

Empowering Voices: Navigating Culturally Responsive Evaluation in Indigenous Communities

Learnings from the Indigenous Advisory Committee to the BC Patient-Centred Measurement Steering Committee

Presented by:
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Indigenous
patient-centred
measurement

Who we are

The BC Office of Patient-Centred Measurement

- Since 2003, the OPCM has collected patient perspectives about experiences and outcomes of care via surveys across health care sectors on behalf of the 7 health authorities and Ministry of Health, guided by the BC Patient-Centred Measurement Steering Committee; for more info: <https://www.bcpcm.ca>



The Indigenous Advisory Committee

- Established in March 2020 to provide input on measurement of Cultural Safety and Humility, to decolonize and Indigenize methodologies for patient-centred measurement and to provide *'just in time'* advice on surveys; for more info: <https://www.bcpcm.ca/indigenous-pcm>



Our (two-fold) Intentions for Today's Session

The Intention of **sharing our work**

To demonstrate the in depth and thoughtful relationships that were built to do this work in a good way



FIRE AGREEMENTS

HOW we work

The Intention of **our work**

To share our efforts to measure patient experiences of **Cultural Safety** of their care, and specifically to hear from **First Nations, Inuit and Métis people**, to improve accountability of the health system to hear and work to improve areas where experiences are not positive

WHAT we have accomplished



FIRE AGREEMENTS

Our Guiding Principle:

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

FNHA’s Policy Statement on Cultural Safety and Humility

Decolonizing and Indigenizing how we work together

Our Fire Agreements serve as an exemplar of how our Indigenous Advisory Committee is working to support cultural safety and humility.

Reflecting on how we are undertaking this work

How do we each bring our knowledge, skills and experience to our gatherings to ensure that what we each contribute is meaningful?

Have I prepared myself?

- ✓ I have gathered knowledge

Have I held myself responsible?

- ✓ I am a safe person

Am I committed to change?

