



Measuring Patient-centred Care: a Planning Meeting to Explore Standardization and Implementation of Patient-Reported Outcome and Experience Measures in Canada

Maria J. Santana, MPharm, PhD
W21C Research and Innovation Centre
O'Brien Institute for Public Health
Cumming School of Medicine

Patient-centred care is defined by the
Institute of Medicine as:



“providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions”

How can we measure patient-centred care?



Patient-reported Outcome and Experience Measures



PROMs and PREMs are validated questionnaires that place the values and perspectives of the patient at the center

Patient-reported Outcome and Experience Measures

Patient Reported Outcome Measures (PROMs)	Patient Reported Experience Measures (PREMs)
Measures impact of an illness or health condition from the patient's perspective	Captures the patient's view of what happened during their healthcare visit (process of healthcare)
Examples: quality of life, symptom severity, functional status, health status	Examples: Communication and trust in staff, cleanliness, timeliness
Used to monitor the progress of a health condition or whether a treatment has been effective by comparing results over time	Used to evaluate and monitor service delivery
Measured from the patient's perspective, usually via questionnaires	
Used together to assess quality of care and services from patient's viewpoint	

PROMs and PREMs

Use of PROMs and PREMs by various users at different levels:

- Clinical
- Administrative
- Policy

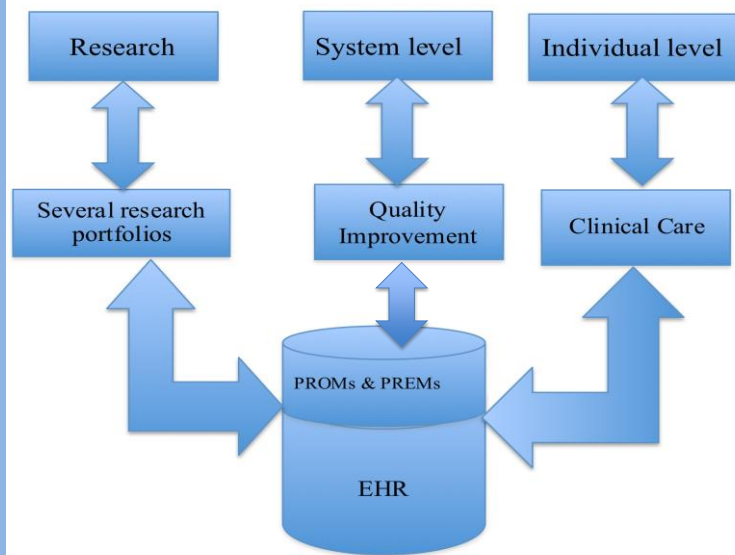
Performance management and benchmarking

- Inform and improve patient-centered care
 - Performance management, quality improvement
- Comparisons with national and international agencies
- Access to comparable pan-Canadian benchmarking indicator reports, including regional and provincial averages

Enriches existing sources of health information

- Complements existing clinical and administrative data available
- Provides data to target quality improvement





A Framework to Describe Potential Use of Patient-Report Outcome and Experience Measures (Santana MJ, 2014)

PROMs and PREMs in Canada

- In Canada there is a diversity of PROMs and PREMs used
- This heterogeneity impedes benchmarking across institutions and provinces
- In addition, standardized approaches for linkage of PROMs and PREMs data with EHRs is far from present
- This situation calls for a new approach to developing programs across the country to support the standardization of PROMs and PREMs

Objectives

1. To share knowledge on national experiences regarding the collection and utilization of PROMs and PREMs
2. To build consensus regarding the selection of specific PROMs and PREMs for Canada as well as the development of standardized approaches to the collection of PROM and PREM data for evaluating Canadian healthcare system performance
3. To explore a strategy for data linkage through the development of a national PROMs database and integration in EHRs

