

British Columbia Patient-Centred Measurement
Indigenous Advisory Committee
Progress & Impact Report
2020-2022



Indigenous
patient-centred
measurement



Data is the story.

Stories have power.

Who is telling, and who has control over, 'our' stories?

– Mark Matthew, Co-chair, BCPCM Indigenous Advisory Committee

The BC Patient-Centred Measurement (BCPCM) Steering Committee's Indigenous Advisory Committee (IAC) was established in March 2020 to provide advice on decolonization and Indigenization of methodologies for patient-centred measurement, generally, and measurement of cultural safety, specifically.

Since its inception two years ago, the IAC has informed the development of a measure of cultural safety from the patient perspective, including experiences of unfair treatment and racism. In addition, the IAC recommended, and the Office of Patient-Centred Measurement adopted, a distinctions-based approach for reporting of BCPCM results.

The IAC's strategic work moving forward will focus on addressing the lack of diverse Indigenous voices and methodologies in mainstream measurement that contributes to health inequities. The goal of the IAC and of the BCPCM Steering Committee is culturally safe measurement inspired by ongoing conversations about thinking and doing measurement differently.

PCM from an Indigenous-lens was a good starting point. Indigenous-led measurement, utilizing Indigenous methodologies that incorporate Indigenous ways of asking, sharing, assigning meaning and importance, and addressing challenges is expected to result in more meaningful improvement in the quality and relevance of health data collected and reported from First Nations, Métis and Inuit. The IAC is now working to articulate pathways to Indigenous-led PCM with methodologies relevant to the worldview of the peoples on whose land the data is collected. The use of Wise Practices is expected to lead to more fulsome, culturally safe participation in data collection and community-relevant analysis. Use of culturally safe methods that respect the sovereignty and self-determination of First Nations, Métis and Inuit is expected to lead to more accurate data that drives system change and improves health and wellness in Indigenous communities.

We will know that we have achieved
cultural safety when the voice of the people
receiving our services tells us we have.

#itstartswithme

FNHA's Policy Statement on Cultural Safety and Humility

About the IAC

The IAC's Indigenous members are leaders at local, regional, national and international levels, reflecting the diversity of First Nations and Métis communities, languages, genders, geographies, and skills and expertise. IAC members provide advice from their own unique perspectives and the structure of the Committee is reflective of Indigenous worldviews. To represent distinctions-based work with intentionality First Nations and Métis co-chairs were invited.

In March 2021, the IAC adopted the teachings of the Sacred Fire to inform a series of Agreements intended to guide the intent and participation of the IAC membership. The IAC's [Fire Agreements](#) serve as decolonized and Indigenized Terms of Reference for the Committee, which meets twice per month and operates at both a strategic level and by providing “just in time” advice to the Office of Patient-Centred Measurement to inform the measurement of cultural safety in sector surveys both in planning and already in the field.

The United Nations Declaration on the Rights of Indigenous Peoples, the Truth and Reconciliation Commission's Calls to Action, BC's In Plain Sight Report and Health Standards Organization's Cultural Safety & Humility Standards form the foundation and provide the roadmap for the Committee's work.



About this report

This report provides a summary of the progress made against the IAC's three-year work plan and, ultimately, the impact the IAC has had on the BCPCM Steering Committee's strategic direction and work to date. Intended to be an annual report, this inaugural version covers the period from the IAC's inception, March 2020, through December 2022.

Impact of the IAC

PROMOTING KNOWLEDGE UPTAKE

As a new Committee, the IAC has been in a formative stage since it was established. There was no precedent for the IAC within the structure of the BCPCM Steering Committee. Much time has been dedicated to establishing a foundation for the IAC, which reflects governance best practices, Indigenous guiding principles, and ambitious goals. Priority has been given to positioning the IAC for long-term success as an integral part of the agenda for PCM in British Columbia. The Terms of Reference, reimagined as the IAC's Fire Agreements, were developed to ensure the IAC would be positioned to showcase how Indigenous knowledge, experiences and ways of knowing can inform and decolonize current PCM processes (i.e., the value chain of survey tool selection and development, data collection processes, analysis, reporting and dissemination and on Indigenous ways of knowing).

