PROMS
A Joint Global Initiative

2026 Plenary Event
November 11th, Baveno (Italy)

Role of Patient Reported Outcomes in treatment development and care: the Global PROMS Initiative recommendations

The primary objective of the **2026 PROMS Plenary Event** is to present and build consensus around the Global PROMS Initiative recommendations for the use of patient-reported outcomes across MS care and treatment development.

8:30-8:40	**Welcome and Introduction**	
	Hans-Peter Hartung	Heinrich-Heine University Düsseldorf
	Lydia Makaroff	MS International Federation
8:40-9:15	Keynote speech Introduced by Paola Zaratin: **Incorporation of the Patient Voice into the Drug Development Process**	Michael Panzara Immunic Therapeutics

SESSION 1:
Towards a patient-reported informed description of multiple sclerosis?

Moderators:	Mario Alberto Battaglia	Italian MS Society
	Rod Middleton	University of Swansea

9:15-9:30	**Patient-Reported Characterization of Functional Domains in Multiple Sclerosis: One PROM Doesn't Fit For All**	Giampaolo Brichetto Italian MS Society Marilena Hadjiyianni PROMS ECT
9:30-9:45	**Large-scale online assessment uncovers a distinct Multiple Sclerosis subtype with selective cognitive impairment**	Annalaura Lerede King's College London
9:45-9:50	**Beyond Conventional PROMs: Hierarchical Clustering for Patient-Centered Symptom Phenotyping and Identification of Proteomic and Immune Signatures**	Sara Samadzadeh Charité Universitätsmedizin Berlin

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SESSION 2:
Meeting Expectations in Clinical Care
SymptoMScreen: the PROMS-recommended multi-symptom tool to support holistic assessment of individual patient experience in routine clinical care
Moderators: Maria Trojano — Università degli Studi di Bari
Hans-Peter Hartung — Heinrich-Heine University Düsseldorf

9:50-10:05	**"Let's Get Personal": Background and Rationale for the Recommendation of SymptoMScreen for Routine Use to Personalize MS Clinical Care**	Robert McBurney Optimal Healthcare Outcomes, LLC
10:05-10:20	**"Good days and bad days": analyses of symptom fluctuations among registrants in the world's largest patient-driven multiple sclerosis (MS) registry**	Ilya Kister NYU MS Comprehensive Care Center
10:20-10:35	**The SymptoMScreen Questionnaire in MS Follow-up Consultations**	Gilles Edan CHU Rennes
10:35-10:50	**Coffee break**	
10:50-11:10	Round Table **Opportunities and barriers to implement SymptoMScreen in routine clinical care** Moderators: Marcus D'Souza — University Hospital Basel Anne Helme — UK MS Society Susanna Van Tonder — PROMS ECT Isaac Kasyoka — PROMS ECT Angela White — PROMS ECT Marilena Hadjiyianni — PROMS ECT Paolo A. Cortesi — Università degli Studi di MI-Bicocca Peter Feys — Hasselt University Sara Samadzadeh — Charité Universitätsmedizin Berlin Emmanuelle Leray — École des Hautes Études en Santé Publique (EHESP)	

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11:10-11:20	**From Barriers to Implementation: Integrating PROMs into Epic Electronic Health Record (EHR) software platform**	William Brown University of Cambridge

SESSION 3:
Meeting PwMS Expectations in Clinical Trial Design
The SAW Index: The PROMS-Recommended Tool for Identifying and Measuring Early MS Progression Through the Patient Experience

Moderators:	Xavier Montalban	Centre d'Esclerosi Múltiple de Catalunya (CemCat)
	Maria Pia Sormani	Università degli Studi di Genova

11:20-11:30	**'Voice of the Patient' Report and PROs: Capturing the Lived Reality of MS**	Angela White PROMS ECT
11:30-11:45	**From Patient Experience to Precise Measurement: How the SAW Index Study addresses the challenges of measuring early progression in MS**	Jeremy Charles Hobart Transform MS, University of Plymouth
11:45-11:55	**New Perspectives in Progressive MS: Patient-Reported Outcomes and Treatment Effects - the Role of PROMs in the OCTOPUS trial**	Sean Apap Mangion University College London

SESSION 4:
From input to Integration

Moderators:	Lydia Makaroff	MS International Federation
	Paola Zaratin	Italian MS Society

11:55-12:10	**Update on European Medicines Agency's work on patient experience data**	Rosa Gonzalez-Quevedo European Medicines Agency (EMA)

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12:10-12:20	**EMA perspective on PROMS recommendations**	*Discussant* Elena H.-M. De Lapiscina European Medicines Agency (EMA)
12:20-12:40	Round Table **How can the SAW Index be incorporated into clinical trial design for treatments targeting progression in MS?** Moderator: Patrick Vermersch	Université de Lille
	Pascal Rufi Licinio Craveiro Michael Panzara Daniel Ontaneda	Sanofi Roche Immunic Therapeutics Cleveland Clinic Mellen Center for Multiple Sclerosis

SESSION 5: Conclusion

12:40-12:50	**Discussion**	
12:50-12:55	**Highlights**	Patrick Vermersch Université de Lille
12:55-13:00	**Closing remarks**	PROMS EC co-chairs

proms-initiative.org

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 on behalf of the Global MSIF Movement