

# DEVELOPING AND IMPLEMENTING A PATIENT REPORTED OUTCOMES NETWORK IN CANADA: POTENTIAL BENEFITS AND CHALLENGES

November 5-6, 2013



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There is growing consensus that the patients' voice not only complements clinical and administrative data, but is essential to broad evaluations of health outcomes and health related quality of life. A national Patient Reported Outcomes (PRO) Network and Platform may facilitate harmonized use of PROs and related measures in Canadian research, clinical practice and population monitoring. Experiences from other countries such as the UK and the US NIH-PROMIS Initiative demonstrate that the development and successful integration of a Canadian PRO Network will require significant investment of resources and coordinated efforts of multiple stakeholders including patients, families, and others with expertise in measurement, research, clinical care, public health, population monitoring, healthcare administration and evaluation, and policymaking. The goal of this meeting is to engage representatives from these groups for thoughtful deliberation about measurement and optimal PROs and methods, infrastructure needs, available resources to develop and sustain a national PRO network, and coordination of efforts with PROMIS and other international initiatives.

## AGENDA

### Tuesday November 5

8:00 – 8:30	<b>Continental Breakfast</b>	
8:30 – 8:45	Welcome and Introductions	Sara Ahmed PhD & Susan Bartlett PhD
8:45 – 9:00	Measuring What Matters	Nancy Mayo, PhD
9:00 – 11:00	PROS from the Patient's Perspective	Anne Lyddiatt
	PROs from the Foundation's Perspective	Rick Riopelle, MD
	PRO Platform for Researchers and Administrators	Rick Sawatzky, RN PhD
	Engaging Agencies at Provincial, National, & International Levels	Stirling Bryan, PhD
	Population Health Monitoring: Statistics Canada Experience	Cathy Trainor, MA
	PROs and Public Health Monitoring	David Buckeridge, MD PhD
	Ethical and Security Considerations for Systematic Collection of PROs	Khaled El Emam, PhD
	Panel Discussion (30 minutes)	All
11:00-11:10	<b>Break</b>	

11:10 - 12:10	The NIH PROMIS Initiative: Past, Present Future Bringing Everyone to the Table / PROMIS International Integrating PROMIS into Research and Care Canadian Experience Using PROMIS The OMERACT PRO initiative	James Witter, MD PhD David Cella, PhD Clifton O. Bingham III, MD Jeffrey Jutai PhD, Claudine Auger PhD Peter Tugwell, MS MD
12:10-12:30	Panel Discussion	
12:30 – 1:15	<b>Lunch</b>	
1:15 – 2:30	Introduction - Small Group Discussions to Identify Priorities	
2:30 – 2:45	<b>Break</b>	
2:45 – 3:45	Small Group Report Backs	
3:45 – 4:00	Preliminary Setting of Priorities	
4:00 – 4:45	Developing the Canada Pro Network and Platform	
4:45 – 5:00	Next Steps	
5:00	Adjourn for day	
7:00	<b>Dinner - Vieux Port Steakhouse, 39 Saint-Paul East, Old Montréal</b>	

### Wednesday November 6

8:00 – 8:30	<b>Continental Breakfast</b>
8:30 – 10:30	Setting of Priorities Working Groups to Develop Canada PRO Action Plan including short and long-term objectives, activities, timelines
10:30 – 10:45	<b>Break</b>
10:45 – 11:45	Report Back from Working Groups
11:45 – 12:00	Summary and Next Steps
12:00	<b>Lunch</b>
1:00	Meeting adjourned