ECONOMIST
IMPACT

Evolving approaches to measuring and managing disability in people with multiple sclerosis in the United Kingdom

Supported by sanofi

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. In the United Kingdom, more than **150,000 people live with MS**, equivalent to around one in every 500 individuals.[1] The disease most often affects adults of working age, with the **average age of diagnosis at just 33 years**, intensifying its impact on employment, independence and quality of life.[2]

As the world's **leading cause of progressive neurological disability among working-age adults**, MS imposes profound social and financial consequences. A study among people with MS in the United Kingdom revealed that although 72% of people with MS were below retirement age, only 36% were in employment.[3] Among those working, 84% reported that MS negatively affected their workplace productivity, underscoring the hidden costs borne by individuals and society.[3]

MS is a costly chronic disease, with the financial burden driven by high expenditures on medications and inpatient care and compounded by substantial indirect losses from reduced productivity and workforce withdrawal. Yet, despite its rising prevalence and profound effects on daily life, **critical gaps persist in how disability related to MS is recognised and managed.**

> 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 the United Kingdom. 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 the United Kingdom.

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 priorities, and public health. However, these are lacking in many European countries, and the United Kingdom has yet to develop national policies for both chronic- and neurological disease management.[4]

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

Source for table data: MS Barometer 2020

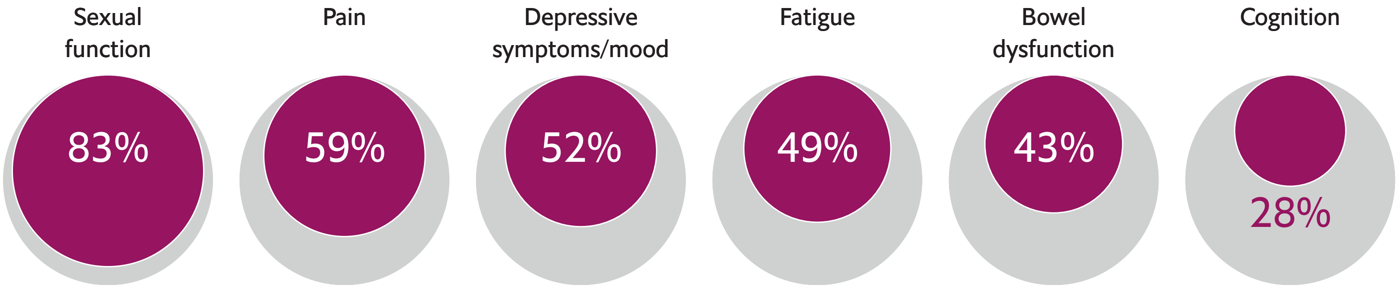
This project was commissioned, funded and reviewed by Sanofi. Economist Impact performed the research independently and retained full editorial control.

> “I think a lot of the time when we’re looking at treatment, we’re measuring how far someone can walk, or measuring how fast someone can put pegs in a hole. It’s not measuring how well did you sleep, how much energy did you have? You know, how are you feeling?”
>
> **Elisabeth Kasilingam,** Chief Executive Officer, European Multiple Sclerosis Platform and Vice-President, European Patients’ Forum

Approximately 80% of people with MS experience fatigue, but our survey found that only 50% of neurologists in the United Kingdom routinely assess it

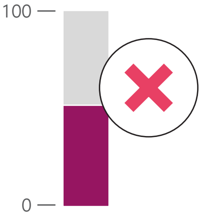
MS is a condition that is characterised by a broad range of symptoms, which vary widely from person to person. Our survey found that neurologists most often assess symptoms affecting mobility and cognitive health, such as walking ability, balance and cognition. Meanwhile, fatigue, pain, sexual function and depressive symptoms 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:**



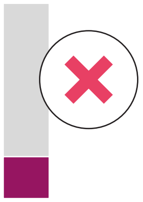
Significant gaps exist in multidisciplinary support for people with MS

Our survey found that:



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

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



More than 20% of multidisciplinary teams lack access to cognitive rehabilitation and physiotherapy

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 fewer than 70% of clinicians, and nine other assessments are in use in the country, applied by 10-50% of clinicians. Many clinician-led assessments are time-consuming to administer, making them impractical for regular clinical practice.

For patient-reported outcome measures (PROMs), the most widely used in the United Kingdom is the Multiple Sclerosis Impact Scale (**MSIS-29**), employed by 78% of neurologists, though six other PROMs are also regularly used.

Most neurologists in the United Kingdom (68%) report that a more comprehensive approach is needed to measure MS-associated disability

Neurologists in the United Kingdom want better and simpler tools.

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

- **66%** report **insufficient time during appointments** to administer standardised measures of disability
- **52%** report a **lack of staff/resources** to support comprehensive assessments
- **47%** report **difficulty integrating measures into workflow** or electronic health records

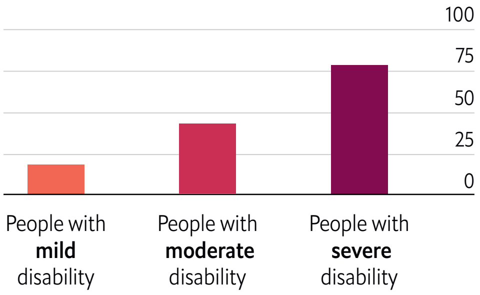
When asked what would most improve assessment of disability in people with MS, respondents identified the following actions as the most promising:

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 medical records
3. **Augmenting the EDSS scale with supplementary assessments** (eg, related to cognitive function and upper limb function) to provide a more holistic assessment

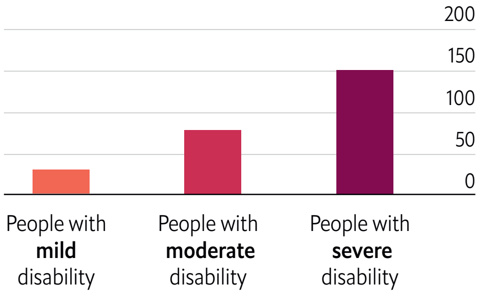
> "The main problem in the UK is the general lack of care provision and needing to align it with a current understanding of the disease and how it is best managed."
>
> **Jeremy Hobart,** Consultant Neurologist, University Hospitals Plymouth National Health Service Trust and Professor, Plymouth University Peninsula Schools of Medicine and Dentistry

Almost 80% of people with MS with severe disabilities are unable to work. Those who do work, take an average of 150 days of leave per year.

