Through our patients’ eyes:

Plans for measuring patient-reported experiences and outcomes of Primary Health Care in British Columbia

Moving towards a learning health care system in primary care in BC, Vancouver

Lena Cuthbertson
Provincial Executive Director
BC Office of Patient-Centred Measurement

Friday, March 6, 2020
The British Columbia Office of Patient-Centred Measurement under the direction of the British Columbia Patient-Centred Measurement Steering Committee gives BC residents a voice in assessing the quality and safety of their care.

Mandate:
To implement a coordinated, cost-efficient, and scientifically rigorous provincial approach to the measurement of patient and family self-reported satisfaction, experiences and outcomes in annually defined priority sectors in order to enhance public accountability, to support quality improvement and evaluation, and to inform research.

For more information: www.bcpcm.ca
Provincially coordinated surveys in BC | 2003-2020

Emergency Department Care

Acute Inpatient Care
(with modules for medical, surgical, peds, maternity, freestanding rehab)

Continuity Across Transitions (CAT)
(2019 ongoing)

Primary Care, MHSU, Surgical Services (THKR)
(in planning for 2020)

Outpatient Cancer Care
(2005/06, 2012/13, 2019/20)
(radiation, IV chemo, non-IV)

Mental Health & Substance Use
(2010/11)
(short stay inpatients/clients)

Long-Term Care (Residents)
(2003, 2015/18)

Long-Term Care (Residents & Families)
(in planning for 2021)

MHSU Families/Supporters
(2011/12)
(of short stay inpatients/clients)

Cancer Survivorship (2016)
(1-3 years post active treatment)
**PREMs + PROMs = Better Together**

- **Patient-Reported Outcome Measures (PROMs)**
  - How are you doing?
  - Measurement of patients’ and families’ perspectives of their health outcomes and quality of life

- **Patient-Reported Experience Measures (PREMs)**
  - How is/was your care?
  - Measurement of patients’ and families’ experiences with the care provided

- **Person-Centred Measurement (PCM)**
  - What matters to you?
  - Measurement of needs and priorities that matter to patients and family caregivers
A Patient-Centred Measurement Value Chain*

Survey Design
- Selecting survey tools with strong psychometrics (selection based on review of literature and environmental scan and psychometric evaluation of tools)
- Developing tools or new questions if needed
- Defining methodology and sampling plan

Data Collection
- Distributing surveys (paper and pencil, phone interview, face-to-face interview, online, tablet)
- Collecting completed responses/surveys

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

Reporting
- Producing reports with both quantitative and qualitative data in various formats to meet stakeholder needs
- Graphical reports, descriptive summary reports, dashboards, storyboards, etc.

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

Action Planning
- Knowledge sharing
- Promoting local QI initiatives
- Secondary analysis and promoting cross-site and regional collaboration
- Recommending targets for accountability & system level improvement

*British Columbia Office of Patient-Centred Measurement, 2020
Patient-Centred Measurement

SCIENTIFICALLY-RIGOROUS SURVEYS/ASSESSMENTS
- Experiences of care
  - Values
  - Needs
  - Preferences
- Outcomes of care
  - Physical health
  - Mental health
  - Social/emotional well-being
- WHAT MATTERS TO PATIENTS

Transform into DATA
- LARGE MAGNIFYING GLASS

VALIDATE
- IDENTIFY
- QUANTIFY

Translate into INFORMATION
- Patients
- Healthcare providers
- Quality improvement teams
- Researchers
- Leaders/policymakers

Lead to action that results in
- BETTER HEALTH
- BETTER CARE
- BETTER USE OF RESOURCES
- BETTER QUALITY OF LIFE

BC PCM Methods Cluster: https://bcsupportunit.ca/patient-centred-measurement
BCPCM Accomplishments (2002-2020)

