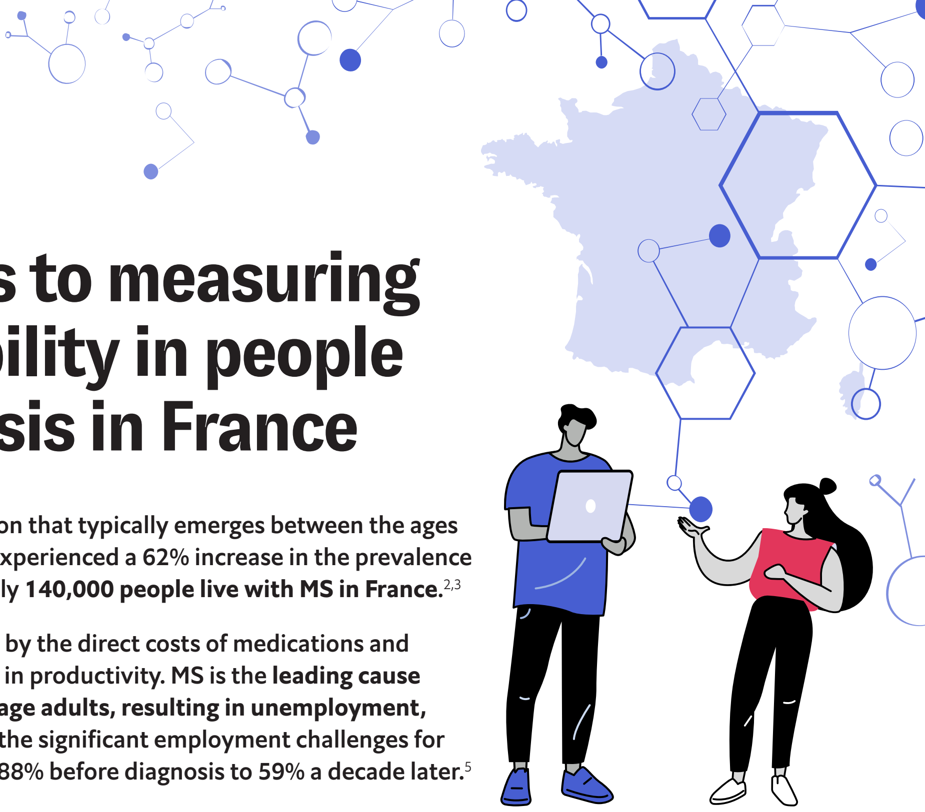


Evolving approaches to measuring and managing disability in people with multiple sclerosis in France

Multiple sclerosis (MS) is a chronic neurological condition that typically emerges between the ages of 20 and 40.[1] Over the past three decades, France has experienced a 62% increase in the prevalence of MS—the most recent estimate indicates approximately **140,000 people live with MS in France.**[2,3]

The economic burden of MS is significant, driven largely by the direct costs of medications and inpatient care, as well as the indirect costs due to losses in productivity. MS is the **leading cause of progressive neurological disability among working-age adults, resulting in unemployment, presenteeism and absenteeism.**[4] French data highlight the significant employment challenges for people with MS, with employment rates dropping from 88% before diagnosis to 59% a decade later.[5]

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

Ambitious national policies, programmes and a government-funded MS registry enhance care for MS in France

National policies, guidelines and registries play a crucial role in managing chronic and neurological diseases, such as MS, as they significantly impact patient care, research priorities and public health. France has a neurological disease management policy and recently published a National Strategy for Neurodegenerative Diseases 2025-2030. This national strategy was developed through an in-depth consultative process involving the Ministries of Solidarity, Health, Disability, Higher Education and Research in partnership with associations representing people living with neurodegenerative diseases, their caregivers, and healthcare professionals.[6,7] The National Strategy's success will depend on adequate resources and sustainable funding to implement the 37 measures identified within. The government also invested approximately €10million over 10 years in the electronic French MS registry and biobank (Observatoire Français de la Sclérose en Plaques-OFSEP), which connects to the French National Health Insurance database.[8] In the 2020 European MS Barometer survey, France ranked second in terms of national scores on MS policy, demonstrating the country's strength in the area.[9]

✗ ✓	National policy for neurological disease management	National policy for chronic disease management	National registry for MS	Treatment guidelines for MS
France	✓	✗	✓	✓
Germany	✗	✗	✓	✓
Italy	✗	✓	✓	✓
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 France. 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 France.

