



Patient Reported Outcomes on MS (PROMS) Initiative Plenary Event November 13th, from 14.00 to 19.00 CET

PROGRAMME

Time (CET)		Topic	Speakers
OPENING Moderators: PROMS Executive Committee (EC) and Engagement Coordination Team (ECT) Co-Chairs Speakers: PROMS Executive Committee (EC) and Engagement Coordination Team (ECT) Co-Chairs, Prof. G. Graffigna			
14.00 – 14.10	10'	Welcome	Speakers: PROMS EC and ECT Co-Chairs <ul style="list-style-type: none"> Mr. Peer Baneke, CEO Multiple Sclerosis International Federation (UK) Prof. Giancarlo Comi, President European Charcot Foundation (Italy) Mrs. Helga Weiland, Multiple Sclerosis South Africa, Co-Chair Engagement Coordination Team (South Africa)
14.10 – 14.25	15'	Keynote speech. “Relevance of Science with and of Patient Input, even more in time of Covid-19 Pandemic”	Speaker: <ul style="list-style-type: none"> Prof. Guendalina Graffigna, Director of the Consumer & Health Research Center - EngageMinds Hub of the Catholic University of the Sacred Heart of Milan, International Expert on Patient Engagement (Italy)

SESSION 1: The PROMS Initiative impacting on what really matter to people with Multiple Sclerosis (MS)

Moderators: PROMS Executive Committee (EC) Co-Chairs

Speakers: PROMS Scientific Steering Committee (SSC) Co-Chairs, Engagement Coordination Team (ECT) Co-Chair

14.25 – 14.40	15'	The PROMS Initiative: unmasking the hidden part of the iceberg?	Speakers: PROMS SSC Co-Chairs <ul style="list-style-type: none">• Prof. Patrick Vermersch, University of Lille's departments of Neurology (France)• Dr. Paola Zarin, Scientific Research, Italian MS Society Foundation (Italy)
14.40 – 14.45	5'	The PROMS Initiative impacting on what really matter to people with MS: the role of the Engagement Coordination Team	Speaker: PROMS ECT Co-Chair <ul style="list-style-type: none">• Dr. Emma Gray, MS Society (UK)
14.45 – 14.55	10'	Q&As on panel discussion (in-person and virtual)	Moderated by PROMS EC Co-Chairs
14.55 – 15.05	10'	Coffee break	

SESSION 2: PROMS WGs proposed actions

Moderators: PROMS Scientific Steering Committee (SSC) Co-Chairs

Speakers: Working Groups (WG) Co-Leaders, People with Multiple Sclerosis member of the Engagement Coordination Team (ECT), "end-users" discussants

15.05 – 15.20	15'	Research, Development and Validation (WG1)	Speakers: <ul style="list-style-type: none">• Working Group n.1 Co-Leaders: Dr. Giampaolo Brichetto (Italy), Dr. Maria Pia Amato (Italy), Dr. Bernard M.J. Uitdehaag (The Netherlands).• Experience and testimonials of People with Multiple Sclerosis engaged in WG1: Ms. Ainhoa Ruiz Del Agua (Spain), Ms. Susanna van Tonder (Luxemburg)
15.20 – 15.40	20'	Discussion with "end-user" stakeholder (Research & Development) Discussion questions: #1 Re-ThinkingMS <ul style="list-style-type: none">• <i>Did the Rethinking MS in Europe Initiative discuss a path toward integrating the patient voice from research to care? What is the lesson learned during your consultation with relevant stakeholders?</i>• <i>Are there any other relevant initiatives we can build on toward a Global Agenda on PROMs integration from research to health care system? What is your learned lessons that can be translated to the global level?</i>	Discussants: <ul style="list-style-type: none">• Ms. Elisabeth Kasilingam, European MS Platform, Re-ThinkingMS Initiative (Belgium)• Dr. Elena Hernandez Martinez De Lapiscina, European Medicine Agency EMA (The Netherlands)• Dr. Sonya Eremenco, The Critical Path Institute PRO Consortium (USA)

		<p>#2 EMA & FDA/Critical Path Institute</p> <ul style="list-style-type: none"> • <i>How new PRO measurements identified by capturing the experiential knowledge of patients can be uptaken by EMA and FDA/C-Path?</i> • <i>What is the value of getting digital endpoints approved by regulators, for drug development and clinical care? What is the current and evolving thinking from the regulators' perspective?</i> 	
15.40 – 15.50	10'	Live questions from the audience (in-person and virtual participants)	Selection of questions. - Moderated by PROMS SSC Co-Chairs
15.50 – 16.05	15'	Clinical Management (WG2)	<p>Speakers:</p> <ul style="list-style-type: none"> • Working Group n.2 Co-Leaders: Dr. Robert Mc Burney (USA), Prof. Gilles Edan (France), Prof. Jeremy Hobart (UK) • Experience and testimonials of People with Multiple Sclerosis engaged in WG2: Mrs. Helga Weiland (South Africa), Ms. Angela White (USA)
16.05 – 16.25	20'	<p>Discussion with “end-user” stakeholder (Clinical Management)</p> <p>#1 Health Care Centers (Decision Maker, also from the economical point of view)</p> <ul style="list-style-type: none"> • <i>We are now mostly evaluating patients in MS centers by using clinical outcomes. Do you envisage an evaluation based on PRO measurements happening soon? Could this end-point also inform MS centers clinical management and its policies?</i> <p>#2 General Neurologists</p> <ul style="list-style-type: none"> • <i>If PRO measures were provided to your patients to report on their condition would the information be helpful or too unsystematic to be useful in the care of your patients?</i> <p>#3 Training needs</p> <ul style="list-style-type: none"> • <i>What are the training needs for general neurologists in incorporating PROs into clinical workflow?</i> 	<p>Discussants:</p> <ul style="list-style-type: none"> • Prof. Xavier Montalban, Multiple Sclerosis Centre of Catalonia (Cemcat), Vall d'Hebron, Barcelona Hospital Campus (Spain) • Dr. Alessandra Protti, Niguarda Hospital, Neuroscience Department (Italy) • Dr. Andrew Solomon, Multiple Sclerosis • Larner College of Medicine at The University of Vermont (USA)
16.25 – 16.35	10'	Live questions from the audience (in-person and virtual participants)	Selection of questions. - Moderated by PROMS SSC Co-Chairs
16.35 – 16.50	15'	Coffee break	