- Coordination of province-wide sector surveys for 16+ 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, including key driver analysis to inform focus for local, regional, provincial improvement efforts
- Practical support for effective use of data for accountability and for QI (target setting, toolkits to support 2° analysis, etc.)
- Public reporting and access to de-identified survey data
- Availability of data to clinicians and analysts across BC via an online platform in “close to real time” (The DART, Dynamic Analysis and Reporting Tool) (since 2017)
- Availability of data to health analysts (since 2018) and researchers (beginning 2019) across BC through Healthideass centralized data warehouse and PopDataBC (17.9M linkable patient records)
Reporting of Results (for every sector survey)

**QUANTITATIVE:** (at unit, facility, HA, and BC levels)

*Static Reports* (since 2003 - statistically weighted, “final” reports with peer group, HA, BC and, where available, national comparisons)

*Dynamic Reporting* (since 2017 - web-based, “close to real time” via our DART interactive platform that allows custom queries and crosstabs while in the field; accessible 24/7)

*Raw Data* (since 2010 - “own data” returned to each HA with identifiers; since 2019 - data available to analysts and researchers with and without linking capability based on access permissions via MoH Healthideas)

**QUALITATIVE:**

Searchable database in our DART platform of de-identified patient comments/narratives by sector at unit, facility, HA, provincial levels, coded by theme and valence (downloadable)
Three types of reports are produced at each reporting level:

**Detailed Reports**: Provide a breakdown of the detailed PREMS & PROMS results (e.g. high scoring, areas of improvement, key drivers, dimensions, response options). Qualitative comments are provided in facility/site level reports.

**Storyboards**: Single-page “dashboards” that provide a high-level overview of the survey results.

Survey administration/methodology, scoring, codebook, and analytical details are available for analysts and researchers in a **Technical Report**.
Health Authorities

The Ministry of Health works together with a provincial health authority, five regional health authorities, and a First Nations health authority to provide high-quality, appropriate and timely health services to British Columbians.

Provincial Health Services Authority

The Provincial Health Services Authority is responsible for:
- working with the five regional health authorities to plan and coordinate the delivery of provincial programs and services;
- governing and managing the organizations that provide specialized health services throughout the province;

Learn more about the Provincial Health Services Authority

Regional Health Authorities

The five regional health authorities govern, plan and deliver health care services within their geographic areas.

The regional health authorities are responsible for:
- identifying population health needs;
- planning appropriate programs and services;
- ensuring programs and services are properly funded and managed;
- meeting performance objectives.

Learn more about the Regional Health Authorities

First Nations Health Authority

The First Nations Health Authority represents a new relationship between B.C.'s First Nations, the Province of B.C. and the Government of Canada. The health authority aims to improve health outcomes for First Nations people in British Columbia.

The First Nations Health Authority is responsible for:
- planning, managing, delivering and funding First Nations health programs and services previously provided by Health Canada's First Nations and Inuit Health Branch;
- working with B.C.'s Ministry of Health and health authorities to address service gaps and improve health outcomes for B.C. First Nations;
- improving the quality, accessibility, delivery, effectiveness and cultural appropriateness of health-care programs and services for First Nations.

Learn more about the First Nations Health Authority

https://www2.gov.bc.ca/gov/content/health/about-bc-s-health-care-system/partners/health-authorities
BC’s Dynamic Analysis and Reporting Tool (DART)
www.bcpcm.com/dart

Using the Patient Experience to Transform Health Care:

British Columbia Patient-Centred Measurement, Reporting and Improvement

Login

Email Address:

Password:

Login
Purpose of The DART

- Allows continual tracking of patient reported experience and health related quality of life measures in “close to real time”
- Designed to support local quality improvement initiatives
- Gives 24/7 access to survey results and resource materials
- Permits custom queries and crosstabs
EVERY sector survey project...requires priority setting and recognition of the differing interests of diverse stakeholders, such as:

- **Timing of data collection and reporting**
  - Real time
  - Retrospective

- **Purpose of data collection**
  - Inform point of care decisions
  - Inform local/regional QI
  - Inform accountability

- **Scope of survey (target population)**
  - Population
  - Sub-population(s)

- **Methodology**
  - Face 2 Face interviews
  - Phone interviews
  - Self-complete (mail/paper, online, etc)
After 16+ years ... we continue to learn and evolve!

