

Frequency and impact of symptoms experienced by people with MS – Results from the global PROMS Initiative survey

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Introduction

Patient-reported outcome measures (PROMs) provide an opportunity to capture experiential knowledge from people living with MS (pwMS), making it scientifically relevant in the era of personalised medicine. The Global PROMS Initiative aims to engage pwMS in developing and prioritising PROMs that provide a picture of their health and wellbeing today and changes over time¹.

This study, utilising the power of science with patient input², aims to capture which symptoms occur most frequently, have greatest impact on the lives of pwMS, and how this varies by demographic group, stage of disease and world region.

Method

An online survey, implemented on SurveyMonkey tool, was **co-designed and piloted by pwMS** before being launched in **7 languages** (English, French, Spanish LA, Portuguese BR, German, Italian and Danish). It was disseminated via MS patient organisations and accessible on a dedicated page within the **PROMS official website for three months**. Participants were asked whether in the past 4 weeks they had experienced any of the **28 listed symptoms** and to rate the level of impact those symptoms had on their lives.

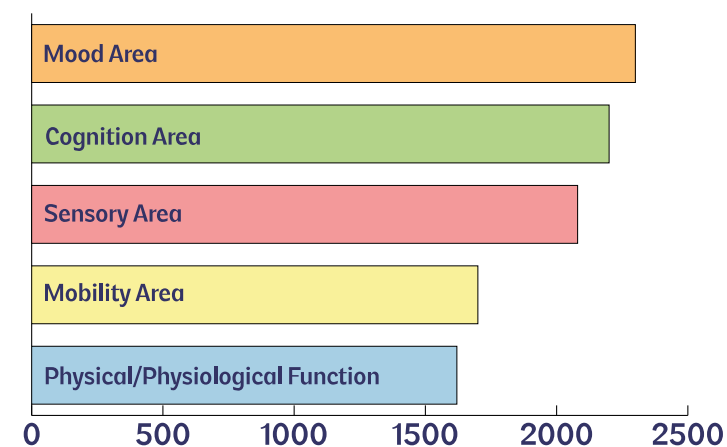
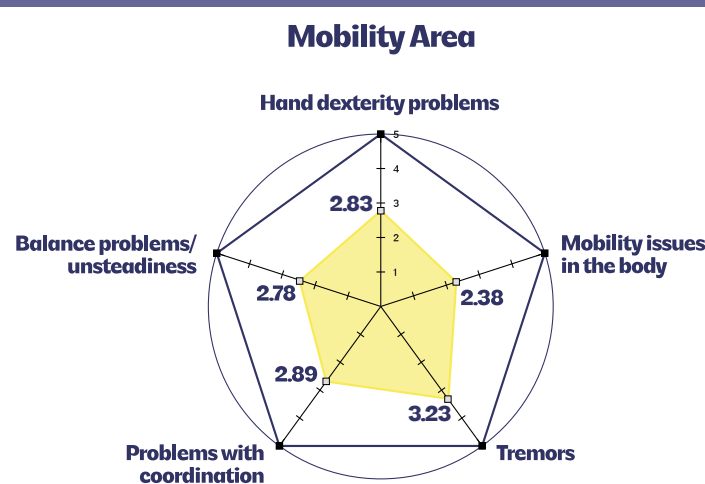
Results

Data was received from **5,218 participants from 69 countries**. Of these, **21% had progressive MS and the average age was 48**.

The top 5 most frequently experienced symptoms were: **fatigue (86%), stress (80%), pain (75%), problems concentrating (75%) and memory problems (74%)**. The survey highlighted the key functional domains for each disease course's symptom prevalence. Mood emerged as the most significant domain in Relapsing-Remitting (RR) cases, while mobility prevails in progressive disease courses. Functional domains' impact in each of the area considered results to be averaged distributed in both ageing and disease course analysis. This confirms that the distribution of the domains within the five areas has been done correctly, as there are no specific symptoms prevailing among the others within each area.

