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

### Background

Patient-centred care (PCC) 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**”[1]. How can patient-centred care be measured? Traditionally healthcare systems have been mainly monitored from physician perspectives. The measures from patient perspectives have not been routinely integrated into the evaluation of healthcare system performance.

Patient-reported outcome and experience measures (PROMs and PREMs) facilitate patient-centric measurements of health outcomes and quality of care. PROMs and PREMs are validated questionnaires that place the values and perspectives of the patient at the center of healthcare practice and service. While PROMs are concerned with the outcomes of a patient’s health condition or disability, PREMs are concerned with their experiences with healthcare delivery.

PROMs are known as: “any report of the patient’s health condition that comes directly from the patient, without interpretation of the patient’s response by a clinician or anyone else”[2]. PREMs are questionnaires designed specifically to assess the patient’s view about the quality of health care received (e.g. timely access to care, communication with health care providers). PREMs were developed to support the evaluation of the quality of health care received by patients and families and have been used to monitor improvement in health care services. **Both PROMs and PREMs are integral to the Canadian Institute for Health Information (CIHR) Strategy for Patient-Oriented Research and should have a central role in Canadian health policy as a lever to improve the quality of patient oriented care** [2][3]. Individual PROMs data can be fed back to clinicians and patients to inform care and treatment. PROMs feedback interventions are heterogeneous; they vary by PROM used, patient population, setting, format and timing of feedback, recipients of the information and level of aggregation of the data [4-11].

A diverse group of measures fall under the PROMs umbrella, including psychological and emotional health, adverse reactions and symptoms. Generally, PROMs include measures of symptom burden that report the frequency, severity, and impact of symptoms. In clinical practice PROMS can be used as a surveillance system; patients can report their symptoms and health status periodically, via their home computer or their electronic mobile system and be monitored for changes in health, leading to adjustments in the frequency of clinic visits depending on how health changes [12-17]. Also, patients can report on their health prior to their clinic visit and the information they provide can be instantly graphically summarized and presented to healthcare providers highlighting health concerns and other problematic issues to their patients. These data can be used along with other clinical information on patients (such as lab test, imaging studies, clinic notes) to inform patient management [13]. Both, PROMs and PREMs data can be stored in the patients’ electronic health records and integrated with other patient clinical data [18-20].

Electronic health records (EHRs) began as an electronic version of the patient record for hospitals and clinics, and have evolved to serve a broader purpose of giving multiple stakeholders, including health care providers, managers and patients, access to a patient’s medical information across the continuum of care. **This linkage can facilitate and support multiple tasks, including improving clinical care, enhancing quality improvement, research, and public reporting.**

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 measures.



Drawing from new insights obtained from our previous work as well as current environmental scan results, **our group, Methods for Research in Public Health (MORE-PH), will significantly advance this area by examining multiple factors beyond barriers to implementation toward national standardization of PROMs and PREMs.**

**Our goal is to produce guidance for Canadian decision makers on where and how best to utilize PROMs and PREMs data to improve the quality of patient care.** This essential knowledge will enable us to develop effective national programs that will allow understanding by what means and in what circumstances the integration of PROMs and PREMs data into the EHRs leads to improvements in patient care.

Given that we at MORE-PH are already collecting important new data on PROMs and PREMs, and we have identified stakeholders' interest at both provincial and national levels, we are uniquely positioned to begin standardizing and implementing interventions to improve understanding by what means and in what circumstances the feedback of PROMs and PREMs data leads to improvements in patient care. **This meeting aimed to advancing the standardization, implementation and integration of PROMs and PREMs in Canada.**

Our group is nested within the [O'Brien Institute for Public Health](#) providing an ideal setting to lead an initiative of this magnitude. The O'Brien Institute for Public Health at the University of Calgary is a virtual hub that integrates research groups, academics, health professionals, community leaders and policy makers across the continuum of care to catalyze excellence in population health and health services research. We strive to produce knowledge and evidence to inform the public health agencies and health systems tasked with keeping us (and making us) healthy. Together, the shared vision of our dedicated members is "Better health and health care."

## **Objectives**

The objectives of the meeting were:

1. To share knowledge on national experiences in patient orientated research, specifically, the collection and utilization of PROMs and PREMs;

2. To explore consensus regarding the collection of specific PROMs and PREMs for Canada as well as the development of standardized approaches to evaluate Canadian healthcare system performance;
3. To explore a strategy for data linkage through the development of a national PROMs database and integration in EHRs.

This meeting took place November 27-28, 2014, at the Cumming School of Medicine, University of Calgary. Sixty invitations targeting faculty and experts leaders in PROMs and PREMs were issued. The agenda was sent in advance to attendees and presenters (see appendix 1 for program-at-a-glance).