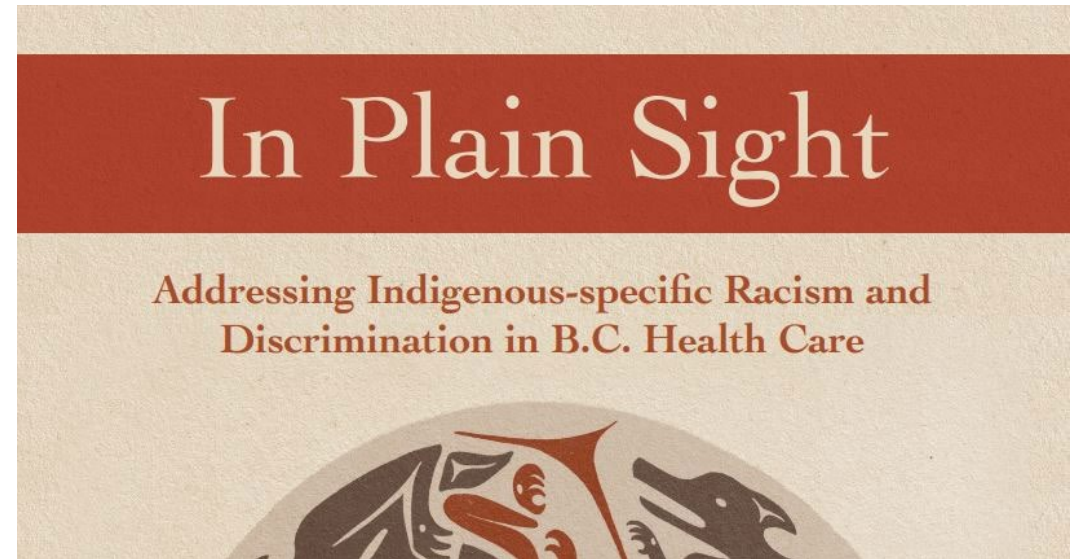
- ✓ I am ready

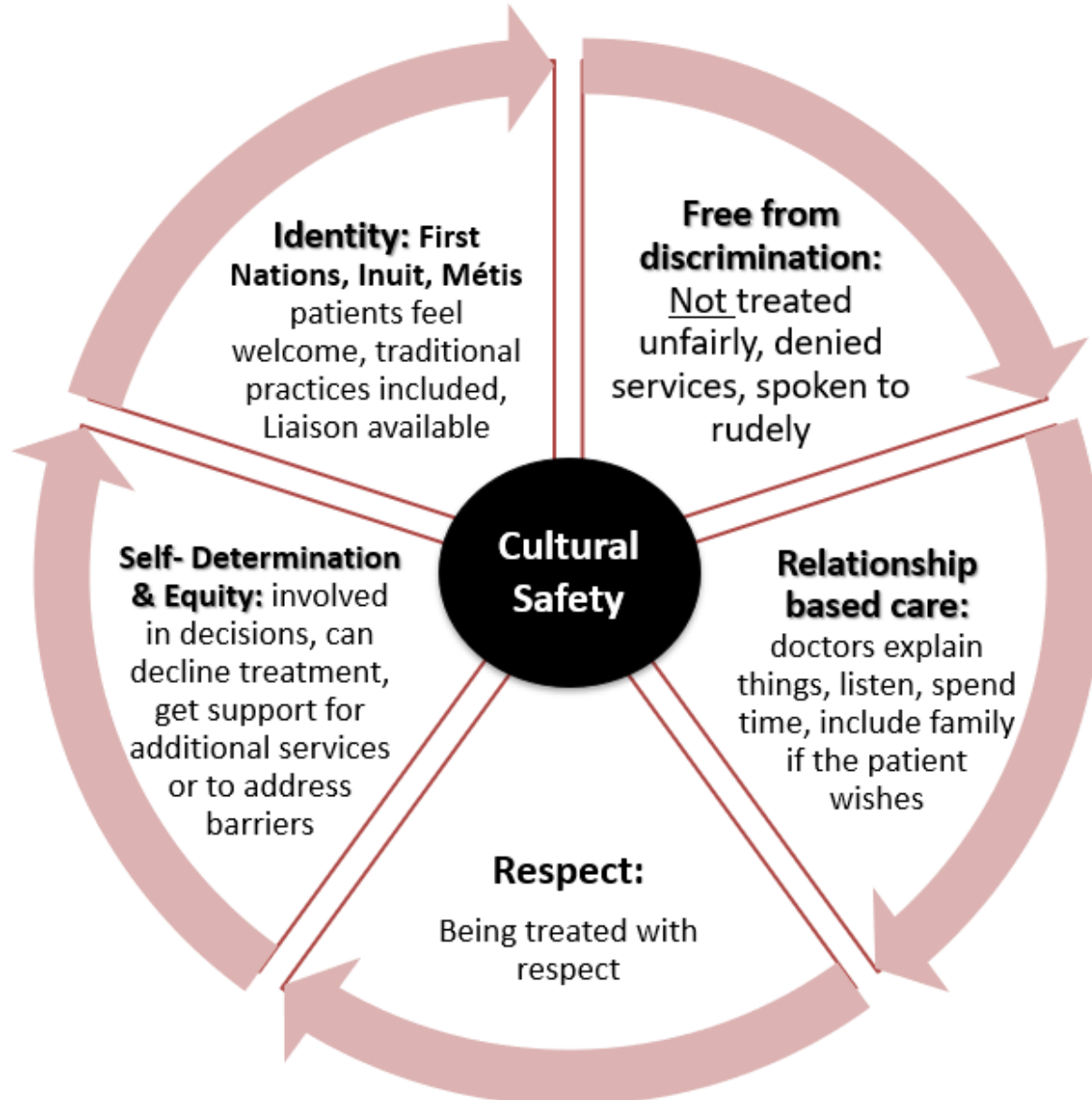


FIRE AGREEMENTS

Why this work is needed

- History of, and ongoing, colonialism and resulting health disparities
- Mistreatment of Indigenous people in the health system and history of racist research
- Mistrust in research, low participation
- To counteract the racism in healthcare, increased focus on Cultural Safety and Humility





