

Patient Reported Outcomes for Multiple Sclerosis

Digital “Science of PwMS input” in the era of personalized medicine

20th November 2024 (14:00-19:00)

Welcome Session and Introduction

14:00-14:10	Welcome	Giancarlo Comi Peer Baneke	European Charcot Foundation MS International Federation
	People with MS expectations: PROMS strategic intent	Helga Weiland	ECT PROMS Co-Chair
14:10-14:20	PROMS Initiative: setting the scene	Paola Zaratini Patrick Vermersch	Italian MS Society Université de Lille

Session 1: PROMs: redefining the state-of-the-art building on science of patient input. Where we are and where we are going

Moderators:	Mario Alberto Battaglia Maria Pia Amato	Italian MS Society Università di Firenze	
14:20-14:35	<i>Keynote speech</i> Accelerating Patient Experience Data (PED) utilization in neurology: a collaborative approach	Frédéric Destrebecq	European Brain Council
14:35-14:50	Phenotyping PwMS experiential knowledge via PROMs	Giampaolo Brichetto Ainhoa Ruiz Del Agua	Italian MS Society ECT PROMS member
14:50-15:00	Fatigability Induced by eXercise in MS: from anecdotal reports to prodromal progressive MS	Don Joseph Mahad	University of Edinburgh
15:00-15:10	Digital “Science of PwMS input”: are we ready?	Angela White	ECT PROMS member
15:10-15:20	Digital phenotyping in MS: are PROMS eHealth tools adequate for assessing functional domains and interdependencies?	Letizia Leocani	Università Vita-Salute San Raffaele
15:20-15:40	Q&A session		
15:40-16:00	Coffee break		

Session 2: Towards digital phenotyping of PwMS groups through ePROMs

Moderators:	Hans-Peter Hartung Marcus D’Souza	Heinrich-Heine University of Düsseldorf University Hospital Basel	
16:00-16:10	<i>Case study</i> ¹ The use of digital cognitive PROMs in developmental age as an early marker of disease in the adult	Maria Pia Amato	Università di Firenze
16:10-16:20	<i>Case study</i> ² Learnings from longitudinal data analyses in Floodlight™ studies	Agne Kazlauskaitė	F. Hoffmann-La Roche Ltd.
16:20-16:30	<i>Case study</i> ³ Mobilise-D, lessons learnt from passive mobility monitoring using a wearable sensor	Gavin Brittain	University of Sheffield
16:30-16:40	The SymptoMScreen (SS-12) questionnaire and Smouldering Associated Worsening (SAW) in MS: How and why a forensic analysis of SS-12 data explains the SAW index study	Jeremy Charles Hobart	University of Plymouth
16:40-16:50	Comments from ECT on the case studies	PwMS	
16:50-17:10	Q&A session		
17:10-17:25	Coffee break		

Session 3: Challenges in handling digital data base: the perspectives of the different stakeholders

Moderators:	Giancarlo Comi Ludwig Kappos	European Charcot Foundation University Hospital Basel	
17:25-17:40	<i>Keynote speech</i> Advancing personalized medicine: the role of digital Data and experiential knowledge in neurology	Shibeshih Mitiku Belachew	Indivi
17:40-17:50	<i>Perspective from clinical trialist</i> Digital PROMs in MS clinical research and trials	Carmen Tur	Multiple Sclerosis Centre of Catalonia (Cemcat)
17:50-18:00	<i>Perspective from clinical practitioner</i> Your experience in using PROMs in MS clinical care: the case of MS Care Unit survey	Per Solberg Sørensen	Danish Multiple Sclerosis Center
18:00-18:10	<i>Perspective from regulatory agency</i> EMA valuable perspective on regulatory frame on novel methodologies if used in the development, use or monitoring of medicinal products pre- or post-authorisation. E.g. Digital endpoint, digital biomarkers	Elena Hernández Martínez De Lapiscina	European Medicines Agency
18:10-18:20	<i>Perspective from policy maker</i> European Health Data Space: the role of patient-generated health data	Fidelia Cascini	Università Cattolica del S. Cuore (UCSC)
18:20-18:30	Results from the poll on patients/citizens perception on health data management MS movement call to action	Anne Helme	MS International Federation
18:30-18:50	Q&A session		

Session 4: Closing

18:50-19:00	Summary of the work done	Paola Zaratini Patrick Vermersch	Italian MS Society Université de Lille
19:00-19:05	Closing remarks	Giancarlo Comi Peer Baneke	European Charcot Foundation MS International Federation