PATIENT-REPORTED EXPERIENCE MEASURES (PREMs) A System that Works for Us

A Summary for Indigenous Patients

FNHA engaged with 11 Indigenous people, including patients, Knowledge Keepers, youth, and health professionals about what matters most in gathering and learning from people's experiences of receiving health care. The goal of these discussions was to find out what would make it safer and easier for Indigenous people to be heard, and to create positive change in healthcare system. This is what we heard.

Healthcare must be in service of Indigenous Wellness

We heard:

Indigenous Peoples have maintained health and wellness for generations through interconnected relationships with land, community, and culture. To truly reflect these perspectives, you need a healthcare system that doesn't just try to fit Indigenous approaches into the way Western medicine works. Instead, you need a healthcare system that creates spaces for Indigenous leadership, and centres Indigenous values and ways of knowing, to better support First Nations health and well-being, not just cure illness.

Start with Relationships

- Health care systems must prioritize trust, reciprocity, and accountability to Indigenous communities and engage meaningfully.
- Health care systems must learn from Indigenous ways of building and repairing relationships to address past harms to Indigenous communities.

Make a Safe Space

- Health care system staff must listen with empathy and humility and use clear, inclusive language.
- You should be able to give feedback in any way that feels safe to you.

Change what does not work

Instead of trying to fit Indigenous peoples experiences into standardized surveys that may be biased and unsafe, build ways of listening that work with us. Health care system staff and programs must recognize and honour the gift of stories.



Thanks to Michael Smith Health Research BC for sponsoring this work



FOR MORE INFORMATION

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



We heard:

Indigenous-specific racism continues to cause harm to our communities every day. You need a health care system that recognizes past and ongoing harm and is accountable for making system-wide change in Indigenous-specific anti-racism and cultural safety and humility.

You need health system partners to work collaboratively with your communities to make care safe and supportive of Indigenous health and wellness.

Practice Lifelong Learning

- Health care systems must ensure all workers receive minimum training in Indigenous-specific anti-racism and cultural safety and humility and provide tools for ongoing learning.
- Health care systems must commit to being in relationship with Indigenous communities to build understanding and reciprocity.

Health care systems must acknowledge and commit to redressing unbalanced power dynamics and challenge colonialism

 Health care systems must uphold communities' self-determination and be accountable to measuring progress in eradicating Indigenous-specific racism and reporting back to communities.

Be Humble

- Health care systems must approach learning about Indigenous peoples and listening with openness, humility and respect.
- Health care systems must commit to learning and honouring community protocols and seeking guidance from communities on reconciling past and ongoing colonial harms.





We heard:

Indigenous Peoples have shared their knowledge and experiences through many reports and recommendations, such as the Truth and Reconciliation Commission, In Plain Sight Report, and Jordan's Principle, to name a few. Now is the time for meaningful action. There is a need for health care systems that listen, take responsibility, and work together with Indigenous communities to provide care that is safer, more respectful, and grounded in Indigenous ways of knowing and being.

Commit to change

- Health care systems must prioritize recruiting and retaining more Indigenous employees across health care settings.
- Indigenous-led supports, such as Elders-in-residence and cultural advocates, should be available to anyone who wants them.
- Health care systems must support families and communities to navigate services and care transitions like when being discharged from hospital.

Uphold self-determination

- Health care systems must recognize the sovereignty of Indigenous communities and share power to create culturally safe programs and tools.
- Those gathering feedback on experiences of care should share information back with communities and learn from each other.

Health care systems must show concrete action from data collected so far and must report on progress to Indigenous patients and communities

- When health systems ask Indigenous people to self-identify, it must be safe and about their needs, not the organizations'.
- Data collected by health systems about Indigenous communities must be used to directly benefit communities and improve care.
- Indigenous communities need to have ownership, control, access and possession (OCAP®) of data collected about them.





We heard:

Indigenous Peoples are experts in their own health and must have a seat at the decision-making table with health care systems. You need health care systems to address power imbalances and let Indigenous communities lead the way in how to meaningfully capture and learn from experiences of care. You want to see more Indigenous people in leadership positions. You need health care systems to uphold communities' sovereignty and innovation and be a respectful partner in working together on meaningful change.

Uphold "Nothing about us without us"

- Health care systems must work with Indigenous Peoples to develop culturally relevant and safe ways of capturing experiences of care
- Health care systems must ask for consent before capturing data about Indigenous peoples and must commit to acting on the expressed needs of Indigenous patients and health care providers.
- Health care systems must create safe spaces for Indigenous staff and patients to share their experiences.

Invest in Resources for Change

- Health care systems must commit to funding Indigenous-led health initiatives
- Indigenous communities need clear, accessible information and resources on patient rights and ways to provide feedback Indigenous patients need access and support to navigate health care confidently.

Include Indigenous Peoples

- Health care systems must make a seat at the table for Indigenous peoples to participate in decision-making.
- We need to hear success stories and how they can lead the way to more positive changes.