IAC Cultural Safety module

- Questions related to **Relationship-based care**, **Autonomy** (involvement in decisions) and **Respect** were considered to be universal aspects of patient experience; many were adopted/adapted from other surveys
- **Identity and Discrimination** were more unique dimensions related to Indigenous Cultural Safety with few examples in existing surveys.
- **Identity** questions were developed to be asked only of Indigenous respondents

See <https://www.bcpcm.ca/indigenous-pcm> for a full description of all questions in BC's Cultural Safety module



**Gathering and
listening is ...
an Indigenous
Methodology**

Key concepts

- Indigenous concepts of evidence are valid ... because Indigenous people say they are valid
- Set safe(r) and critical spaces
- Ensure everyone knows the purpose
- Participants are compensated for their time and contributions
- Address a problematic topic early and bring forward solutions prior to harms
- Listen to those who have shared experiences
- Take the time that is needed

Connecting concepts and partnerships

System Improvement

- Indigenous inclusion
- Policy enhancements
- More relevant measures

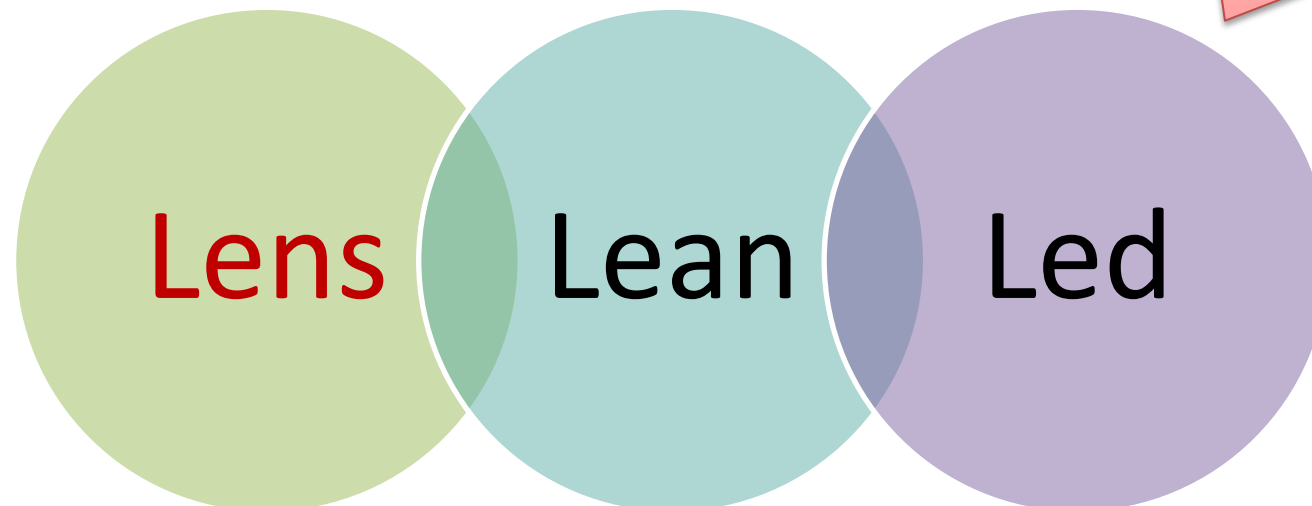
NOTE: This is where our work to date has been situated.

System & Indigenous Partnership

- Joint decision making
- Co-design
- New standards

Indigenous Management

- Self determination
- Direct investments
- System recognition



At the heart
of every
data point in
healthcare is
a person.