The IAC accepts that the BC Office of PCM, with humility, has acknowledged that until the IAC was struck, no such process existed to ensure Indigenous representation and leadership was in place to lead to meaningful change in patient-

centred measurement. The OPCM and the BCPCM Steering Committee, at its November 2021 Strategic Planning session, committed to moving towards decolonization of colonial methods and processes in patient-centred measurement.

The collaboration between the OPCM and the IAC has been recognized nationally and internationally as having set a leadership example of what Reconciliation can look like for other groups. In the May 5, 2021 issue of Health Affairs, the IAC's work was recognized,

“... we urge inclusion of specific concepts and questions related to racism and ethnic bias in care experiences. For example, the Office of Patient-Centered Measurement within the British Columbia Ministry of Health now asks questions such as, “Did you feel you were treated unfairly due to your race or cultural background?”, in standardized provincial surveys. Questions that explicitly address “cultural safety” and unfair treatment and discrimination in care delivery were designed in consultation with an Indigenous Advisory Committee. We strongly support efforts along these lines in the ongoing review and revision of patient surveys. The inclusion of racial/ethnic groups and organizations in the development and testing of survey questions ... is imperative.”



In February 2022, the province of Quebec as a part of the inquest into the death of Joyce Echaquan, a 37-year-old Atikamekw woman who died on September 28, 2020 in the Centre Hospitalier de Lanaudière in Saint-Charles-Borromée, invited the IAC to share the Fire Agreements and to provide advice on measurement of cultural safety from the patient perspective.

On September 16, 2022, the Canadian Institute for Health Information (CIHI) hosted the webinar, “Addressing Anti-Indigenous Racism in Canada’s Health Care Systems Through Measurement and Indigenous Data Governance”; the IAC was invited to participate as one of three panelists.

[The recording is available here.](#)

DEVELOPING A MEASURE OF CULTURAL SAFETY

One of the earliest and far reaching impacts of the IAC to date has been the development of a *Cultural Safety from the Patient Perspective* module of questions that address five domains, including discrimination and unfair treatment. These questions, alongside disaggregated reporting of Indigenous identity, have now been included in the BCPCM provincially coordinated Emergency Department, Acute Inpatient (including maternity, pediatrics and surgery), Long Term Care, Home Support, and pending Mental Health and Substance Use sector surveys. Initial psychometric analyses of the items developed and

selected by the IAC for measuring the concept of cultural safety has been initiated. These analyses, using real data from BCPCM provincial surveys, explored whether the questions, together and individually, demonstrate the psychometric characteristics necessary to comprise a single overall measure of cultural safety. Although this is a work in progress, the intent is to ensure the IAC's measure of cultural safety will drive greater accountability at a system level, and a more deliberate and concrete focus on metrics to track, evaluate and report on progress against the findings of the [In Plain Sight report](#).



Domains of the IAC's Cultural Safety from the Patient Perspective Module

Full description of the domains and all the questions of the module can be found [here](#).

Cognitive Testing of the Cultural Safety from the Patient Perspective Module Questions with Indigenous respondents

These are examples of probes informed by the IAC for cognitive interviews conducted by Indigenous staff of the OPCM with Indigenous respondents about the question developed to ask about unfair treatment due to race or cultural background. Cognitive testing confirmed the question measured what was intended and although it triggered emotional feelings should be included with a trigger warning.

What would “unfair” treatment look like to you?

“*Pushed aside, rushed out, or overlooked while seeking care, not having concerns addressed*”

**Does this question trigger emotional feelings for you?
If so, would you feel able to answer this question?**

“*This question does trigger emotions ex. Experiences of the woman in Quebec...; It's not a new thing for a First Nations person to experience nor answer. Yes, I would answer*”

On a scale from 1 to 5, did you feel that this is an important question to ask patients?

