Measuring Patient Reported Experience of Care in British Columbia

Performance Anxiety: CHSPR 2014 - Health Policy Conference
Vancouver
February 25, 2014

Lena Cuthbertson, Co-chair, BC PREMS
What are we trying to accomplish?

In British Columbia:

1. ...measurement of the quality of the health care system “through the patient’s eyes”

2. ...translation of patient-centred data into information and information into action to improve BOTH experience and outcomes for patients and their families at the point of care AND at the level of the system
What are we trying to accomplish?

Today at this conference:

**Dialogue about ... the science of performance measurement**

- Share the learnings from a decade of patient-centred data collection and reporting in BC about the science of the measurement (and our evolving understanding) of patient satisfaction, patient experience, and patient-centred care,

**Dialogue about ... best practices for reporting on performance**

- Share promising practices developed in BC for reporting quantitative and qualitative information about the quality of care and services from the perspective of those who have received care (patients and families)
Coordinated, province-wide surveying in BC… a look back
(1) In 2000 and 2001, the Institute of Medicine issued two reports, To Err is Human and Crossing the Quality Chasm, documenting a glaring divergence between the rush of progress in medical science and the deterioration of health care delivery.
<table>
<thead>
<tr>
<th>Through the Patients Eyes (Picker Institute, 1986) (8 dimensions)</th>
<th>Model for Patient &amp; Family Centred Care (IPFCC, 1992) (4 core concepts)</th>
<th>Achieving an Exceptional Care Experience (IHI, 2012) (5 primary drivers)</th>
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<tbody>
<tr>
<td>Respect for patient values &amp; preferences</td>
<td>Respect and Dignity</td>
<td>Respectful Partnerships</td>
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<td>Information, Communication &amp; Education</td>
<td>Information Sharing</td>
<td>Evidence Based Care</td>
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<td>Coordination of Care</td>
<td>Collaboration</td>
<td>Leadership</td>
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<td>Involvement of Family</td>
<td>Participation</td>
<td>Hearts &amp; Minds</td>
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<td>Emotional Support</td>
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<td>Physical Comfort</td>
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<td>Preparation for Discharge / Continuity &amp; Transitions in Care</td>
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<td>Reliable Care</td>
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<td>Access</td>
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Mandate of BC PREMS
(BC Patient Reported Experience Measures Steering Committee)

To develop a coordinated, cost-efficient, and scientifically rigorous provincial approach to the measurement of patient experience in order to:

1. enhance public accountability

2. support quality improvement
BC PREMS Guiding Principles:

- Promote a common, scientifically rigorous, province-wide approach to measurement of patient satisfaction and experience;
- Work towards evidence-based benchmarks that will enable objective comparisons and trending over time;
- Compliment existing national and/or provincial measurement strategies;
- Minimize data collection burden for Health Authorities;
- Provide satisfaction data that supports and promotes quality improvements efforts at the point of service; and
- supports the accountability of the health care system;
- Recognize that the strategy and process for a complex undertaking such as this will evolve over time.
**Survey Design**
- Selection of survey tools with strong psychometrics
- Development of tools or custom questions
- Defining methodology (survey design and sampling plan)

**Data Collection**
- Distributing surveys
- Collecting completed responses/surveys

**Data Processing**
- Processing surveys
- Collating results
- Case mix adjustment; weighting for disproportional sampling, if necessary
- Analyzing data

**Reporting**
- Production of reports
- Quantitative and qualitative
- Graphic and narrative

**Sharing Results**
- Dissemination of results to all stakeholders
- Public Reporting

**Action Planning**
- Knowledge sharing
- Promoting “mini surveys or point of service QI initiatives
- Secondary analysis and promoting x-HA collaboration
- Recommending targets for accountability & system level improvement

**BC PREMS’ mandate**
From data collection…
To dissemination of results…
To acting on results…
REPEAT!

“Only when data has been analyzed, interpreted and presented in a manner that makes it understandable and useful to others does it become information”

Michael Murray, PhD
What are PREMS?
Patient-Reported Experience Measures

Self-report instruments (surveys, questionnaires) used to obtain patients’ appraisals of their experience and satisfaction with the quality of care and services.