The first day opening included a welcome message from Drs. Hude Quan and Maria Santana, followed by presentations from experts. The session was chaired by Sandra Zelinsky - Patient and Community Engagement Research (PACER). The objective of the first day was to share knowledge on national experiences in patient orientated research, specifically, the collection and utilization of PROMs and PREMs as well as to discuss standardized approaches to the collection of data and to explore a strategy for data linkage.

The second day, chaired by Dr. Santana, started with a presentation examining the potential harms of a patient-centred care paradigm by Dr. Leduc, followed by two hours of group discussions. Group discussions focused on addressing priorities for measurement patient-centred care and how to make this measurement actionable, specifically using PROMs and PREMs.





## **Presenters**

PROMs and PREMs at the [Canadian Institute for Health Information](#) (CIHI): Measuring Patient-Centred Care. **Ellis Chow**



Clinical and administrative data, and PROMs and PREMs are used to evaluate quality of care and service outcomes. PROMs and PREMs can be used by various users at different levels and they enrich existing sources of health information. However, the availability of numerous measurements tools/surveys with various complexity and application, the diversified approaches to PROMs and PREMs in Canada across regions and jurisdictions, and the use of different data collection methods, timing to administer questionnaires, sample size, and response rates make the measurements in patient-centred care more challenging. CIHI has the potential to support a standardized program for PROMs collection and reporting in Canada. In Spring 2014, CIHI began developing the Canadian Patient Experiences Reporting System (CPERS) that will be available to accept data next April 2015.

Click [HERE](#) for the presentation.

A decade of Measuring Patient Reported Experience of Care in British Columbia  
**Lena Cuthbertson**

Measurement of patient-centred care is influenced by what people want when they need care. From 2003 to 2014 the BC PREMS' mandate developed from data collection to dissemination of results to acting on results, and 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, provide practical support for an effective use of data for QI and for accountability, public reporting of results, and develop a "modular" approach.

Click [HERE](#) for the presentation.



PREMs and PROMs in AHS: Measurement and dissemination strategies  
**Carolyn De Coster**

The importance of measuring patient experience is to understand what we do to patients and how well we are doing it. 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. Results are publicly reported and internally disseminated. Click [HERE](#) for the presentation.



The Health Quality Council of Alberta: Overview, PREMs, PROMs and Patient Engagement Activities  
**Carmella Steinke, Markus Lahtinen, Tim Cook**



The Health Quality Council of Alberta (HQCA) is an independent corporation with a mandate to promote and improve patient safety and health service quality on a province-wide basis. 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. Over the years, the HQCA studied the concerns with breakdowns in the continuity of care. 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. Click [HERE](#) for the presentation.

## 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. Results from the survey, created to collect information about PROMs and PREMs, show that a list of 70 stakeholders was identified, 32 participated in the survey and 29 of them study and collect PROMs/PREMs. Much of the PROMs/PREMs work in Alberta is completed by researchers, managers and clinicians at universities and health care delivery organizations. There is more work in PROMs and a smaller proportion in PREMs. EQ5D and CAHPS are the measures mainly collected for Quality Improvement and research.

Click [HERE](#) for the presentation.



## The Role of Patient-Reported Outcome Measures in Clinical Care

**Maria J. Santana**



A Patient-Reported Outcome is defined as “any report of the status of a patient’s health condition that comes directly from the patient without interpretation of the patient’s response by clinician or anyone else”. Today, PROMs are used in clinical practice, program evaluation and quality improvement to ensure focus on the patient rather than the disease.

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.

Click [HERE](#) for the presentation.

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. Click [HERE](#) for the presentation.



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 through a daily use of WOMAC (for functional status) , EQ-5D (for quality of life), and Patient Feedback. They often use other tools to measure Quality of Life: SF-12/36 and HUI-3, Functional Status: Harris Hip Score, Knee Society Score, HOOS & KOOS, and Hospital Experience: HAPSQ.

In their experience PROMs is used to describe, inform, and predict Quality.

Click [HERE](#) for the presentation.



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

**Francis Lau**



The Electronic Health Record is a repository of patient data over time that it is mainly used to deploy EHR for Canadians, provide key information to clinicians and improve patient experience for Canadians.

Several studies suggested the integration PROMs and PREMs into EHR as a strategy to improve primary care. Accordingly, recommendations and implications for EHR have been identified with an emphasis on some implication issues such as, 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 consequences. Click [HERE](#) for the presentation.