16.50 – 17.05	15'	eHealth (WG3)	Speakers: <ul style="list-style-type: none"> • Working Group n.3 Co-Leaders: Dr. Letizia Leocani (Italy), Dr. Robert Hyde (Switzerland) • Experience and testimonials of People with Multiple Sclerosis engaged in WG3: Ms. Marni Hall (USA), Ms. Joanna Dronka-Skrzypczak (Poland)
17.05 – 17.25	20'	Discussion with “end-user” stakeholder (eHealth) Discussion questions: #1 <ul style="list-style-type: none"> • Cardiology and Duchenne’s diseases: How have the introduction and integration of eHealth tools and measures influence/changed the care setting in cardiology and Duchenne disease? • Parkinson: Are there any successful stories toward ePROMs validation in Neurological conditions, such as Parkinson? #2 Cardiology, Duchenne’s Disease and Parkinson: <ul style="list-style-type: none"> • What are the barriers that you have faced to get digital endpoints approved by regulators? 	Discussants: <ul style="list-style-type: none"> • Cardiology E Health applications: Prof. Jens Eckstein, Ltd. Arzt Cardiology and CMIO of the University Hospital Basel (Switzerland) • Duchenne Muscular Dystrophy Gait measure: Prof. Laurent Servais, MDUK Oxford Neuromuscular Centre, Department of Paediatrics, University of Oxford, Oxford (UK) • Parkinson, University of Toronto, Prof. Alfonzo Fasano, Edmond J. Safra Program in Parkinson’s Disease, Morton and Gloria Shulman Movement Disorders Clinic, Toronto Western Hospital, UHN; Division of Neurology, University of Toronto; Krembil Brain Institute Toronto, Ontario (Canada)
17.25 – 17.35	10'	Live questions from the audience (in-person and virtual participants)	Selection of questions. - Moderated by PROMS SSC Co-Chairs
17.35 – 17.47	12'	Healthcare Systems (WG4)	Speakers: <ul style="list-style-type: none"> • Working Group n.4 Co-Leaders: Dr. Usman Khan (UK), Prof. Lorenzo Mantovani (Italy) • Experience and testimonials of People with Multiple Sclerosis engaged in WG2: Dr. Guy Peryer (UK)
17.47 – 18.13	25'	Discussion with “end-user” stakeholder (Healthcare Systems) Discussion questions: #1 Canadian MS Society <ul style="list-style-type: none"> • <i>Do you have examples of the successful adoption of PRO measurements in health policy and practice within your country? If not, what do you think are the barriers?</i> 	Discussants: <ul style="list-style-type: none"> • Dr. Pamela Valentine, Canadian Multiple Sclerosis Society (Canada) • Ms. Magdalena Gari, Esclerosis Múltiple Uruguay EMUR (Uruguay) • Prof. Oriana Ciani, SDA Bocconi School of Management Government, Health & Not-for-profit Division - Health Economics & HTA (Italy) • Prof. Per Soelberg Sørensen, Rigshospitalet, University of Copenhagen, Danish Multiple Sclerosis Center, Department of Neurology (Denmark)

		<p>#2 Uruguay MS Society</p> <ul style="list-style-type: none"> • <i>Are Patient Reported Outcomes talked about and used in your country?</i> • <i>What do you think the challenges are in getting health policy makers to consider PROs when making decisions?</i> <p>#3 Health-economist</p> <ul style="list-style-type: none"> • <i>Are there any successful stories in the uptake of Patient Reported Outcomes by Healthcare Systems as criteria for evaluation and decision making (e.g. access to treatments, reimbursement, evaluation of cost-efficacy, etc.)?</i> • <i>How can we use PROs to increase/restrict/tailor access to treatments (pharmacological and rehabilitation), and reimbursement (outcomes generic or specific to people with MS)?</i> <p>#4 A case study: the MS Care Unit</p> <ul style="list-style-type: none"> • <i>Considering the MSCU case study, where do you see that PROMS have the possibility to innovate toward personalized care?</i> 	
18.13 – 18.23	10'	Live questions from the audience (in-person and virtual participants)	Selection of questions. - Moderated by SSC Co-Chairs
18.23 – 18.35	12'	Coffee break	
<p>CLOSURE Moderators: Executive Committee (EC) Co-Chairs Speakers: Executive Committee (EC) Members</p>			
18.35 – 18.50	15'	Summary of hot points	Speakers: <ul style="list-style-type: none"> • Prof. Hans Peter Hartung, University of Düsseldorf (Germany) • Dr. Timothy Coetzee, Chief Advocacy, Services & Science Officer, National MS Society (US)
18.50 – 19.00	10'	Wrap-up and Closing remarks	Speaker: <ul style="list-style-type: none"> • Prof. Mario Alberto Battaglia, President of Italian MS Society Foundation