PROMs and PREMs Forum

DAY 1- Thursday, November 27, 2014			
TIME	DESCRIPTION	DETAILS	LOCATION
7:45-8:30	Registration & Breakfast	Poster/Booth session - networking	HMRB Atrium
8:30-8:45	Welcome	Welcome – Hude Quan Overview of agenda – Maria Santana	W21C Multipurpose Room
8:45-10:00	PROMs initiatives in Canada PREMs in British Columbia and Alberta	<ul style="list-style-type: none"> • Ellis Chow - Canadian Institute for Health Information • Lena Cuthbertson • Carolyn De Coster (AHS) 	W21C Multipurpose Room
10:00-10:30	Break	Poster/Booth session – networking	HMRB Atrium
10:30-11:00	PROMs and PREMs in Primary Care	<ul style="list-style-type: none"> • Scott Oddie (PCN-AHS) 	W21C Multipurpose Room
11:00-12:00	The HQCA: Overview, PREMs, PROMs and Patient Engagement	<ul style="list-style-type: none"> • Tim Cooke • Markus Lahtinen • Carmella Steinke 	W21C Multipurpose Room
12:00-1:00	Lunch	Poster/Booth session – networking	HMRB Atrium
1:00-1:30	PROMs and PREMs Environmental Scan in Alberta	<ul style="list-style-type: none"> • Danielle Southern 	W21C Multipurpose Room
1:30-2:30	PROMs in Clinical Care	<ul style="list-style-type: none"> • Maria J. Santana • Shannon Groff • Christopher Smith 	W21C Multipurpose Room
2:30-3:00	Break	Poster/Booth session – networking	HMRB Atrium
3:00-3:30	Integration of PROMs/PREMs into EHRs	<ul style="list-style-type: none"> • Francis Lau 	W21C Multipurpose Room
3:30-4:00	The Validation and Utilization of PROMs and PREMs for Health Services and Clinical Practice	<ul style="list-style-type: none"> • Richard Sawatzky 	W21C Multipurpose Room
4:00	Closing Remarks – Maria Santana		W21C Multipurpose Room
DAY 2-Friday, November 28, 2014			
TIME	DESCRIPTION	DETAILS	LOCATION

DAY 2-Friday, November 28, 2014			
TIME	DESCRIPTION	DETAILS	LOCATION
8:30-9:00	Registration & Breakfast		HMRB Atrium
9:00-9:10	Welcome /Introduction	Overview of agenda – Maria Santana	W21C Multipurpose Room
9:10-9:30	Patient-Centred Care	<ul style="list-style-type: none"> • Charles Leduc 	W21C Multipurpose Room
9:30-11:30	Working Group session	<ul style="list-style-type: none"> • What should be priorities? • Building consensus regarding: <ul style="list-style-type: none"> ○ Collection ○ Use • Integration & 	W21C Multipurpose Room
11:30-12:00	Lunch		W21C Multipurpose Room
12:00-1:00	O'Brien IPH seminar	<ul style="list-style-type: none"> • Patient Engagement Researchers -Hidden Pathways Project: Enriching PROMs and PREMs? 	HSC G500
1:00-1:15	Return to W21C		
1:15-2:30	Next Steps	Open discussion – Hude Quan and Maria Santana	W21C Multipurpose Room
2:30	Closing Remarks – Maria Santana		W21C Multipurpose Room

Welcome to the Forum



Drs. Quan and Santana



Sandra Zelinsky (PaCER) - Chair



PROMs and PREMs at
the Canadian Institute
for Health Information

The Canadian Patient
Experiences Reporting
System (CPERS)

Ellis Chow

A Decade of Measuring Patient Reported Experience of Care in British Columbia

Lena Cuthbertson



- BC PREMs' mandate- development include data collection, dissemination and acting on results
- In 11 years the BC PREMs was able to:
 - coordinate province-wide surveys
 - obtain feedback from more than 1 million users of health care services across 13 sectors/subsectors and all age groups,
 - report and analyze quantitative and qualitative data

PREMs and PROMs in AHS: Measurement and dissemination strategies

Carolyn De Coster



- In 2013, AHS was part of the development of the Canadian version of H-CAHPS with CIHI.
- AHS pilot tested the Canadian version, which is a 32 item survey, collected through a computer-assisted Telephone Interview (CATI), up to 42 days post-discharge

The Health Quality Council of Alberta: Overview, PREMs, PROMs and Patient Engagement Activities

Carmella Steinke, Markus Lathinen, Tim Cook



- From 2003 HQCA has been conducting surveys to examine patient experiences with various healthcare services including emergency departments, family doctors, specialist physicians, community walk-in clinics, hospitals, mental health, diagnostic imaging, pharmacists, public health, and Health Link.
- In 2010 HQCA established a Patient/family Safety Advisory Panel to include patient and family perspective and it has been supporting the use of PROMs in Alberta since the Collaborative Planning Workshop 2010 Edmonton.