“*Oh, it's a definite 5 — It's so important to measure the level of discrimination so that it can be addressed. Thank you for being brave to ask these questions. Thank you, thank you, thank you.*”

CHANGING THE WAY PCM IS CONDUCTED

The IAC's strategic work plan aims to address health inequities by addressing the lack of diverse Indigenous voices and methodologies in mainstream measurement, by challenging the assumptions of the dominant systems' perspectives and by creating space for First Nations, Métis and Inuit to join the conversation on providing culturally safe measurement. The IAC will continue to provide an Indigenous-lens, as needed, however, the emphasis will begin to shift to Indigenous-led measurement that highlights measures and indicators relevant to First Nations, Métis and Inuit wellness providing contextual strengths-based solutions. The use of Wise Practices is expected to ensure more fulsome, culturally safe participation in data collection

and community-relevant analysis. Use of culturally safe methods that respect the sovereignty and self-determination of First Nations, Métis and Inuit will lead to more accurate data that drives system change and improves health and wellness in First Nations, Métis and Inuit populations. The IAC will showcase an abstract to showcase its efforts to transition to Indigenous-led approaches to PCM at the 2023 International Society for Quality of Life (ISoQoL) conference in October. The IAC has partnered on a panel presentation with colleagues in New Zealand who have developed a Māori Health Equity Report, with the Health Quality Council of Alberta and the Cree Pimatisiwin & Blackfoot Kipaitaiipiwahsinnooni.

FORGING STRONG RELATIONSHIPS

Significant effort has been dedicated to building strong relationships between the IAC and the staff of the OPCM. The focus on relationships has supported open and direct conversations. The IAC developed a cultural safety training program for OPCM staff, delivered jointly by First Nations Health Authority and Métis Nation BC (MNBC) members.

Overall, the IAC has been well supported by the staff of the OPCM. The approval of the BCPCM Steering Committee's two-year Action Plan, 2023 to 2025, provides an opportunity to allocate a formal budget and staff allocation to the IAC for its ongoing work and for the implementation of IAC and BCPCM identified priorities.

Relationships have also been initiated with the health authority Vice Presidents of Indigenous Health; the IAC co-chairs are members of the VP-Indigenous Health Subcommittee on Cultural Safety Measurement (one as a liaison to the IAC; the other representing MNBC). The VP of Indigenous Wellness and Reconciliation at Providence Health Care has engaged with the IAC to support continued refinement of the cultural safety module, requesting support from the OPCM for cognitive testing with the goal of the finalization of a set of indicators for regular reporting, in a manner aligned with Indigenous data governance and CIHI's indicators for measuring cultural safety in health systems.

PROMOTING IAC EFFORTS

The IAC informed the content of a webpage on the bcpcm.ca website dedicated to promotion and knowledge translation of Indigenous PCM (see: [Indigenous PCM](#)). In the late winter and early spring of 2022, the IAC collaborated with Indigenous artist, Kwexata'Isip (Ovila Mailhot), Nlaka'pamux and Stó:lō Nation, on the development of our Indigenous PCM logo and an artistic representation of our Fire Agreements. Ovila Mailhot was invited to explain the inspiration for the graphic designs on a [recorded video](#).

IAC members are now documenting the journey of Indigenous PCM from its inception in 2020. The focus is on critical reflexivity, questioning what can be learned in hindsight from the IAC's work to date and how and what could be done moving forward to further decolonize those processes. The perspectives of both members of the IAC and the OPCM will be showcased and the paper submitted for publication.