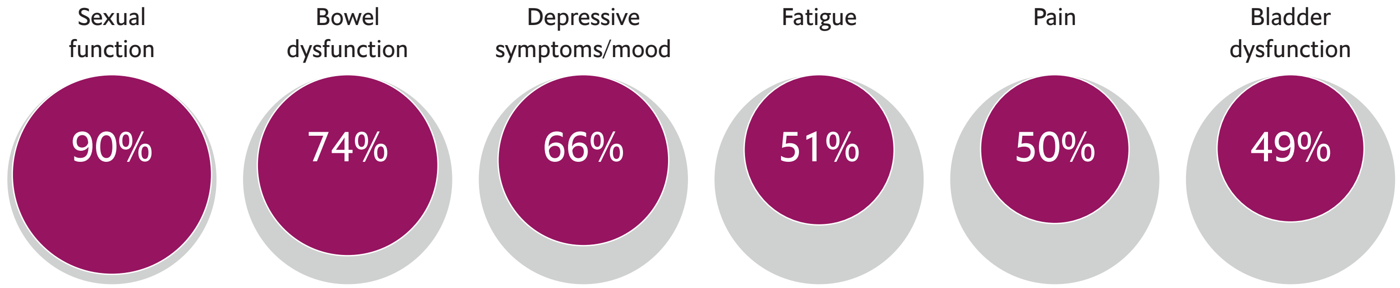
This project was commissioned, funded and reviewed by Sanofi. Economist Impact performed the research independently and retained full editorial control.

> **“Fatigue, urinary problems, sexual problems and pain are key under-recognised symptoms. Many neurologists do not ask about these “invisible symptoms”, which can significantly impact daily life, because they are unfamiliar with them or lack readily available solutions. Referral to appropriate specialists within a multidisciplinary team is key to holistic MS care.”**
>
> **Jérôme De Sèze,** Professor of Neurology and Neuroimmunology Department Head at the University Hospital of Strasbourg

Over 95% of people with MS in France experience fatigue, but our survey found that less than 50% of neurologists routinely assess this symptom

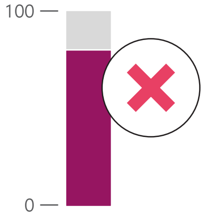
MS leads to a wide range of disabilities, causing diverse symptoms that vary between patients. Our survey found that neurologists in France are more likely to assess symptoms such as cognitive function and walking ability, but less likely to assess symptoms such as bowel function and trouble sleeping, which profoundly affect quality of life yet often go unrecognised. Consequently, patients risk going untreated, allowing symptoms to worsen, which impacts their well-being 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:



More than 80% of multidisciplinary teams lack access to sexual and reproductive care

More than 60% of multidisciplinary teams lack access to speech and language therapy, continence care/urology and MS specialist nursing

More than 30% of multidisciplinary teams lack access to mental healthcare and occupational therapy

Limitations in disability assessment scales also contribute to gaps in holistic assessment and management of MS

No assessment or scale is used universally across France; the most widely used is the **Timed 25-foot walk**, performed by 83% of neurologists in the country. The next most frequently used assessment tool are patient-reported outcome measures (PROMs), with the MS Impact Scale-29 (**MSIS-29**) used by 67% of neurologists and the Expanded Disability Status Scale (**EDSS**) used by one in two neurologists in France.

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

Neurologists in France want better and simpler tools.

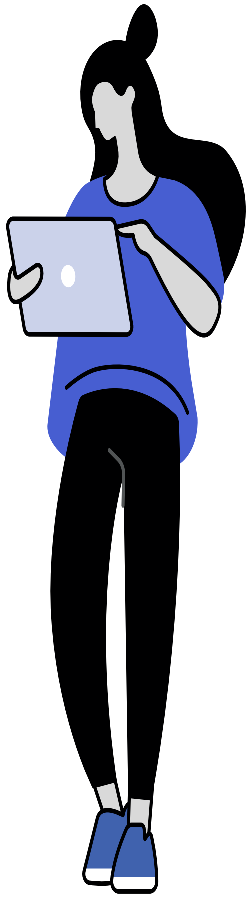
Our survey found that many barriers exist to assessing disability in people with MS:

- **56%** report that **patient fatigue or cognitive limitations impact assessment accuracy**
- **54%** highlight a **lack of staff and resources** to support comprehensive assessments
- **53%** note 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:

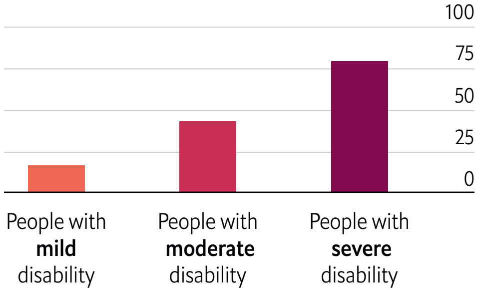
1. **Simplifying disability assessment tools** so that they can be completed in a short period of time
2. Improving options for **remote assessment of disability (eg, telemedicine)**
3. Developing **technology-based solutions** to extract information from electronic health records to calculate standardised disability scores