• Typically address various composites/domains/dimensions of patient-centred care
• Provide information from patients’ perspectives without interpretation from a ‘middle man’
• Provide quantitative and qualitative feedback to drive service improvement at the local level or for system level improvement
• May or may not include patients’ self reports of the outcome of the care experience or self-rated health status
What are PREMS? Patient-Reported Experience Measures

 ✓ Collected in a uniform manner
   • Asking the same questions in the same way so answers are influenced by the respondents' experiences, NOT due to how the questions are worded/asked

 ✓ Tells us what our patients and families “really think”
   • Collected so patients and family members feel no fear of retaliation (confidential and/or anonymous)

 ✓ Focuses on what is important to patients and their families (not providers)

 ✓ Provides a “snapshot” or baseline against which to compare progress with improvement efforts over time & against others

 ✓ Provides information that is representative of the whole population
satisfaction
Results provide a global rating.
“Overall, how satisfied were you with the quality of care and services you received?”

experience
Results provide a measure of acceptability.
“Were you involved in decisions about your care as much as you wanted?”

“outcome”
Results provide a measure of self perceived health status and quality of life concerns.
How would you rate your health? How would you rate your quality of life?
PREMs + PROMs = Better Together
Essential building blocks for patient-centered care

To achieve a complete view of the quality of care, it is desirable to combine measures of experience with measures of outcome.
Lena Cuthbertson & Rick Sawatzky, Jan 31/2014
Accomplishments of BC PREMS
2003 to 2014

• Coordination of province-wide surveys in BC for 11 years

• Feedback from more than 1 million users of health care services across 13 sectors/subsectors and all age groups

• Quantitative AND qualitative reporting and analysis

• Practical support to make effective use of data for QI and for accountability

• Public reporting of results
From whom have we heard?

- Acute Inpatients (medical, surgical, pediatrics, maternity, rehab)
- Outpatient Cancer Care Patients (radiation, IV chemo, non-IV)
- Emergency Department Patients
- Mental Health & Substance Use Clients
- Mental Health & Substance Use Families/Supporters
- Long-Term Care Residents
- Long-Term Care Families & Frequent Visitors
<table>
<thead>
<tr>
<th>Year</th>
<th>Sector</th>
<th>Methodology</th>
<th>Timeframe</th>
<th>Response Rate</th>
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<tbody>
<tr>
<td>2003</td>
<td><strong>Emergency</strong></td>
<td>Mail; Random sample 103 facilities</td>
<td>Point in time -- 3 months July 1&lt;sup&gt;st&lt;/sup&gt; to September 30&lt;sup&gt;th&lt;/sup&gt; , 2003</td>
<td>37.6%</td>
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<tr>
<td></td>
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<td>As above 111 facilities</td>
<td>Point in time – 3 months February 1&lt;sup&gt;st&lt;/sup&gt; – April 30&lt;sup&gt;th&lt;/sup&gt; , 2007</td>
<td>32.5%</td>
</tr>
<tr>
<td>2007 to 2015</td>
<td></td>
<td>Continuous 111 facilities</td>
<td>May 1&lt;sup&gt;st&lt;/sup&gt;, 2007 to March 31, 2015</td>
<td>31.1%</td>
</tr>
<tr>
<td>2004</td>
<td><strong>Long Term Care</strong></td>
<td>RESIDENTS: Interview; Census 102 facilities</td>
<td>Point in time -- Oct 2003 to March 2004</td>
<td>48.4%</td>
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<tr>
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<td>FAMILY/FREQUENT VISITOR: Mail; Census 102 facilities</td>
<td>All residents and their most frequent visitor (who was sometimes a family member, but not always) in directly funded and managed facilities</td>
<td>69.8%</td>
</tr>
<tr>
<td>2005</td>
<td><strong>Acute Inpts</strong></td>
<td>Mail 80 hospitals</td>
<td>Point in time – 3 or 6 months</td>
<td>42.2%</td>
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<tr>
<td>2008</td>
<td>Medical, Surgical, Maternity, Pediatrics Freestanding Rehab</td>
<td></td>
<td>I) June 1&lt;sup&gt;st&lt;/sup&gt; to Nov 30&lt;sup&gt;th&lt;/sup&gt;, 2005</td>
<td>52.8%</td>
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<tr>
<td>2011/12</td>
<td></td>
<td></td>
<td>II) Oct 1&lt;sup&gt;st&lt;/sup&gt; to Dec 31&lt;sup&gt;st&lt;/sup&gt;, 2008</td>
<td>42.8%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>III) Oct 1&lt;sup&gt;st&lt;/sup&gt;/11 to Mar 31/12</td>
<td></td>
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<tr>
<td>2006</td>
<td><strong>Outpatient Cancer Care</strong></td>
<td>Mail 5 regional cancer centres and 45 community cancer hospitals/services</td>
<td>Point in time -- 6 months</td>
<td>60.2%</td>
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<tr>
<td>2012/13</td>
<td></td>
<td></td>
<td>I) Nov 15&lt;sup&gt;th&lt;/sup&gt;, 2005 to May 15&lt;sup&gt;th&lt;/sup&gt;, 2006</td>
<td>48.9%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>II) June 15 to December 16, 2012</td>
<td></td>
</tr>
<tr>
<td>2010</td>
<td><strong>Mental Health &amp; Substance Use</strong></td>
<td>FAMILY/SUPPORTERS: Short stay Inpatient care Handout with telephone follow up</td>
<td>Point in time – 6 months</td>
<td>70% MH</td>
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<td></td>
<td></td>
<td></td>
<td>Oct 12&lt;sup&gt;th&lt;/sup&gt;/2010 to April 11&lt;sup&gt;th&lt;/sup&gt;/2011</td>
<td>60% SU</td>
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<tr>
<td>2014</td>
<td></td>
<td>Development of Survey Tool</td>
<td>Focus groups, cognitive interviews, pilot testing – in progress</td>
<td>TBD</td>
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What have we learned?
The results from the surveys are **VALUED**...