## 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. The utilization of PROMs through e-QOL assessment instruments brings benefits to patient and clinicians, enhance visualization and monitoring of patient concerns through ongoing and immediate feedback, and PROMs and PREMs information become part of administrative data for program evaluation, cost-effectiveness analysis, and resource allocation.

Click [HERE](#) for the presentation.

## Patient and Family Burden of Management: We Need New Knowledge

**Charles Leduc**

Patient-centred care makes patients and their loved ones an integral part of the team and puts responsibility for important aspects of self-care and monitoring in patients' hands, but 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.

It is important to create new knowledge about the impact of historical oppression on PROMs and PREMs, how PROMs and PREMs can be influenced by personal values, our dominant culture and a western scientific tradition of "wanting to do good". It is part of our duties to understand our clinical and scientific blindness and its influence on PROMs and PREMs.

Click [HERE](#) for the presentation.



### **Presenters**



### **Seminar Presentation**

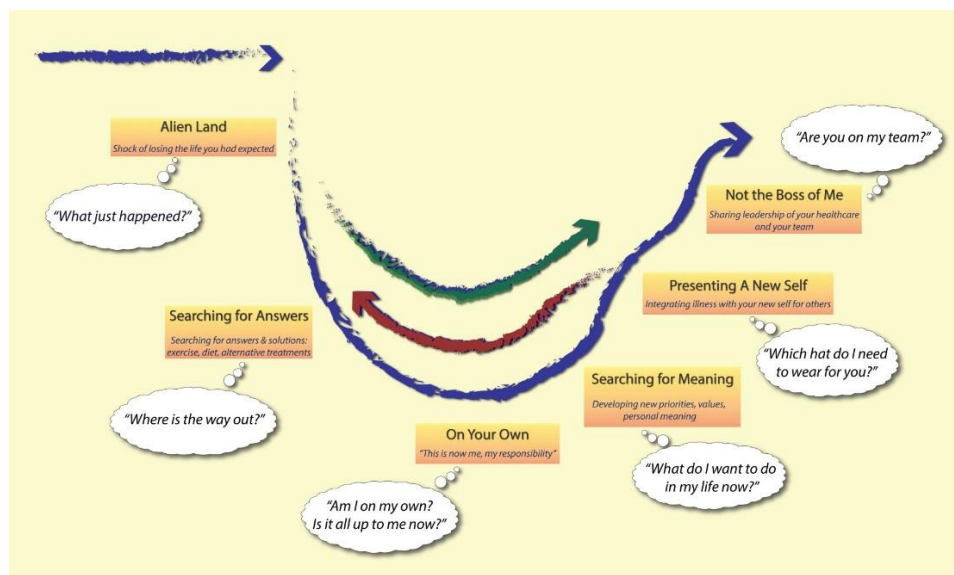
Sandra Zelinsky, Chris Hylton, Yvette Swedson - Patient and Community Engagement Research

Patient and Community Engagement Research (PACER) is a research training program within the O'Brien Institute for Public Health at the University of Calgary. PACER works to create the partnerships and infrastructure needed to transform the role of patients and families in health and health culture experience through the training patients and/or family members to become patient engagement researchers designing and conducting health experience research and to work in collaboration with health providers, planners and researchers. Click [HERE](#) to listen to the seminar recording on Adobe Connect.



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.” The authors identified six non-linear stages depicted in Figure 1.

Figure 1



### Groups Discussions

After acquiring a wealth of information from all the presentations, we organized group discussions. The attendees shared round tables with six or seven other participants to address the following questions:



In order to advance the measurement of patient-centred care PCC, what are the priorities to be addressed?

How can we use PROMs and PREMs to measure PCC in health care?

From measurement to actions: what to do next?



Each table had a 'note-taker' and a 'presenter'. After forty-five minutes of discussion the 'presenter' shared the main points with the rest of the audience and thirty minutes were allocated for general discussion.



### **Discussion Points**



**Q1: In order to move forward in terms of patient-centred care, what are the priorities to be addressed?**

Plethora of terms and how does it fit into patient-centred care

What is our goal in terms of patient-centred care

Engage with patients to find out needs and to access with low capacity

Create model with patients and families

To keep a repository of PROMs and PREMs that are being used and to implement them

Do a critical appraisal of measures available

Closer reflection of instruments that we have available

Need to recognize unrepresented definition of PCC

Selection bias

**Q2: How can we use PROMs and PREMs to measure PCC in health care?**

PREMs vs PROMs dependent on how they are used

Potential of PREMs and PROMs combined/married together

PROMs to trigger decisions in clinical care

All levels to be included: patient, provider, administrator, and political

If they are used, make sure they are actionable

Need to engage people who want to bring data and consider privacy issues

Privacy makes system less flexible

Need to broaden base of where data comes from

Complexity of systems talking to each other

Engage patient more deeply

Need to address underlying technological infrastructures

Not just provincial but international

Whatever measures we select have to be relevant to clinicians, patients, and system