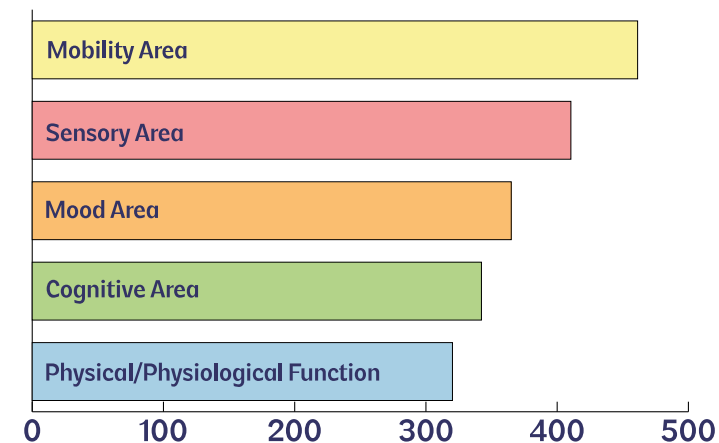
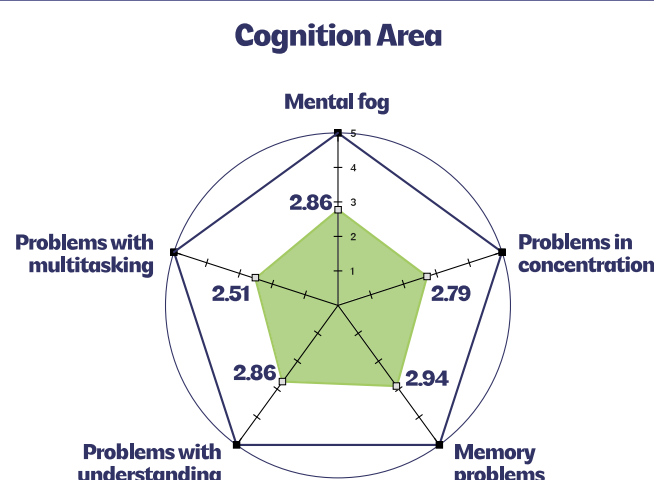
Mean symptoms prevalence for Relapsing-Remitting (RR) group: 3,616 people
(without fatigue: due to its high prevalence unrelated to disease course and age, was excluded from the histograms displaying the prevalence analysis)

Mobility Area impact for RR group



Mean symptoms prevalence for Secondary Progressive (SP) group: 609 people
(without fatigue: due to its high prevalence unrelated to disease course and age, was excluded from the histograms displaying the prevalence analysis)

Cognition Area impact for SP group



Scan the QR code to explore the functional domains co-created with pwMS and the full graphics of symptom impacts for the RR and SP groups



Conclusion

- The preliminary outcomes from the survey underlined that the patient journey is not just about disease progression but also involves navigating through various functional domains that change with the disease and population ageing.
- Identifying distinct clusters of PwMS who share symptom patterns across functional domains and experiential knowledge, along with their interdependencies, will pave the way for a personalized application of PROMs from clinical trials to clinical practice and vice versa.

An initiative jointly led and coordinated by the European Charcot Foundation and the Multiple Sclerosis International Federation (MSIF), with the Italian MS Society acting as the lead agency for and behalf of the Global MSIF Movement. We are grateful to the members of the PROMS Research, Development and Validation working group for their contribution to this work: <https://www.frontiersin.org/journals/neurology/articles/10.3389/fneur.2024.1407257/full>

¹ Zaratini, P., et al. (2022). The agenda of the global patient reported outcomes for multiple sclerosis (PROMS) initiative: Progresses and open questions. *Multiple Sclerosis and Related Disorders*, 61, 103757. <https://doi.org/10.1016/j.msard.2022.103757>

² Zaratini, P., et al. (2022). The MULTI-ACT model: The path forward for participatory and anticipatory governance in health research and care. *Health Research Policy and Systems*, 20(1), 22. <https://doi.org/10.1186/s12961-022-00825-2>