Been there, done that ....

✓ From PREMS only data collection ... to PCM (PREMS + PROMS = Better Together)
✓ From data collection & reporting only...to supporting action and tests of change
✓ From presenting only numbers... to numbers illustrated with stories
✓ From data collection for QI & accountability... to making linkable results available to researchers (SPOR funding) and analysts for 2⁰ analysis via Healthideias
✓ From static reports to providing “close to real time” results in a dynamic web platform

On the horizon ...

➢ Changing from a sector/location of care focus ...to asking patients about their experiences across their episode/the continuum of care (CAT survey)
➢ Leveraging technology and social media (Quora, Yelp, Rate my MD, etc)
➢ Building provincial capacity for PCM via our SPOR Methods Cluster research priorities, funded projects and post-doc fellows and via our bcpcm.ca website
Progress To date:

- Survey purpose and scope defined
- Core survey instrument selected
- Gap analysis completed (BC info needs vs core instrument)
- High level project plan and target timelines defined

Immediate Next steps:

- Adopt, adapt, and/or develop question lines to address gaps
- Develop sample frame and survey mode
- Issue RFP (Request for Proposal) to procure data collection vendor/partner
- Conduct Privacy Impact Assessment
Primary Care Patient Survey

Purpose

To gather information from the perspective of people accessing and/or needing primary health care about how well the Primary Care health care system is meeting the needs of British Columbians.
Primary Care Patient Survey

Scope

1. To provide information from the patient perspective to inform system accountability and evaluation, and where possible, to promote community level quality improvement.

2. To strive to include people experiencing barriers to care due to multiple intersecting determinants of health who have historically not participated in surveys. This may include, but is not limited to Indigenous, homeless, LGBTQ2, recent immigrant and refugee populations.

3. To measure how well PCNs are impacting patient assessments of the quality of care (i.e., PCN core attributes): currently (current state); is changing over time (trending over time); and is changing compared to non-PCN communities.
Review of Literature and Environ Scan of Primary Care Surveys

Conducted in early 2019 to identify:

- Psychometrically robust survey tools in use in the Primary Care sector in Canada and internationally;

- Tools that can be used to establish a baseline, as well as future trending measurements, regarding patient experiences and outcomes of PC care in BC over time;

- Tools in use in other jurisdictions for potential benchmarking purposes;

- Tools that showed alignment with key attributes for PCNs/PC from the BC Ministry of Health Policy Instrument (September 20, 2017) and General Policy Direction on Establishing Primary Care Networks.
General **Findings** of the Review/Scan

- 14 tools identified that met evaluation criteria; **none** met **all** of BC’s information needs;
- Tools varied in quality and in the amount of information available regarding their performance;
- In spite of these shortcomings, **six tools** seen as contenders for the starting point for customizing a survey that meets BC’s needs.

**General Findings of the Review/Scan**

- USA: CAHPS Clinician & Group Survey with Patient-Centered Medical Home and Health Information Technology Supplemental Items (CG CAHPS)
- Alberta: Primary Care Patient Experience Survey (AB-PES)
- USA: Primary Care Assessment Tool (PCAT)
- New Zealand: Adult Primary Care Patient Experience Survey (NZPES)
- NHS: GP Patient Survey (GPPS)
- Scottish: Health & Care Experience Survey (HCES)
Alberta’s Patient Experience Survey (AB-PES) stood out, because it...

Has a Canadian foundation for its design and testing
- Alberta’s starting point was the CG CAHPS with significant customization and improvement to the:
  - recall period
  - response scale

Attempts to overcome the problem of negative skewing in the data
- In recent conversations with HQCA they reported empirical evidence showing this has been successful;

Provides the potential for benchmarking of results between BC and AB

Caveats:
Not all topics of interest to BC covered; will need to be augmented for BC

AB-PES includes a generic PROMs, the EQ-5D-5L; BC currently uses the VR-12 in all other sectors except upcoming Total Hip & Knee Replacement sector survey
Outcome of Gap Analysis

