

# Patient Reported Outcomes for MS Initiative

## Ensuring representativeness of PRO assessment

16:00-16:20

### Welcome & Opening

Giancarlo Comi | **European Charcot Foundation**  
Helga Weiland | **South Africa MS Society**  
Peer Baneke | **MS International Federation**

### The PROMS Initiative: setting the scene

Patrick Vermersch | **Université de Lille**  
Paola Zaratin | **Italian MS Society**

16:20-17:05

SESSION 1

### Barriers and current limits in PROMS collection and use

Moderator: Gilles Edan | **Centre Hospitalier Universitaire de Rennes**

The collection and use of PROs in MS clinical care: preliminary results from WG2 literature review  
Robert McBurney | **Accelerated Cure Project for MS**

What is happening in clinical practice has to be related to what is happening in clinical trials? How? Paul Kamudoni | **Merck Healthcare KGaA**

Uptake of PROMS in healthcare decision making at system level: early results from the WG4 field study  
Usman Khan | **Katholieke Universiteit Leuven**

Q&A

17:05-17:20

Coffee break

17:20-18:20

SESSION 2

### Challenges: the patient perspective

Moderator: Mario Alberto Battaglia | **Italian MS Society**

#### Keynote Speech

Equity, diversity and inclusion in PRO data collection: MS as a case study

Samantha Cruz Rivera | **Centre for Patient Reported Outcomes - University of Birmingham**

Q&A

**Round table:** How can we boost participation and increase representativeness of PROMS for people with MS and underserved groups?

Moderator: Anne Helme | **MS International Federation**

Helga Weiland | **South Africa MS Society**

Joanna Dronka-Skrzypczak | **PROMS Engagement Coordination Team**

Susanna van Tonder | **PROMS Engagement Coordination Team**

Emma Gray | **PROMS Engagement Coordination Team**

Guy Peryer | **PROMS Engagement Coordination Team**

Ainhua Ruiz Del Agua | **PROMS Engagement Coordination Team**

Angela White | **PROMS Engagement Coordination Team**

Michael Thor | **MS International Federation**

Annesa Amjad | **UK MS Society**

18:20-18:30 **Coffee break**

18:30-19:05 **SESSION 3**

### How to address the gaps in existing PROMS

**Moderator:** Hans-Peter Hartung | **Heinrich-Heine Universität Düsseldorf**  
Bernard Uitdehaag | **MS Center Amsterdam, Amsterdam UMC**

Researching, Developing and Validating new PROMS

Giampaolo Brichetto | **Italian MS Society**

The “MyMood” case study

Ludovico Pedullà | **Italian MS Society**

The regulatory framework: FDA/regulatory authorities’ perspective and actions

Timothy Coetsee | **United States MS Society**

**Q&A**

19:05-19:15 **Coffee break**

19:15-19:50 **SESSION 4**

### Digital PROMS: the future of remote monitoring and self-management

**Moderator:** Robert Hyde | **Independent Healthcare Industry Consultant**

The PROMS eHealth catalogue: preliminary outcomes from the WG3 landscape analysis

Letizia Leocani | **University Vita-Salute San Raffaele**

The ALAMEDA project: leveraging AI to bridge the early diagnosis and treatment gaps in brain diseases

Rachele Paolucci | **Italian MS Society**

The potential of digital PROMS to make patient input reliable and help measure domain interdependencies. Myth or reality?

Johan van Beek | **Biogen**

Licinio Craveiro | **Roche**

**Q&A**

19:50-20:00 **Closing remarks**

Giancarlo Comi | **European Charcot Foundation**

An initiative jointly led and coordinated by the **European Charcot Foundation** and the **Multiple Sclerosis International Federation**, with the **Italian MS Society** acting as the lead agency for and behalf of the Global MSIF Movement



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