

When Experience Matters: How Patients Are Shaping the Future of Treatment Progression in Multiple Sclerosis

A new Editorial and a Correspondence in *The Lancet Neurology* argue that the daily lived experience of people with MS must shape research, care, and future therapies.

For many people living with multiple sclerosis (MS), the hardest parts of the disease are not always visible on scans or captured by medical tests. Severe tiredness, pain, problems with memory or concentration, difficulties using the hands, walking, seeing, or coping emotionally can strongly affect everyday life. Yet these symptoms are still not measured consistently in research studies or routine care.

A recent editorial published in *The Lancet Neurology*¹ highlights the need for a change in how MS progression and treatments are evaluated. The message is clear: to understand whether a therapy truly works, researchers and doctors must pay closer attention to the real experiences of people living with MS. Looking only at relapses, MRI scans, or disability scores is no longer enough.

In the same issue², experts involved in the Global PROMS Initiative³ reinforce this idea. They point out that even when treatments appear successful by traditional medical measures, many people with MS still struggle with symptoms that reduce their quality of life or perceive that their disease is progressing. This is where patient-reported outcome measures (PROMs) become essential.

The Global PROMS Initiative brings together people with MS, clinicians, researchers, patient organisations, regulators, and pharmaceutical companies to promote the consistent and worldwide use of these measures. Through a governance group called the Engagement Coordination Team, people living with MS contribute their unique experiences directly to the initiative. This ensures that their perspectives are not only heard but also scientifically relevant, influencing research, clinical trials, and everyday care. PROMs make these experiences visible and measurable, giving researchers, doctors, and regulators insights of how the disease truly impacts daily life and whether treatments are making a real difference.

This shift is also gaining attention from regulatory authorities. Recent work by the European Medicines Agency⁴ shows growing recognition of the importance of patient experience data when evaluating new therapies.

For people living with MS, this is more than a scientific conversation—it's recognition. It signals that their voices, challenges, and priorities are central to shape the future of treatment progression in MS.

And there is hope. Meeting this challenge is possible because this dialogue comes at a pivotal moment in multiple sclerosis diagnosis and treatment^{5,6}. It represents a shift toward therapies that not only slow disease progression but also improve quality of life, giving people with MS the chance to live better, every single day.

References

1. Editorial. **Patient-reported outcomes and multiple sclerosis therapies.** *The Lancet Neurology.* 2025;25(2):115.
2. Zaratin P, et al. **Patient-reported outcomes and multiple sclerosis therapies.** *The Lancet Neurology.* 2025;25(2):128–129. doi:10.1016/S1474-4422(25)00482-X
3. <https://proms-initiative.org/>
4. European Medicines Agency (EMA). **Reflection paper on the use of patient experience data in regulatory decision-making.** Amsterdam: European Medicines Agency; 2023. Available from: https://www.ema.europa.eu/en/documents/scientific-guideline/reflection-paper-use-patient-experience-data-regulatory-decision-making_en.pdf
5. Montalban, X · Lebrun-Frénay, C · Oh, J · et al. **Diagnosis of multiple sclerosis: 2024 revisions of the McDonald criteria** *Lancet Neurol.* 2025; **24**:850-865
6. Kuhlmann, T · Moccia, M · Coetzee, T · et al., the International Advisory Committee on Clinical Trials in Multiple Sclerosis **Multiple sclerosis progression: time for a new mechanism-driven framework** *Lancet Neurol.* 2023; **22**:78-88