4 Gap “Bundles” defined

Gap Bundle #1
- Attachment
- Access
- Clear communication
Chair: Jennifer Ellis

Gap Bundle #2
- Cultural safety, humility & related concepts
- Equity considerations and representation of marginalized groups
Co-chairs: Diana Clarke & Jillian Jones

Gap Bundle #3
- Team-based care
- Transitions of care
Chair: Lillian Parsons & Sherry Gill

Gap #4
- Caregiver distress
Chair: Ourania Chrisgian
Gap bundle # 2: Cultural Safety & Humility/Equity

An Indigenous Advisory Group (IAG) has been struck to determine how best to measure patient experiences related to cultural safety and humility for both the Primary Care and the MHSU sector surveys.

The IAG will be co-chaired by Diana Clarke, Director, Cultural Safety and Humility (First Nations Health Authority) and Jillian Jones, Policy Analyst (Métis Nation BC) to advise on CS&H/equity themes for both sector surveys; the IAG will report to the BCPCPM Steering Committee.

**Short term mandate**: To recommend themes and question lines for the current survey cycle (for both the PC and MHSU surveys);

**Long(ger) term mandate**: To explore the issues of CS&H/equity in to inform future survey cycles.

Aboriginal Health Leads across BC have been invited to join the IAG.
### Steps to address Gaps

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gap Analysis</strong></td>
<td>A Primary Care Working Group identified the gaps in the AB-PES tool; results presented to the CG for review and feedback.</td>
</tr>
<tr>
<td><strong>Sourcing Survey Items</strong></td>
<td>Existing validated survey items will be examined from the 14 tools identified via the lit review/scan (Primary Care tools crosswalk), or from BCPCM surveys from other sectors, or from tools found in the grey/white literature.</td>
</tr>
<tr>
<td><strong>Adopting, Adapting and Creating</strong></td>
<td>Candidate survey items will be adopted (word-for-word) or adapted (changes to question wording or response options) or created to reflect the identified gaps.</td>
</tr>
<tr>
<td><strong>Confirming Survey Items</strong></td>
<td>Presentation to and discussion with the CG by each of the Gap Bundle Task Groups will engage broader input to ensure the suggested question lines reflect and address the identified gaps.</td>
</tr>
<tr>
<td><strong>Finalization of Items</strong></td>
<td>Survey items and response options, including word-smithing, will be finalized prior to moving to cognitive testing.</td>
</tr>
<tr>
<td><strong>Cognitive Testing</strong></td>
<td>Testing of the new questions and the entire survey tool with target respondent population to confirm...the questions, from the patient perspective, measure what we intend them to measure and that the survey questions are important to patients in the context of PC service delivery in BC.</td>
</tr>
</tbody>
</table>
Another source of information to inform question lines to address the gaps identified to meet BC’s information needs are the open text, narrative comments from every sector survey in the bcpcm DART (close to real-time web-based reporting platform in response to the final question on every survey:

*Is there anything else you would like to tell us about your (xxxx) experience? We would like to know...*

*What is the most important change we could make on/in this (xxxx)? We welcome your additional comments.*
Patients’ **open text comments related to Primary Care** from other sector surveys

*Source: bcpcm DART*

<table>
<thead>
<tr>
<th>Search terms</th>
<th>Yield (ED 2018, n = 14,076)</th>
<th>Yield (Acute IP 2016/17, n = 24,168)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• My Doctor</td>
<td>75 comments for “my doctor”</td>
<td>97 comments for “my doctor”</td>
</tr>
<tr>
<td>• My Physician</td>
<td>1 comment for “my physician”</td>
<td>2 comments for “my physician”</td>
</tr>
<tr>
<td>• General Practitioner</td>
<td>11 comments</td>
<td>5 comments</td>
</tr>
<tr>
<td>• GP</td>
<td>41 comments</td>
<td>64 comments</td>
</tr>
<tr>
<td>• Family Doctor</td>
<td>130 comments</td>
<td>88 comments</td>
</tr>
<tr>
<td>• Family Dr</td>
<td>15 comments</td>
<td>7 comments</td>
</tr>
<tr>
<td>• Family Physician</td>
<td>13 comments</td>
<td>4 comments</td>
</tr>
<tr>
<td>• Nurse Practitioner</td>
<td>8 comments</td>
<td>1 comment</td>
</tr>
<tr>
<td>• NP</td>
<td>2 comments</td>
<td></td>
</tr>
<tr>
<td>Total:</td>
<td>296 comments</td>
<td>Total: 268 comments</td>
</tr>
</tbody>
</table>
“Went to my doctor (works 2 days a week -- leaving in July so I will go into the thousands and thousands of locals who have NO doctor. He looked up my visit and there was NOTHING RECORDED. I really don't know what we can do here in this community.”