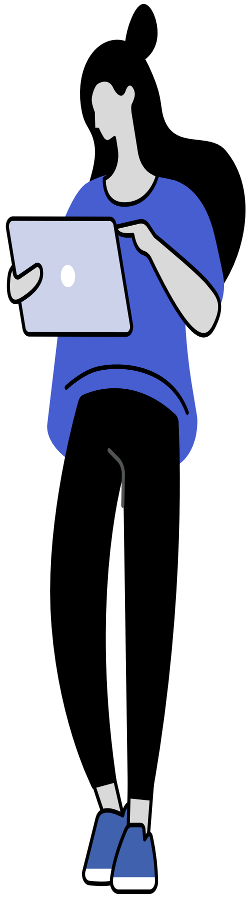
% of people with MS who are currently unemployed due to MS



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



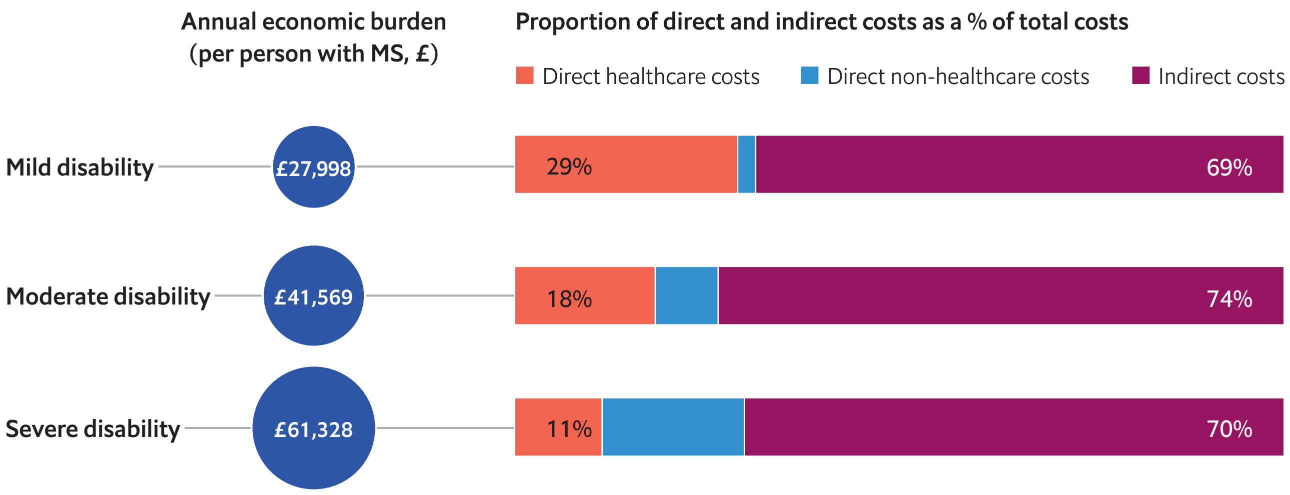
As MS advances, the financial burden faced by patients and their caregivers increases substantially

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

Direct healthcare costs come from 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 **£61,328**, more than double the annual cost of someone with mild disability.

Our model estimates the annual economic burden of MS in the UK to be over £3.9 billion.



Where to go from here?

Make “invisible symptoms” more visible: symptoms such as fatigue, pain and changes in sexual function are common in MS but often not assessed by neurologists in the United Kingdom. Neurologists should ask about these symptoms and their impacts more routinely to ensure that patients receive timely support or treatment adjustments.

Address gaps in multidisciplinary care: MS centres in the United Kingdom offer strong support in physiotherapy and cognitive rehabilitation, but access to other key services—such as continence care and mental health care—is limited, and care coordination remains underdeveloped. To better manage disability and simplify continuity of care for patients, team-based care should be expanded, with missing specialities being more integrated into MS care teams.

Modernise disability assessment: neurologists in the United Kingdom 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 directly benefit disease management in patients with MS, but also support better policymaking and optimise resource allocation within the health system.

Support patients’ ability to work: MS disproportionately affects people of working age, and many patients in the United Kingdom face loss of income, financial insecurity and reduced independence, while society absorbs the cost of lost productivity and increased reliance on social support systems. To mitigate this, there is a need for more inclusive workplace policies, rehabilitation services and flexible employment options to facilitate patients’, and their caregivers’, productivity and independence.

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, comprehensive data registries 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. MS Trust. How common is multiple sclerosis? [Internet]. Available at: https://mstrust.org.uk/information-support/about-ms/how-common-multiple-sclerosis.

2. MS International Federation. Atlas of MS. Factsheet - United Kingdom. [Internet]. Available at: https://atlasofms.org/fact-sheet/united-kingdom.

3. Thompson A, Kobelt G, Berg J, et al. New insights into the burden and costs of multiple sclerosis in Europe: Results for the United Kingdom. Multiple sclerosis (Houndmills, Basingstoke, England). 2017;23(2_suppl):204-16.

4. 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.

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.

©Economist Impact 2025