"What a better way to stimulate quality improvement than hearing it from patients. Patient satisfaction impacts everything we do.”
- ED Manager

"If we didn’t have this data, the patient experience may not have been hardwired into the health authority’s strategic plan.”
- BC PREMS Representative
The Focus of BC PREMS...

Survey results = The voice of our patients

Results are meant to **complement** other sources of information about the quality of care at the point of care and at the system level
The path travelled for **REPORTING BC Patient Experience Data**...

**The journey CONTINUES (2011 and beyond...)** How can we ensure that the results add *(more!!)* value to this process? How do we manage within a limited budget? How do we focus on what pts have told us (seamless care)?

**The NEXT step (2007)**
Information is intended to be used to **support improvement of the patient experience at the point of care and at the system level**; we begin **continuous** surveying.

**Our journey BEGINS (2003)**
Our PIT survey results yielded **comparable, statistically valid measures** of the voice of B.C.’s patients in priority sectors, starting with the Emergency Department.
The challenge: to create **FASTER**, **BETTER** and **EASIER** to read reports!

**Timeliness:** Infrequency of reports meant data geared to system level improvement only

**Burden of Data:** Frontline staff and leaders were overwhelmed by the amount of information

**Accountability:** Frontline staff and leaders were overwhelmed by the amount of information

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**FASTER!** Introduce more frequent reports that would allow quicker access to the results

**BETTER!** Introduce reports that are more succinct and focused

**EASIER (to read)!** Create reports that represent a quick snapshot of patients’ experiences and relevant at the facility level
Statistics are people with the tears wiped off.

Prof. J. Selikoff
INTEGRATED *qualitative, quantitative, and annotated* reports now provide timely monthly information to support the people who are directly involved in care to better understand the perceptions of THEIR patients about THEIR patients’ care experiences.

The solution! REAL examples, from REAL people, for REAL stories…
Components of Monthly Reports

Principle: Frontline leaders and clinical teams should monitor quality of care from the patient’s perspective as often as they monitor budgets, labour distribution, overtime, etc.