Free sharing of data through being transparent

### **Poster Presentations**

There were seven posters presented by:

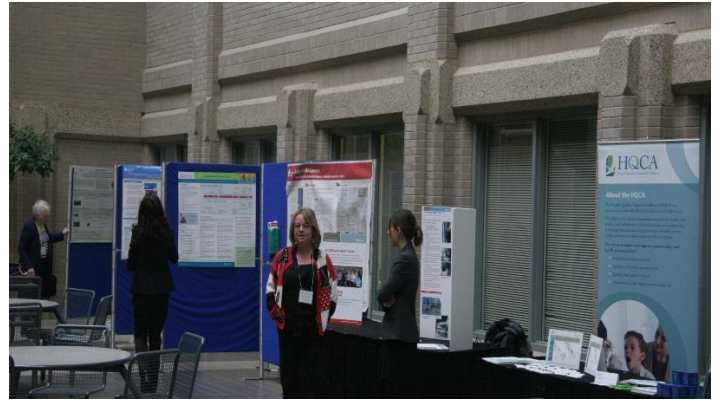
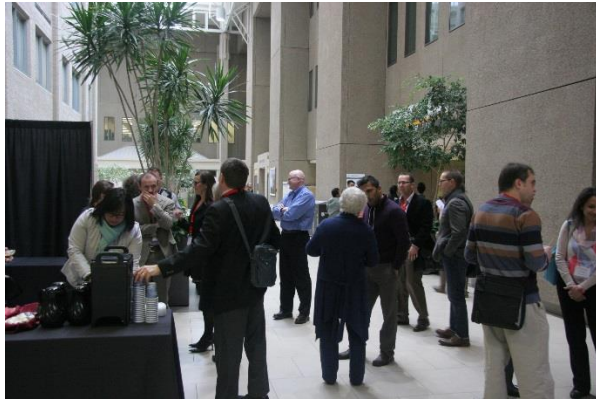
Dr. Sara Ahmed from McGill University presented “Creating the National Patient Reported Outcome Network”.

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”.



Also two of the local patient advisory teams (Health Quality Council of Alberta and Citizen Advisory Team - South Health Campus) set up booths to show case their work related to patient-centred care.

The Health Quality Council of Alberta presented their project about “Continuity of Care” and “Continuity of Care Experience in Alberta”. The project addresses Albertan journey through the continuum of care.

The Citizen Advisory Team at South Health Campus presented their work, “Embedding Family Presence & Patient and Family Centred Care Culture” describing the engaging process of families and patients into their patient-centred culture.

To view the posters, click [HERE](#)

### **Next steps**

Dr. Hude Quan summarized the key points of the presentations highlighting the follow:

Patient engagement from beginning; need to know that the information is relevant and needed, and what will be done with the data

Tools need to be reevaluated today-Validation

Potential of PREMs and PROMs combined/married together

Multidisciplinary groups need to be engaged

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

### **Attendees Evaluation**

Two evaluations forms, one for each day, were offered to participants for completion at the end of the day. The evaluation after day one included three questions on a 5-point scale that ranged from “Not at all” to “Very useful” as well as a text box for general comments. The high level questions intended to provide guidance for next forum opportunities: **1) How informative was the Forum; 2) How productive were the discussions? ; 3) I intend to apply the learning to my future practice /research.** (Appendix 2)

The evaluation for day two included three questions:

1) How satisfied were you with the exploration of the event’s theme; 2) How relevant were the keynote presentations?; 3) A follow up event would be beneficial to advance the national initiative on PROMS and PREMs/ How likely are you to attend future PROMs and PREMSs events? These questions were on the same 5-point scale as the form from day one. Also this evaluation form included two open text boxes, one asking “What did you like best about the event?” and the other “additional comments”. (Appendix 3)

The completion rate was 70%, unfortunately we failed to remind participants to complete the evaluation forms. Available results clustered at the top of the scale (most useful to very useful)



indicating that the majority of attendees were satisfied overall with the event (60%) and a similar proportion of participants would likely attend future PROMs and PREMs events. Application of the learning to future practice and/or research varied between highly possible (47%), mostly possible (33%), and somewhat possible (13%).

Most participants felt that the event theme was explored satisfactorily. Participants indicated that the discussions were generally productive and most of the keynote presentations were relevant to the event theme.

