



PATIENT-REPORTED EXPERIENCE MEASURES (PREMs)

A System that Works for Us

Upholding Indigenous Perspectives and Decolonizing Patient-Centred Measurement for Health System Partners

This summary shares key findings and wise practices for culturally safe patient-reported experience measurement with Indigenous people based on FNHA research exploring how to ask Indigenous people about their health care experiences in a good way.

We interviewed 11 Indigenous people with a wide range of experiences and perspectives. They consisted of patients, Knowledge Keepers, youth, and health professionals. We hope these learnings will help make it safer and easier for Indigenous people to be heard and drive change in the health care system.

Key Findings

Theme 1: Indigenous Wellness Systems

Indigenous people have always valued knowledge, learning, and healthy living practices. These practices have helped keep communities strong for generations. It's important for health care to recognize and support Indigenous cultures and languages.

Theme 2: The Harms of Colonialism and Indigenous-specific Racism

The history of colonialism and racism impacts how Indigenous people feel about and navigate the health care system. This discrimination greatly affects their health.

Theme 3: Indigenous Voices for Change

It's important for Indigenous people to share their health care experiences, so the system can improve.

Theme 4: The Way Forward: Nothing About Us Without Us

The future of health care for Indigenous people must be shaped by Indigenous people themselves.

“Sharing your health care experiences can help transform and improve and enhance medical and health services on- or off-reserve, in cities and towns, or directly in community. The more people decide to openly share their experiences, it only helps our future generations get better quality of life that we’ve been fighting for our whole lives.”

Adam Gauthier
Tla’amin/Cree/Métis child and youth coordinator

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 Michael Smith
**Health
Research BC**

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Contact the Research and Knowledge Exchange team at: RKE@fnha.ca
or visit www.fnha.ca/what-we-do/research-knowledge-exchange-and-evaluation

Wise Practice

1

Explore ways to embed Indigenous worldviews and perspectives of health and wellness into the health care system



Indigenous people have maintained wellness for generations through interconnected relationships with land, community, and culture. To truly reflect these perspectives, health care systems must move beyond trying to fit Indigenous approaches into existing Western frameworks. They should create spaces for Indigenous leadership in shaping policy, research and standards. By centering Indigenous values, health care can better support First Nations well-being and improve health outcomes for all.

Prioritize Relationships

- Invest time in building relationships with Indigenous communities and Friendship Centres.
- Use relational approaches (e.g. healing circles) for patients and staff to foster relationships and address past harms.

Communicate Thoughtfully

- Listen with empathy while avoiding jargon and stigmatizing language.
- Provide a range of modalities to hear from patients.

Be Open-minded and Flexible

- Be mindful to avoid bias in surveys. Change or discard tools if they are unsafe to Indigenous people.
- Incorporate storytelling approaches and honour the gift of the stories shared.

"I think the only thing that I hope... that people learn more about [is] the protocols of our people so they can really begin to understand what they need to do. But also keeping in mind that it would also be a really good thing for them as well, and it could enhance their ability to provide better health care service to the Indigenous population by understanding them more than they do now. So they need to learn that. They need to know that we have – when we talk about protocols it's all-inclusive of our way of life."

Dr. Barney Williams, Knowledge Keeper



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Wise
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2

Foster Accountability and Addressing Indigenous-specific Racism in Health Care



Indigenous-specific racism remains a significant barrier to equitable health care. To address this, the health care system must embrace transparency, cultural safety, and systemic change, grounded in respect for Indigenous rights and worldviews. By recognizing past and ongoing harms, health system partners can work collaboratively to create culturally safe environments that prioritize Indigenous health and wellness.

Promote Lifelong Learning

- Educate yourself and ensure all workers receive training in Indigenous-specific racism and cultural safety and humility.
- Promote engagement with Indigenous communities to build understanding and mutual respect.

Challenge Colonialism

- Work to balance power dynamics. Avoid one-size-fits-all approaches and prioritize community-specific strategies.
- Develop and enforce cultural safety policies. Measure and share progress with communities.