Indigenous
patient-centred
measurement

For more information, please contact: info.bcpcm@providencehealth.bc.ca

BC's Cultural Safety from the patient perspective module/questions are posted on our website:
<https://www.bcpcm.ca/indigenous-pcm>



Creating a Path Forward
A ROADMAP FOR DEVELOPING INDIGENOUS PATIENT-REPORTED
OUTCOME AND EXPERIENCE MEASURES

Project Timeline: 2020-2021

Publications: 2021 & 2023

Presented by:
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Empowering Voices: Navigating Culturally Responsive Evaluation in Indigenous Communities



Research Team



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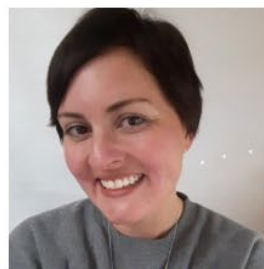
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Advisory Group Members (including patient representatives)

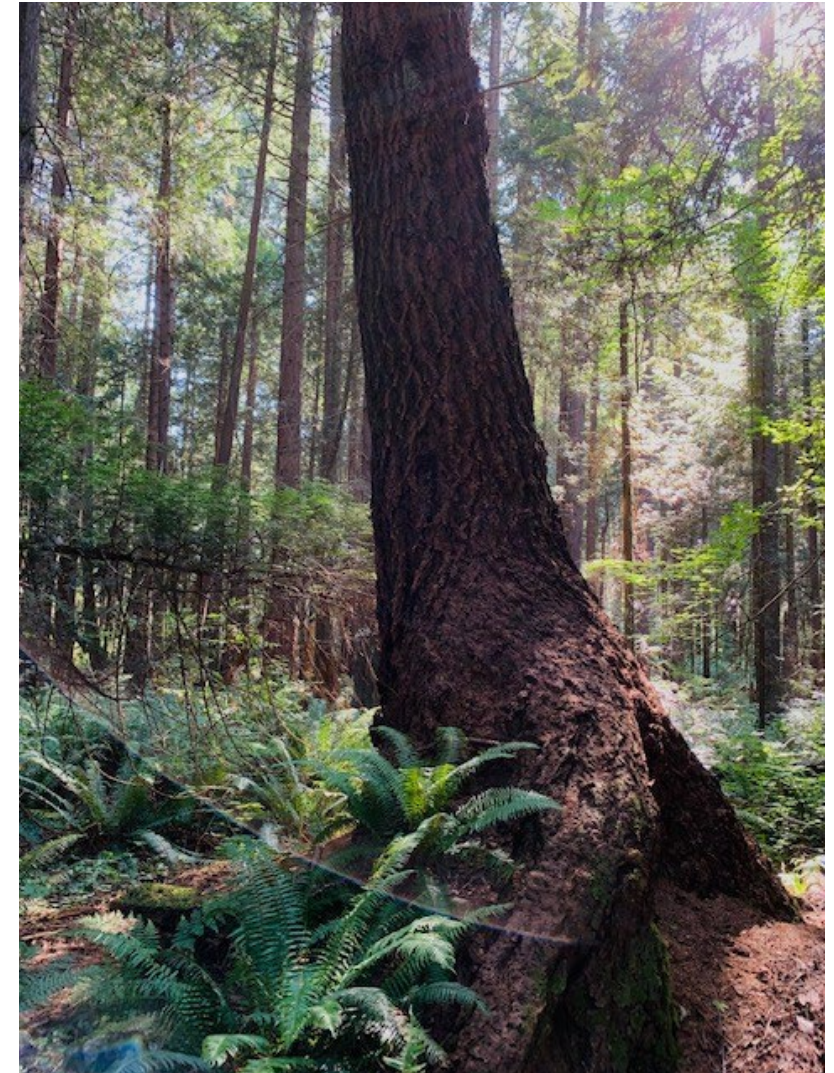
The Pathways document was created as part of a joint research project between the University of British Columbia and the BC Children's and BC Women's Hospital and Health Centres (C&W)'s Indigenous Health Program and funded by the BC Support Unit.

We Respectfully Acknowledge...