Some participants suggested ideas to improve future PROMs and PREMs events, such as: bigger room, different location, more microphones, more opportunities for discussions/dialogue versus full day presentation, provide slide presentation handouts ahead of time, registration and refreshments and posters closer to the event room.

### **Acknowledgements**

We would like to thank all forum participants, the committee members and communication team for your support, the Ward of the 21<sup>st</sup> Century (W21C) for hosting the forum, our funding agencies- Campus Alberta and Alberta Innovates - Health Solutions, and the O'Brien Institute for Public Health, University of Calgary.

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References

1. Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Vol. 6. Washington, DC: National Academy Press; 2001.
2. US Department of Health and Human Services Food and Drug Administration. Guidance for industry: patient-reported outcome measures: use in medical product development to support labeling claims. 2014. 2009.
3. Health Outcomes of Care: An Idea Whose Time Has Come. Canadian Institute for Health Information. Health outcomes Report, 2012.
4. DoH. (2010). Equity and Excellence: Liberating the NHS. London.
5. Devlin, N. J., & Appleby, J. (2010). Getting the most out of PROMs: putting health outcomes at the heart of decision making. London: The King's Fund.
6. Greenhalgh, J. (2009). The applications of PROs in clinical practice: what are they, do they work and why? *Quality of Life Research*, 18(2009), 115-123.
7. Greenhalgh, J., Long, A. F., & Flynn, R. (2005). The use of patient reported outcome measures in clinical practice: lacking an impact or lacking a theory? *Social Science and Medicine*, 60, 833-843.
8. Valderas, J. M., Kotzeva, A., Espallargues, M., Guyatt, G., Ferrans, C. E., Halyard, M. Y., Revicki, D. A., Symonds, T., Parada, A., & Alonso, J. (2008). The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature. [Review] [64 refs]. *Quality of Life Research*.17(2):179-93.
9. Marshall, S., Haywood, K. L., & Fitzpatrick, R. (2006). Impact of patient-reported outcome measures on routine practice: a structured review. [Review] [46 refs]. *Journal of Evaluation in Clinical Practice*, 12(5), 559-568.
10. Espallargues, M., Valderas, J. M., & Alonso, J. (2000). Provision of feedback on perceived health status to health care professionals: a systematic review of its impact. *Medical Care*, 38(2), 175-186.
11. Greenhalgh, J., & Meadows, K. (1999). The effectiveness of the use of patient-based measures of health in routine practice in improving the process and outcomes of patient care: a literature review. [Review] [66 refs]. *Journal of Evaluation in Clinical Practice*, 5(4), 401-416.
12. Santana MJ, Feeny D, Weinkauf J, Nador R, Jackson K. et al. The use of patient- reported outcomes becomes standard practice in the routine clinical care of lung-heart transplant patients. *Patient Relat Outcome Meas* 2010;1:93-105.
13. Santana MJ, Feeny D, Johnson JA, et al. Assessing the use of health-related quality of life measures in the routine clinical care of lung-transplant patients. *Qual Life Res* 2010;19:371-9.
14. Santana MJ and Feeny D. Framework to assess the effects of using patient-reported outcome measures in chronic care management. *Qual Life Res*. 2014 Jun;23(5):1505-13.
15. Snyder CF, Aaronson NK, Choucair AK, Elliott TE, Greenhalgh J, Halyard MY, Hess R, Miller DM, Reeve BB, Santana M. Implementing patient-reported outcomes assessment in clinical practice: a review of the options and considerations. *Qual Life Res*. 2012 Oct;21(8):1305-14.
16. Santana MJ, Feeny D, Jackson K, Weinkauf J, Lien D. Improvement in health-related quality of life after lung transplantation. *Can Respir J*. 2009 Sep-Oct;16(5):153-8.

17. Santana MJ, Feeny DH. Using the health utilities index in routine clinical care: process, feasibility, and acceptability: a randomized controlled trial. *Patient*. 2009 Sep 1; 2(3):159-67.
18. Sawatzky R. Patient Reported Outcome Canada. Background Information for the Canadian Institute for Health Measures (PROMs) for Information's PROMs Business Planning (2014). Report.
19. Wu AW, Kharrazi H, Boulware LE, Snyder CF. Measure Once, Cut Twice – Adding Patient-Reported Outcome Measures to the Electronic Health Record for Comparative Effectiveness Research. *Journal of clinical epidemiology* 2013;66(8 0):S12-S20. doi:10.1016/j.jclinepi.2013.04.005.
20. Lau F, Price M, Bassi J. Creating Strategic Change in Canadian Healthcare. Conference White Paper Working Drafts. School of Health Information Science, University of Victoria