> **"The best tool we can use is our ears to listen to a person with MS. It is critical to discuss and understand how the condition truly impacts their daily life."**
>
> **Jérôme De Sèze,** Professor of Neurology and Neuroimmunology Department Head at the University Hospital of Strasbourg

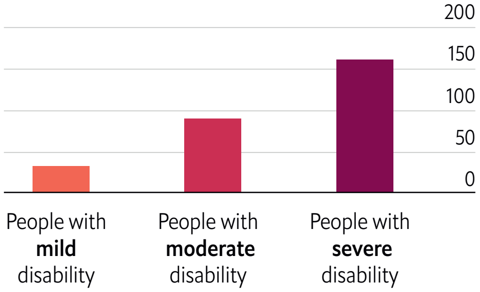


Almost 80% of people with MS with severe disabilities are unable to work.

% 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



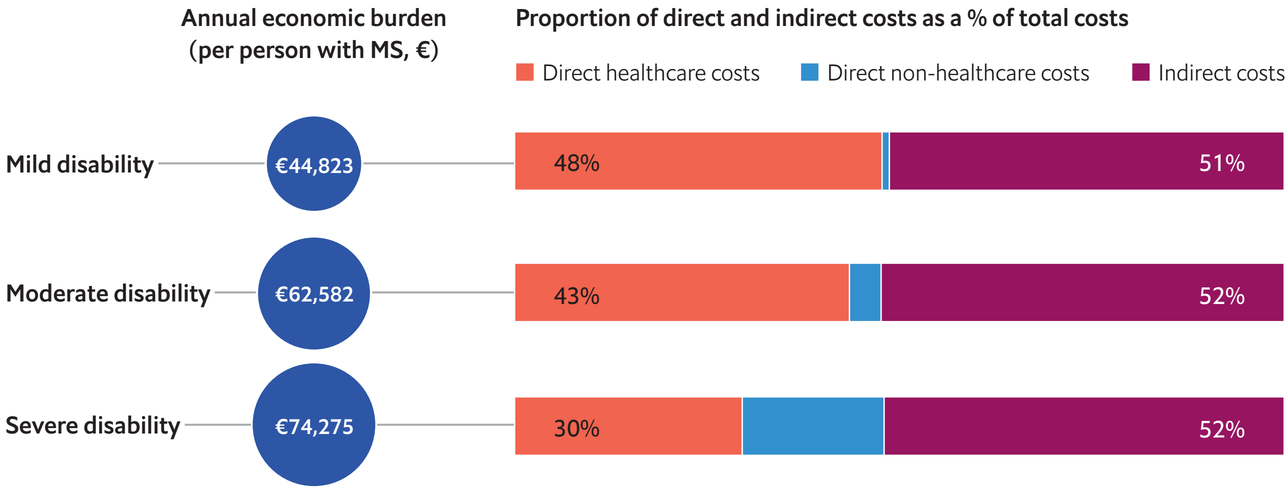
Mild disability: EDSS 0-3.5; moderate disability: EDSS 4-6.5; severe disability: EDSS 7-9.5

The economic burden on patients, health systems, carers and society increases as disability worsens

Our economic model found that as MS advances, costs incurred by people with MS, particularly direct non-healthcare 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 **€74,275**, almost double the annual cost of someone with mild disability.

Our model estimates the annual economic burden of MS in France to be over €4.2 billion.



Where to go from here?

Address gaps in multidisciplinary care: access to many key services is uneven, despite the proven effectiveness of multidisciplinary care in managing MS symptoms. To better manage disability and simplify care coordination for patients, team-based care should be expanded, with services such as mental health and continence care co-located or virtually integrated into MS clinics to reduce fragmentation of care. Additionally, the psychological burden experienced by caregivers should be systematically addressed through integrated support services and mental health interventions, as caregiver well-being has a direct impact on both patient outcomes and the overall effectiveness of the care team.

Modernise disability assessment: neurologists in France 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 also support better policymaking and optimise resource allocation within the health system.

Leverage digital and remote monitoring tools: neurologists in France 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.

Support people with MS in employment: a significant proportion of patients with MS in France—including those with mild and moderate disability—are either unemployed or employed part-time. Although the country has implemented measures to enhance employment opportunities for people with disabilities, including free access to occupational medicine physicians and support for job adaptation based on individual capabilities, these programmes require greater visibility to boost uptake and sustain employment.[10] Additionally, increasing access to flexible work arrangements for caregivers will significantly reduce the financial burden on families and society.

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.

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