- Sharon Jinkerson-Brass, Community Elder, artist and community-based researcher
- Elder Rebecca Brass
- Willie Ermine
- Dr. Jenny Morgan (EdD)
- Elder Shane Point, Musqueam First Nation
- Dr. Lori d'Agincourt-Canning (PhD)
- Dr Shabnam Ziabakhsh (PhD)
- Dr. Soodi Joolae (PhD)
- All our ancestors...

Background

- One way to capture the patient voice is through patient-reported outcome (PROMs) and patient-reported experience measures (PREMs).
- PROMs and PREMs are standardized, validated survey tools that measure respectively patients' views of their health status and experience while receiving care.
- PROMs assess elements of patients' self-reported health, functionality, and quality of life, while PREMs measure quality of care by asking about patients' experience with care.



Background...cont.

- Within colonial systems there is limited understanding of how to develop or adapt self-reported outcome and experience measures to reflect Indigenous knowledge and worldviews.
- There are also very few surveys that have been developed for Indigenous peoples.
- Culturally appropriate PROMs and PREMs are needed to inform policy and program initiatives, planning and evaluation.



Research Questions

1. What are existing patient-reported outcome measures (PROMs) and experience measures (PREMs) that have been developed or adapted for Indigenous peoples?
2. What recommendations and best practices can be proposed to support the development or adaptation of PROMs and PREMs for Indigenous peoples?



Conceptual Frameworks

1. **Two-Eyed Seeing** (Marshall et al., 2015) – Respecting and incorporating both Indigenous knowledge, ways of knowing and research with western knowledge and practices.
2. **Cultural safety** – Creating safe spaces, practicing cultural humility, practicing reflexivity
3. **Strength-based** – Seek to understand positive factors, protective factors and resiliency.



Project Inception

- Collaborative Community Partnerships (both Indigenous and non-Indigenous)
- The Canoe (Elder Shane Point, Musqueam First Nation)/ Project Values
- Dreaming/Capacity Building
- Etiquettes and Protocols/Two Eyed Seeing
- Intergenerational Wisdom/Institutional Knowledge
- Creating a Legacy/Project Life-Cycle and Beyond



Project Inception

- Terms of reference: language inclusive of Indigenous values
- Indigenous Leadership, trauma informed
- Elder invited as a collaborative partner
- Formed an Advisory Council
- Created Elder-In-Training Position
- Creating knowledge carriers beyond the end of the project



The Research Team Processes

- Witnessing/validation
- Connecting with Spirit/relationship building
- Oneness/equality
- Honoring our Ancestors/citing sources
- Honoring our MMIWG2S/reconciliation



The Research Team Processes

- Elder/Elder-in-training opening and closing meetings/
- Creating the Sacred Fire
- Creating our Bundle



Bundle Ceremony



Bundle Work: <https://www.youtube.com/watch?v=Sgj5I4nEMfk>

Introduction of Team:



https://www.youtube.com/watch?v=ID9uK8Ku_yQ

Pathways Project:



<https://www.youtube.com/watch?v=yAt2EC1wCO0&t=4s>



Collaborating with Research Participants

- Welcoming etiquettes
- Reciprocal knowledge sharing
- Humanity and Humility
- Using Experiential Knowledge





Collaborating with Research Participants

- Interview Guide Development
- Team Introductory Video
- Inviting Storytelling



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Methods:

