

Bladder health and lived experience in MS take centre stage at EAU Congress 2026

MSIF presents new evidence from the Global PROMS Initiative, showing how patient-reported outcomes can help improve care, research, and shared decision-making in multiple sclerosis.

The Multiple Sclerosis International Federation (MSIF) took part in the European Association of Urology (EAU) Congress 2026, where patient voice and patient-reported outcomes were highlighted as essential tools for improving care in multiple sclerosis.

During EAU Patient Day, MSIF joined the Patient Advocacy Poster Session to share how lived experience can inform better understanding of bladder health in MS and support more responsive, person-centred services. The session underlined a simple but important message: when people living with MS are asked about the symptoms that matter most to them, they identify needs that are often missed in routine clinical practice.

As part of the scientific programme, Lydia Makaroff, Chief Executive of MSIF and EC Co-Chair PROMS Initiative, presented new evidence on “Bladder health and lived experience in multiple sclerosis outcome measurement.” Her presentation drew on data from the Global PROMS Initiative, which collects patient-reported outcomes from people with MS across countries and health systems.

The findings show that bladder problems are among the most frequently reported challenges in MS. More than 5,000 people from 70 countries have contributed to the dataset, and 69% reported bladder-related difficulties. These results reinforce the importance of including outcomes that reflect daily life, not only clinical indicators.

“Lived experience gives us a clearer picture of the real burden of MS,” said Lydia Makaroff. “Bladder symptoms are common, they affect independence and quality of life, and they are still too often under-recognised in care and outcome measurement.”

Bladder dysfunction can affect confidence, sleep, work, social participation, and emotional wellbeing. Many people with MS adapt their routines around access to toilets, limit travel, or avoid leaving home altogether. Yet these symptoms are not always discussed during consultations, and support is often fragmented across neurology, urology, and community care.

This is where patient-reported outcomes become especially important. By capturing what people with MS experience in their everyday lives, PROMS helps identify unmet needs and provides evidence that can be used to improve communication, service design, and shared decision-making.

As one participant described it: “I always need to know where the nearest bathroom is. It limits everything.”

MSIF also contributed to the session “BCLEAR: Shared Decisions, Stronger Care — Addressing Clinician Needs Across Europe,” which brought together clinicians, primary care representatives, and patient advocates. The discussion focused on how clearer communication, accessible information, and time to reflect can strengthen shared decision-making across the care pathway.

Another session, “Living with urinary incontinence as a comorbidity: patient perspectives,” explored how continence issues are experienced by people living with MS and why they remain overlooked in clinical conversations. Speakers highlighted the stigma around urinary symptoms and the need for a more proactive, sensitive approach from healthcare professionals.

The event also marked the launch of the policy report *Coexisting Conditions: Urinary Incontinence as a Non-Communicable Disease Comorbidity*, developed within the Urge to Act initiative led by the European Association of Urology Policy Office. The report calls for a “continence health in all policies” approach, recognising the broad impact of continence health across long-term conditions and survivorship.

For the Global PROMS Initiative, this work shows the value of listening to people with MS and using their input to shape better research and care. By making patient-reported outcomes visible and actionable, PROMS helps ensure that what matters to patients is not only heard, but measured and integrated into practice.