ECONOMIST IMPACT

EMSP 2026 Annual Conference Poster Submission

Event: April 24-25, Berlin

Theme Alignment:

- Data, registries and data driven evidence
- Cross-cutting themes

Measuring what matters: The critical gap in multiple sclerosis disability impact

Background: Multiple sclerosis (MS) imposes a substantial burden on individuals, health systems and societies. The Expanded Disability Status Scale (EDSS) remains the dominant tool for assessing disability, yet it captures a narrow range of functions and may not align with how people with MS experience symptoms in daily life. As disease-modifying therapies increasingly aim to delay disability progression, there is a need to quantify the economic consequences of disability and to examine whether current assessment practices reflect patient priorities and lived realities.

Methods: We modelled the annual economic burden attributable to disability in people with MS in France, Germany, Italy, Spain, Sweden, the UK and the US. Costs (direct healthcare, direct non-healthcare and indirect costs) were stratified by EDSS-defined disability level (mild, moderate, severe). We surveyed 850 neurologists on routine disability assessment, performance measures and patient-reported outcome measures used, and barriers to more holistic assessment. We interviewed 14 multidisciplinary experts, including HCPs, patient advocacy leaders and people living with MS, to explore experiences in disability measurement and management.

Results: The economic burden of MS is substantial, **with annual per-person costs exceeding per-capita GDP in all study countries**. When stratified by disability in Germany, Italy, Sweden and the UK, costs among people with severe disability are more than twice those with mild disability. Gaps in multidisciplinary support are pronounced: only 19% of MS care teams provide access to sexual and reproductive health services, despite many people with MS being diagnosed during their prime reproductive years.

Conclusion: Disability accumulation in MS is a major driver of individual and societal costs, which rise sharply as the disease progresses. There is an urgent need for all stakeholders in the MS ecosystem to rethink how disability and symptoms are assessed, moving towards person-centred, multidimensional approaches that better capture the lived realities of people with MS.