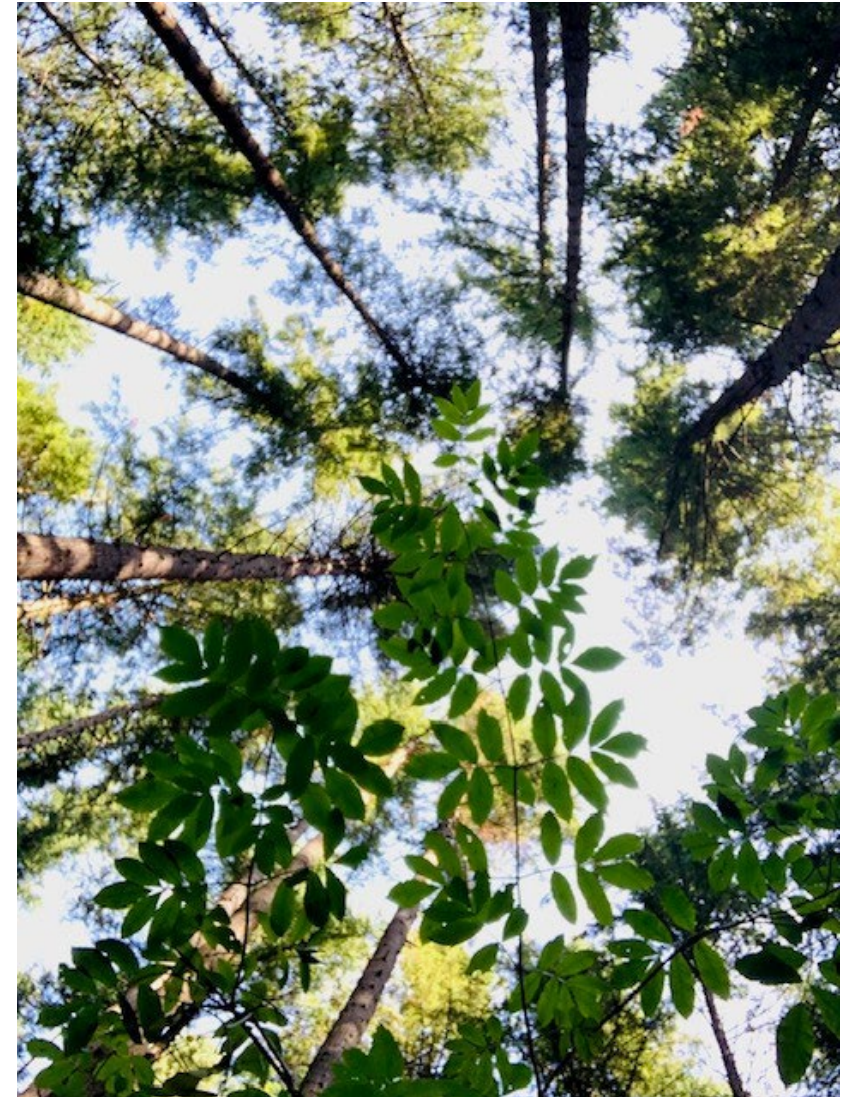


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Participants	Profile
Researchers (n = 14)	<ul style="list-style-type: none"> • 3 self-identified as Indigenous from New Zealand; 5 not Indigenous; 6 unknown • 7 lived in Canada; 5 in New Zealand; 2 in Australia • 13 were affiliated with universities; 1 worked as a health consultant • All had expertise in the development or adaption of PROMs or PREMs for Indigenous peoples
Community leaders (n = 14)	<ul style="list-style-type: none"> • 9 self-identified as Indigenous; 2 non-Indigenous; 3 unknown • Indigenous participants were from: <ul style="list-style-type: none"> ○ <i>Grand Rapids First Nations</i> ○ <i>Ktunaxa Nation</i> ○ <i>Lil'wat nation</i> ○ <i>Nunavut territory (Inuit)</i> ○ <i>Okanagan Nation</i> ○ <i>Titqet Nation</i> ○ <i>Whitefish River Nation</i> • 14 lived in Canada: British Columbia, Nunavut Territory, Ontario • Roles: Elder, Director, Health Lead, Community Planner, Nurse, Operations Lead, Educator, and Research Advisor • All had experience with patient engagement or the use of PROMs and PREMs with Indigenous peoples in their roles
Community members (n = 15)	<ul style="list-style-type: none"> • 15 self-identified as Indigenous • Communities/peoples/ Nations/regions/bands: <ul style="list-style-type: none"> ○ <i>Anishinaabe</i> ○ <i>Gitksan territory</i> ○ <i>Kamloops Indian Band</i> ○ <i>Kahkewistahaw First Nation</i> ○ <i>Lac Seul First Nations</i> ○ <i>Metis/Icelandic</i> ○ <i>Metis Nation</i> ○ <i>Mohawk</i> ○ <i>Nunavut territory (Inuit)</i> ○ <i>Oneida Nation</i> ○ <i>Sto:lo Nation</i> • 15 lived in Canada: British Columbia, Northwest Territories, Alberta, Saskatchewan and Ontario • 9 lived off reserve; 3 lived on reserve; 3 unknown • 7 females; 7 males; 1 transmale • Age range: 22 to 66 • All had experience accessing health care; some had experience completing PROMs and/or PREMs