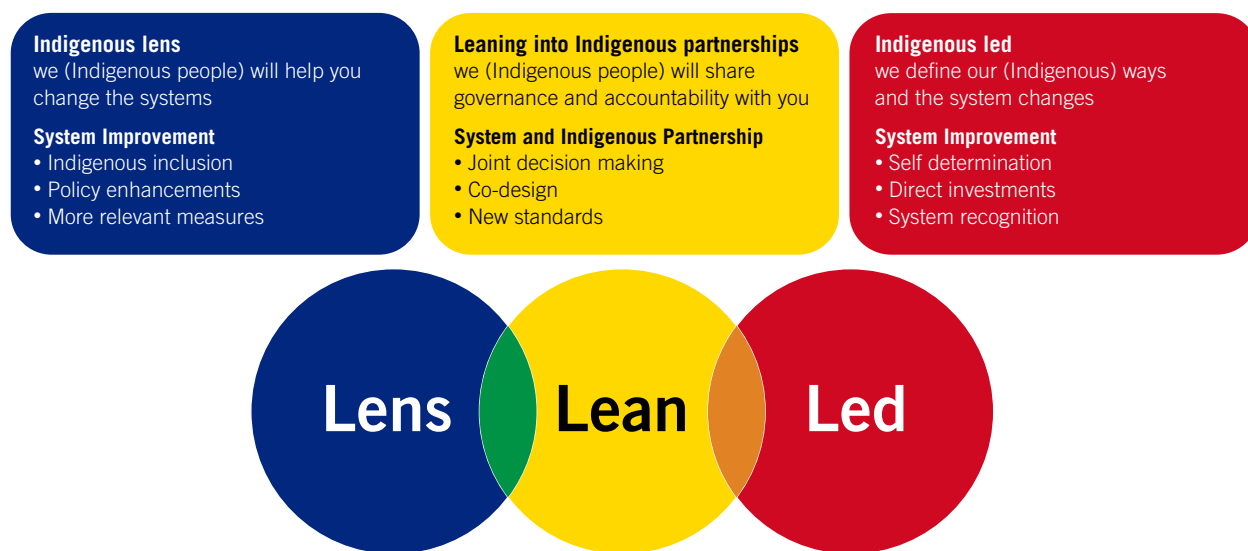


Looking ahead

CONNECTING CONCEPTS & PARTNERSHIPS

The IAC's plans for Indigenous PCM are big. As the IAC looks ahead to the next year, the focus will be on concrete advice to the BCPCM Steering Committee on specific Indigenous-led PCM that incorporates Indigenous knowledge

into measurement of cultural safety from the Indigenous patients' perspective. The graphic below illustrates the IAC's conceptual model for the work ahead.



Over the next two years, the IAC will:

- Continue to enhance systems work through intentional inclusion and investment in mechanisms that enhance the presence and value of Indigenous Patient Voices.
- Look for opportunities to establish common elements of patient feedback processes and share knowledge about promising approaches.
- Not be solely reliant on retrospective measures.
- In addition the IAC will be proactive in reaching into Indigenous communities for their perspectives on health care harms (their experiences and outcomes) and promising practices (to inform PCM methods).
- Ensure linkages to local and system level quality improvement as an incentive for change.
- Link to value based health care (VBHC) approaches that will allow measurement to confirm that as Indigenous experiences improve (i.e., reduction in measures of racism, unfair treatment and discrimination), health outcomes will improve and unnecessary (and costly) medical interventions will decrease.

IAC Members

Acknowledgement: We humbly acknowledge the contributions of our founding members, Jillian Jones (Co-chair, MNBC), Diana Clark and Dion Thevarge ((Co-chairs, FNHA), Megan Miscovic (FNHA) and Terri Gillis (MNBC), as well as the support from the OPCM, including Lisa Corscadden, Meghan Muller, Setareh Nourani, Zeena Yesufu and Lena Cuthbertson. Current IAC members are listed below.



Mark Matthew, Simpcw First Nation, IAC Co-Chair, Director of Indigenous Health, BC Patient Safety and Quality Council



Stephen Thomson, Métis Citizen, IAC Co-Chair, Director, Health Governance, Métis Nation British Columbia



Namaste Marsden, Gitanyow Nation, Daxgyet Director, Gitanyow Hereditary Chiefs



Nancy Laliberté, Nehiyaw iskwew/ Métis, Senior Director, Systems Transformation, Indigenous Health, Provincial Health Services Authority



Mathew Fleury, Nēhiyawak (Mistawasis Nēhiyawak; Plains Cree), Gimewan Niimi/Rain Dancer, Manager, Research and Knowledge Exchange, First Nations Health Authority; Adjunct Professor, Faculty of Health Sciences, Simon Fraser



Jenny Morgan, Gitxsan First Nation. Lax Gibuu (Wolf clan) from the House of Wii Muk'willixw, Assistant Teaching Professor, School of Social Work, University of Victoria.

“This work almost needs to come with a statement of limitations. We have modified the conventional, the western approach to measurement. We have been innovative, some would say it has even been a game changer, but it has its limitations. So, we need to keep the door open to improve on our work ... lay a foundation for people to do better. Our work is the culmination of the last 7 generations and it is for us to put it out for the next 7.”

— Stephen Thomson, IAC Co-Chair