Move Forward with Humility

- Approach learning about Indigenous Peoples with openness, humility and respect.
- Work to reconcile past and ongoing colonial harms on Indigenous Peoples.
- Learn and honour community protocols. Seek guidance if you need clarification

"I don't believe in collecting data if you're not going to use the data for a purpose. So if they are going to utilize it, there needs to be some benchmarker in there. So if everybody's putting five on their number one to ten then you know, have a plan and tell the people the plan. After 50 five in a row then we're going to do something else because this isn't working. So you can survey people all you want and there will be no improvement...It has to improve upon the health care system and even if it's complicated it still has to have some kind of defined process because people don't want to do it if they're not going to be heard and it's not going to improve upon anything."

Patient Partner



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3

Move Forward on Existing Recommendations by Indigenous Peoples for Cultural Safety in Health Care



Indigenous people have shared their knowledge and experiences through many reports and recommendations (e.g. the Truth and Reconciliation Commission and In Plain Sight reports). Now is the time for meaningful action. Health care systems need to listen, take responsibility, and work together with Indigenous communities to make care safer, more respectful, and grounded in Indigenous ways of knowing.

Push for Change

- Recruit and retain more Indigenous employees across health care settings. Provide Indigenous-led supports, such as Elders-in-residence and cultural advocates. Support families and communities in navigating the health care system.
- Create opportunities to collaborate. Share decision-making power with Indigenous communities in co-creating PREM tools to ensure community benefit and effectiveness.
- Conduct lateral knowledge exchange between areas receiving patient feedback (e.g. quality offices, health authorities, etc.).

Use Existing Data and Recommendations

- Do not collect new data for data's sake. Avoid re-traumatization and overburdening of Indigenous people by leveraging and sharing existing data to inform future actions.
- Commit to transparency and accountability in implementing policy and practice changes, reporting changes to Indigenous patients and communities.

Measure Meaningfully

- Implement culturally safe self-identification processes, centering patient needs and being transparent about how data will be used, especially its benefit to patients.
- Only collect Indigenous data that directly benefits Indigenous people and leads to real improvements in health care.
- Update policies and practices to align with OCAP® principles and the CARE Principles of Indigenous Data Governance to honour community ownership and control over data.

“We have...Truth and Reconciliation recommendations, we have In Plain Sight recommendations, we have Jordan’s Principle recommendations, we have Joyce’s Principle recommendations and who is actually moving forward on these recommendations. Who is accountable?”

**First Nations/Métis Patient
Quality Professional**



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4

Redress Power Imbalances to Uphold Indigenous Health Sovereignty and Innovation



Indigenous people are experts in their own health and must have a seat at the decision-making table in health care systems. Addressing power imbalances and supporting Indigenous leadership in PREM initiatives are essential to fostering health sovereignty and innovation. Co-designed processes rooted in respect, self-determination, and cultural safety are key to making meaningful change.

Nothing About Us Without Us

- Recognize Indigenous people as decision-makers, not just participants in PREM initiatives.
- Develop Indigenous PREM methods, measuring what matters to communities in culturally safe and relevant ways (e.g. storytelling) to make PREM safe for Indigenous patients and providers.
- Include the voices of those whose stories may not align with typical narratives.

Provide Appropriate Resources and Capacity

- Sustainable funding and support are essential for Indigenous-led health innovation.
- Resource PREM structures that are independent from the institutions providing care.
- Create accessible communication campaigns (newsletters, posters, social media, etc.) and teach patient activation to increase patient awareness of their rights and navigate the system.

Celebrate Good Work

- Share success stories to inspire and build on positive changes.

Make Space

- Change requires a diversity of Indigenous people, including Elders and youth, leading PREM work.

“What is important is considering how co-designed is your process? Are you, as non-Indigenous people, developing patient-centred and patient-reported experience measurements independent of those partners that you want and need to hear from? If you are, that’s not in alignment with the criteria, it’s not in alignment with your obligations to collaborate with Indigenous leadership. In the end it is critical to reflect on how are you being inclusive of those populations that require specific and distinct relationships?”

Mark Matthew, former FNHA quality professional and and technical advisory committee member



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