Patient-centred Oriented Research: An Environmental Scan on the Use of Patient-Reported Outcome Measures in Alberta

Danielle Southern

- An environmental scan on the use of PROMs and PREMs in Alberta was conducted to determine the purpose of using these measures, to identify the different measures used, and to explore standardization of the use of measures across the Province



The Role of Patient-Reported Outcome Measures in Clinical Care

Maria J. Santana



- Several healthcare settings have been using PROMs all over the world including UK, USA, New Zealand, and Canada.
- There is a number of options and considerations to take into account prior to clinical implementation such as training health care providers in the interpretation of the measures

Utilizing Patient-Reported Outcomes to Drive Person-Centred Across Cancer Control Alberta,

Shannon Groff



- In a long term AHS Cancer Centers aim to have patients entering their reported outcomes electronically and that data will flow directly into their EMR, PROs data will include both standardized, generic, and disease specific indicators, and PRO collection, analysis and reporting should be sustainable and integrated into standard processes and IT infrastructure.

Using PROMs and PREMs to Impact Clinical Care

Christopher Smith



The Alberta Bone and Joint Health Institute reports the use of PROMs and PREMs in Elective Total Joint Arthroplasty

Measuring Patient-Centred Care Integration of PROMs/PREMs into Electronic Health Records (EHRs)

Francis Lau

Recommendations and implications for EHR have been identified with an emphasis on some implication issues:

- adding any data to EHR is challenging
- collecting/storing social-behavioral data in EHR
- collecting/using self-reported data
- privacy protection
- resource considerations
- linking to public health and community

agencies anticipating/preventing unintended



The Validation and Utilization of PROMs and PREMs for Health Services and Clinical Practice

Richard Sawatzky



The validation of PROMs for Health Service has been encountering challenges related to **diversity and response shift**.

People may not interpret questions in the same way, which **threatens the comparability of score across individuals or groups**.

Patient and Family Burden of Management: We Need New Knowledge

Charles Leduc



We need to know more about the burden of disease management, the potential harms of a Patient- Centred Care Paradigm, the risks of developing resilience, the workload-capacity imbalances

Sandra Zelinsky, Chris Hylton, Yvette Swedson
Patient and Community Engagement Research



Sandra, Chris and Yvette presented a project “Hidden Pathways of Chronic Illness”. The authors explained the methodology used with the objective of “conceptualize and share what patients learn through their experience with chronic illness, and expand the clinical understanding of patients' pathways with chronic illness.”

Posters presentations

- Dr. Sara Ahmed from McGill University presented “Creating the National Patient Reported Outcome Network”.
- Dr. Nancy Marlett, University of Calgary presented “Uncovering Hidden Pathways of Chronic Illness: Patients Analyze their Lived Experiences”.
- Dr. Svetlana Shklarov, University of Calgary, presented “Partners in research: Patient Initiatives in Health Experience Research”.
- Ms. Carmella Steinke, Health Quality Council of Alberta, presented “Continuity of Patient Care”.
- Ms. Sandra Zelinsky, PACER, presented “Safe Surgery Checklist (SSC) Surgery Strategic Clinical Network”.

Other presentations

- Local patient advisory teams set up booths to show case their work related to patient- centred care:
 - **Health Quality Council of Alberta- “Continuity of Care”** and “Continuity of Care Experience in Alberta”. The project addresses Albertan journey through the continuum of care
 - **Citizen Advisory Team - South Health Campus- “Embedding Family Presence & Patient and Family Centred Care Culture”** describing the engaging process of families and patients into their patient-centred culture

Groups Discussions



The attendees shared round tables with six or seven other participants to address the following questions:

1. In order to advance the measurement of patient-centred care PCC, what are the priorities to be addressed?
2. How can we use PROMs and PREMs to measure PCC in health care?
3. From measurement to actions: what to do next?

Conclusion

- Patient engagement from beginning
- Multidisciplinary groups need to be engaged
- Potential of PREMs and PROMs combined/married together
- Tools need to be reevaluated today - Validation
- Need to know what will be done with the data
- Need to address underlying technological infrastructures
- Lots of data being collected (HQCA, DIMER) centralized warehouse to help people in operations and leadership
- Complexity of systems talking to each other
Provincial structure and understanding of what each structure does

Q & A