1. **Quantitative Results**
   - Scientifically robust results displayed in run charts with confidence intervals

2. **Qualitative Results**
   - Patient comments to ‘give life’ to the numerical data

3. **Annotations**
   - Used to explain trends. Add flags in the data and ask prompting questions for those at the point-of-care (front line leaders and clinicians) to consider/answer
Stage 1: Qualitative & Quantitative Reports

Patient Comments Reports
Developed from open-text responses to, “Is there anything else you would like to tell us about your Emergency Department visit?”

Monthly ED Run Charts
A graphical representation of 9 indicator Qs to illustrate trends by detecting variation and ‘flags’
Linking Qualitative & Quantitative Feedback

Sample of an annotated MONTHLY ED Report
“Overall, how would you rate the quality of care you received in the ED?”

Comment [LP1]:
OBSERVATIONS: The score for April is not only above the current long-term average (Avg. = 4.0) but is also the HIGHEST score to date! Congrats!!
QUESTIONS: Although St. Paul’s has a very high overall score, do you think there was anything or any area that particularly excelled in the Spring?
ACTIONS: Watch this indicator over the next few months to see if the scores continue to be above-average.

Comment [LP2]:
Patient Comment: “Very thankful for the calibre of care and the caring attitude of all the staff!” (April 2012)
“Did you have to wait too long to see a doctor?”

Comment [LP3]:
OBSERVATIONS: The score in May is not only well above the current long-term average (Avg = 53% positive) but is also one of the higher scores to date! Awesome!
ACTIONS: Watch this indicator in the coming months to see if the extremely high scores continue or if the scores move back down to the average benchmark.
“Were you told what danger signs about your illness or injury to watch out for when you got home?”
"How would you rate the courtesy of the ED staff?"

Comment [LP5]:
OBSERVATIONS: PERFECT SCOOOOORE!!

Comment [LP6]:
Patient Comment:
"The visit was much quicker than we expected. Dr. XXXXX had an excellent bedside manner and was extremely caring + helpful" (April 2012)
Now, a look forward …
… a(nother) change in direction
Definition of Patient experience...

"The sum of all interactions, shaped by an organization’s culture, that influence patient perceptions across the continuum of care."

The Beryl Institute
BC ED: Continuity and Transition

Provincial - Overall Report: Continuity and Transition (ED Can) (Q2474)

Percent Positive

Change: 0.2

Provincial - Decongestion Facilities: Continuity and Transition (ED Can) (Q2474)

Percent Positive

Change: 1.8
ED explained danger signals

Were you told what danger signals about your illness or injury to watch out for when you got home?
“Did they tell you when you could resume your usual activities, such as when to go back to work or drive a car?”

<table>
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<tr>
<th>Sub-Sector</th>
<th>2005</th>
<th>2008</th>
<th>2011/12</th>
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<tbody>
<tr>
<td>All Sectors Combined</td>
<td>47.5%</td>
<td>45.8%</td>
<td>44.5%</td>
</tr>
<tr>
<td>Pediatrics</td>
<td>54.5%</td>
<td>55.8%</td>
<td>60.0%</td>
</tr>
<tr>
<td>Maternity</td>
<td>43.4%</td>
<td>44.7%</td>
<td>48.0%</td>
</tr>
<tr>
<td>Rehab</td>
<td>N/A</td>
<td>N/A</td>
<td>32.7%</td>
</tr>
<tr>
<td>Inpatients</td>
<td>47.9%</td>
<td>45.7%</td>
<td>43.6%</td>
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- This question is in the **CONTINUITY & TRANSITION** Dimension
- Lowest performing item in BC ...
- 4 of 5 items in this Dimension show a decline for Med/Surg Inpatients and Rehab is lowest of all subsectors
VISION 2014 and beyond
Continuum of Care Surveys

Availability of information from the perspective of patients about the quality of their care that ... follows their “JOURNEY” across the CARE CONTINUUM

• Ambulance Care/Transfer Services → ED
• Emergency Department Care → Acute IP
• Emergency Dept Care → Home/Home Care
• Acute Inpatient Care → Home/Home Care
Findings from the Literature (Dec 2013)*