Pathways

- Pathways document includes **13 protocols**, number of **Teachings** for each, and **Stories**.
- Protocols have been organized using the Medicine Wheel, based on teachings of our project Elder. We invite other communities to re-frame these protocols based on their own cultural frameworks or symbols as appropriate.
- We also view our Pathways as a living document, with more protocols and teachings integrated, as new knowledge is uncovered and old wisdom is incorporated.



Protocols

Emotional

- Build meaningful and reciprocal relationships with Indigenous community partners; recognize the importance of speaking heart to heart
- Accountability: Ensure results are shared and used to inform changes and communicate how those changes were implemented

Spiritual

- Create ethical space
- Ensure ceremony and storytelling are a critical part of project from beginning to end
- Apply Indigenous lens and/or knowledge congruent with Indigenous worldviews to question/content development

Physical

- Establish a study team grounded by Indigenous peoples
- Ensure ethical data ownership, collection and storage
- Administer the survey using culturally appropriate methods (including in-person or orally over the phone)

Mental & Intellectual

- Identify Indigenous community-specific priorities; conduct needs assessment, literature review and environmental scan
- Invite and create content with Indigenous community members leaders and experts
- Ensure Indigenous peoples' knowledge are reflected in the survey tools
- Validate: Ensure cultural appropriateness, acceptability, relevancy, validity and reliability of survey questions
- Analyze data using both Indigenous and western worldviews

Protocol 2: Build meaningful and reciprocal relationships with Indigenous community partners; Recognize the importance of speaking heart to heart

Teachings (examples):

- Build relationships without an agenda— is there opportunity, capacity, interest to collaborate outside of the study
- Plan for long term relationship as opposed to project based
- Ensure time and space to create meaningful relationships
- Meet face-to-face whenever possible

Story:

“...our research centre has been going for a long time, since 1992, and so there are some deeply-established relationships and some deep-established relationships of trust and that is real currently. And the thing is you can never take those relationships for granted and you have to front up. So you actually have to show face in the community, you cannot sit from your desk and type them emails and just keep typing emails and expect them to jump every time you want something....” - Grape, Researcher



Protocol 3: Create ethical space

Teachings (examples):

- Connecting and balancing Indigenous and Western worldviews to guide the process
- Create space for study elements to shift and grow and adapt—how could projects adapt as group learning happens; remain flexible
- Ensure appropriate reciprocity for each participant and that they are honoured (compensated) for their time



Story:

“What might work for here, might not be the same for another Indigenous community somewhere else. So it's important that whether you're – no matter what race you are as a physician - that you have to understand the protocol of where you're working.” – PQ, Community Member

Protocol 11: Administer the survey using culturally-appropriate methods (including in-person or orally over the phone)

Teachings (examples):

- Build relationships with survey participants prior to data gathering (e.g., by engaging in meaningful introductions)
- Provide a “gift” for survey completion – as a way to honour people’s time and voices
- Administer the survey face-to-face or orally as much as possible
- Use Indigenous interviewers if survey is administered orally
- Consider when it might be appropriate for someone to complete the survey on someone’s behalf (e.g. a family member, advocates or provider)
- Provide support and have follow up mechanisms when asking sensitive information

Story:

“...I feel with an Indigenous interviewer, you kind of relate more to them through lived experiences. And I don't even know how to put it, but it definitely would make a difference on how comfortable you would be in answering questions and having a feeling that that person understands where you're coming from.”