“Worst problem was **not having a family doctor in town**. Means we may have to move back to the Island where we still have one. Too frustrating going back and forth between doctors, hospitals and health systems. Have seen 13+ doctors since early November and that probably delayed much needed treatment. But **we need a family doctor, a go-to person when we need answers. For now we have to sit and wait in Emergency - not a good use of ED resources, and perhaps counterproductive to general health to be waiting amongst respiratory viruses, especially if immune-compromised.”

“I personally have an NP who actually is my 'family Doctor' and has energy and time for me . Very up to date and efficient. Our clinic provides everything we need except for very severe cases.”
“It would have been great if the doctor's record had been forwarded to my own doctor. That would help him greatly if he knew what happened to me at the hospital, like for example what did they do to lower my blood pressure or sugar level. It would have been really nice if they sent that information to my doctor.”

“When I got home I phoned the hospital with a concern and was told to phone my Doctor. I could not get an appointment for 1 week so I ended up waiting in our local Emergency for 3 hours.”

“More beds and the staff to service them well. Advocate for more GPs in the community. Without them the Emergency ward becomes a de facto clinic for medical interactions that do not really constitute emergencies.”
Primary Care
Patient Experience Survey 2020/21
Timeline

Jan – Dec ‘19
- Review of literature and environmental scan of tools completed
- Consultation Group formed to guide survey planning & implementation
- Two Working Groups struck: 1) To define survey purpose and scope (done and CG endorsed)
  2) To reviewed lit review/scan recommendations and confirm core survey instrument (AB-PES selected & endorsed by CG)
- Gap analysis completed, identifying thematic topics areas missing from core survey (four gap bundles)
- Struck four Task Groups to recommend adopting, adapting, and/or developing custom questions to address the four gap bundles

Jan – April ‘20
- Indigenous Advisory Group struck to make short and long term recommendations re Cultural Safety & Humility question lines & Indigenous Methodologies for PCM, representativeness, etc.
  - Task Groups will recommend custom questions to address gap bundles
  - Develop cognitive test plan, including recruiting and training of surveyors (timing to leverage MHSU cog testing plans)
  - Use historical/projected service volumes and locations/peer groups to develop sampling strategy and sampling plan
  - Confirm source of patient records to field survey (? Healthideas/ MSP)

May – Sept ‘20
- Recruit patients and conduct cognitive testing; number of rounds to be determined
- Finalize survey tool
- Plan survey administration
- Begin discussion of reporting framework to inform RFP
- Issue RFP for data collection vendor/partner
- Conduct Privacy Impact Assessment (PIA)
- Plan privacy/security audit of data collection vendor
- Develop communication plan (?? launch public awareness campaign, plan for public reporting

Oct ‘20 onward
- Develop reporting framework (inclusive of defining peer groups, desire for “close to real time” reporting (for QI at local level) throughout period of data collection, static “final” reports, etc)
- Begin data collection!!!

Jan ’21 onward
- Analyze results and develop static reports
- Plan for public release of results
- Evaluate survey methodology and administration
- Conduct psychometric testing of survey(s)
- Make refinements to survey tools, if necessary
- Begin planning and budgeting for second or ongoing survey cycle(s)

Draft: March 2020
At the heart of every data point in healthcare is a person. Data points in healthcare are a person.