- Continuity of care is an active area of interest
- Since 2011: Move from setting/condition specific to multidimensional tools (i.e., tools covering multiple transitions and types of patients)
  - Multidimensional usually means primary and outpatient physician specialist care with limited inclusion of hospital care (generally with no differentiation between ED and AC)
  - Absolutely no mention of ambulance/transfer service
- Conclusion, this field is young
  - Several tools are still undergoing development
  - Most have limited use/testing
- Language is an issue: Not all tools have been tested in English
- Promising questions, but no “ready to wear tools”
- Most of the domains that have been found fit into the three types of continuity: relational, informational, and managerial

* A Review of the Literature: Measuring the Patient Experience Across a Continuum of Care Transitions
By: Faye Schmidt, Ph.D. For: BC PREMS and the BC Continuum of Care Surveying Consultation Group
December 12th, 2013
## CONTINUITY ACROSS TRANSITIONS OF CARE

*is the experience of consistent, connected, coordinated care that...*

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<td>Includes meaningful relationships:</td>
<td>Is supportive of information sharing:</td>
<td>Is managed over time, place and providers:</td>
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<td>Builds confidence and trust between the patient and his/her key support person(s) and care provider(s)</td>
<td>Ensures the information needs of the patient and, where appropriate his/her family/supporter(s) are met. Ensures timely and accurate flow of relevant information to the patients’ key care providers.</td>
<td>Ensures the experience of the patient is seamless across: changing care needs, care providers, time, and settings.</td>
</tr>
<tr>
<td>JAN</td>
<td>FEB</td>
<td>MAR</td>
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**BC PREMS WORKPLAN 2014**

**SURVEYING ACROSS CARE TRANSITIONS: 3 PHASES**

1. **ED STATUS QUO**
   - SELECT ITEMS TO INCLUDE
   - DETERMINE ITEMS TO OMIT
   - DEVELOP SAMPLE PLAN

2. **DEVELOP CONTINUITY MODULE (CM); select PROMS items/tool**
   - SELECT VENDOR
   - TEST ITEMS

**ED SURVEYING WITH CONTINUITY MODULE + PROMS v1**

- EVALUATE PHASE 1, ED+CM

**ACUTE IP SURVEYING WITH CONTINUITY MODULE + PROMS v2**

- EVALUATE PHASE 2, ACUTE+CM

**ED/ACUTE BLENDED SURVEYING WITH CONTINUITY MODULE + PROMS v3**

- EVALUATE PHASE 3, BLENDED

- LTC? IPCC? TBD
So, what are we most proud of?

- Engagement of patients and professionals in expert Consultation Groups to plan every aspect of every survey in BC
- Development of questions, modules, and survey instruments that focus on:
  - The patient perspective on Patient safety
  - Self-reported ethnicity
  - The patient perspective on how well we address Emotional Distress and Support for Outpatient Cancer Care
  - The Family/Supporter experience while a loved one is receiving short stay Mental Health & Substance Use Care; the patient perspective on stigma
  - The patient and provider perspective on Surgery, Maternity, Pediatrics, Rehab
- Development of indicators that are added to Health Authority Balanced Scorecards, including Mission indicators for faithbased facilities
- Development of processes to permit return of raw data WITH identifiers for all surveys
- Building of capacity to use baseline data to develop real time patient and family feedback for QI that ... translates data into information, and information into action
- Engagement of non-clinicians
1. Measuring patient experience is NOT an amateur sport.

2. Measuring patient experience is a science…and an art.

3. Patients are integral in survey design, defining what is important and ensuring that questions measure what we intend them to measure.

4. Patient experience reports should be available as readily and frequently as other management reports.

5. Like accountability for patient safety, accountability for positive patient experience should rest with everyone.

6. Without accountability frameworks, action on results takes a back seat to other issues.

7. Improving the performance of one location will not improve the system as a whole.
For further information....

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Link to BC PREMS survey results:
http://www.health.gov.bc.ca/socsec/surveys.html