-Jackie, Community Member

“And even if something arrives in the mailbox, you know most people will not respond, because it's not because they don't want to, it's just – it's just not the way we sort of do business.” – PQ, Community Member



Protocol 13: Accountability: Ensure results are shared and used to inform changes and communicate how those changes were implemented

Teachings (examples):

- Ensure accountability to the community; need to be committed to respond to community/patients' needs
- Asking people to identify as Indigenous on surveys requires a commitment on the part of the health system to recognize impact of colonial oppression on Indigenous peoples and to be prepared to respond through reconciliatory strategies
- Ensure results are used in a “good way” - not perpetuating stereotypes
- Consider whether study findings could have negative effects or harm the community
- Share results and changes/improvements as the results of feedback with patients/community members

Story:

“ I want people to know I’m Indigenous, not necessarily because I need to be cared for, for Indigenous things. It’s more so that I want people to know I’m Indigenous so they’d know I’ve been cared for unfairly in the past. And therefore I might be wanting to feel extra cared for now. That’s what I think when I answer yes I’m Indigenous, it’s not because I need you to bring in the sage, it’s because I need you to understand that I already feel on edge. I already feel untrusted in the situation, I already feel like I’m coming out of my comfort zone more than other people.” – Paul, community Member

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The Future Path...

- Investment in cultural aspects (budgets and other resources should account for Indigenous collaboration and leadership)
- Importance of rituals and food to bring community together
- Meeting in person (considering the pandemic)
- Incorporating storytelling in our processes
- Collaborative research process (e.g. coding)
- Hold space for importance of process and create meaningful places for Indigenous ways of being in research
- Inform the REB with the components that are not there which create spaces for Indigenous peoples within ethics process
- Co-Creation of other processes to inform structural change (such as an Indigenous Research Ethics Board)

Publications to date

d'Agincourt-Canning, L., Ziabakhsh, S., Morgan, J., Jinkerson-Brass, E. S., Joolae, S., Smith, T., Loft, S., & Rosalie, D. (2023). Pathways: A guide for developing culturally safe and appropriate patient-reported outcome (PROMs) and experience measures (PREMs) with Indigenous peoples. *Journal of Evaluation in Clinical Practice*. <https://doi.org/10.1111/jep.13947>

d'Agincourt-Canning, L., Ziabakhsh, S., Morgan, J., Jinkerson-Brass, E. S., Joolae, S., Smith, T., Loft, S., & Rosalie, D. (2023). Addressing the need for Indigenous-specific PROMs and PREMs: A focus on methodology. *Journal of Evaluation in Clinical Practice*. <https://doi.org/10.1111/jep.13952>

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ORIGINAL PAPER

Journal of Evaluation in Clinical Practice
International Journal of Public Health Policy and Health Services Research



Pathways: A guide for developing culturally safe and appropriate patient-reported outcome (PROMs) and experience measures (PREMs) with Indigenous peoples

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Abstract

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ORIGINAL PAPER

Journal of Evaluation in Clinical Practice
International Journal of Public Health Policy and Health Services Research



Addressing the need for Indigenous-specific PROMs and PREMs: A focus on methodology

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Abstract

Purpose: Differences in Indigenous worldviews, practices and values highlight the

Preview of Published Scoping Review to come...



Inventory of Existing Tools

31 tools in our inventory

- 10 from Canada
- 9 from United States
- 10 from Australia
- 2 from New Zealand

- 26 patient-reported outcome measures
- 6 patient-reported experience measures
- 2 had elements of both PROMs and PREMs

Preview of Published Scoping Review to come...



Inventory of Existing Tools

Key learnings from the tools:

- Strength/resiliency focused
- Use of cultural frameworks (e.g., Medicine Wheel)
- Holistic conceptualization of health
- Balanced approach
- Culture as protective factor to wellness
- Respect and ethical consideration in framing questions
- Focus on relational wellbeing; focus on collectivism

For More Information & To Download Our Slides

SCAN ME

