A LIVING REPORT

A SYSTEM THAT WORKS FOR US:

Upholding Indigenous Perspectives for Decolonizing Patient-Centred Measurement

First Nations Health Authority
Health through wellness

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Wise Practices

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Project Leads

Namaste Marsden
Diana Clarke
Megan Misovic

Project Team Members (FNHA and partners)

Dr. Kara Turcotte
Mathew Fleury
Dr. Brittany Barker
Katie Bauder
Payal Batra
Riley Bizzotto
Delaram Farshad
Adam Finch
Leena Hasan
Dr. Ashok Krishnamurthy
Nancy Laliberte
Alexa Norton
Erika Pulfer
Sophia Speier
Dion Thevarge

Technical Advisory Committee

Elder Syexwaliya, Ann Whonnock, Skwxwu7mesh Uxwumixw (Squamish Nation)

Darlene Wolfe, Indigenous patient partner

Victoria English, Indigenous patient partner

Christine Hunt, Indigenous patient partner

Dr. Danièle Behn Smith, Deputy provincial health officer

Jessy Dame, Métis RN, MSc

Janelle Tom on behalf of Dr. Nel Wieman, Office of the Chief Medical Officer, First Nations Health Authority

Dr. Becky Palmer, chief people, nursing & health professions officer, former chief nursing officer, First Nations Health Authority

Mark Matthew, Health Quality BC director of Indigenous health and patient & public engagement, former FNHA director of community engagement

EXECUTIVE SUMMARY

Learnings identified in the *In Plain Sight* report (Addressing Racism Review Team, 2020) confirmed that Indigenous Peoples[1] in British Columbia face systemic discrimination and racism in the health care system. It is well documented that the health care system frequently provides inadequate or inappropriate – if not discriminatory – care for Indigenous people in Canada, which can result in them delaying or avoiding accessing care and exacerbates existing health disparities. Patient-centred measurements (PCMs), such as patient-reported experience measures (PREMs), are a tool to monitor, learn from and improve patient safety and experiences in health care. PCM is the systematic measurement of health outcomes, health care experience and health status that is directly reported by patients. PREMs involve asking patients about their experiences in the health care system, typically through surveys. The responses are used by health care organizations, decision-makers and health care practitioners to inform quality improvement, policy development and service delivery and can also be a source of information for First Nations organizations, communities and leadership to advocate and seek quality services for their clients and citizens. However, Indigenous people are less likely to engage with and self-identify on these measures, resulting in a lack of Indigenous perspectives being included. It is crucial that PREMs for Indigenous people are conducted in culturally safe ways so that their voices and perspectives can be shared to support advocacy and quality of care for Indigenous people.

This research project used a twofold approach to better understand the state of cultural safety in PREMs: a scoping review and key informant interviews with 11 Indigenous individuals who held perspectives as patient partners, Knowledge Keepers or youth, or who had expertise in health administration, quality and clinical practice. Key informants discussed how PREMs could be implemented in meaningful, respectful and culturally safe ways with Indigenous people.

1 The term Indigenous Peoples in this report refers to First Nations, Inuit and Métis Peoples. The plural "Peoples" recognizes the diversity of distinct Indigenous groups of the land that is now known as Canada.

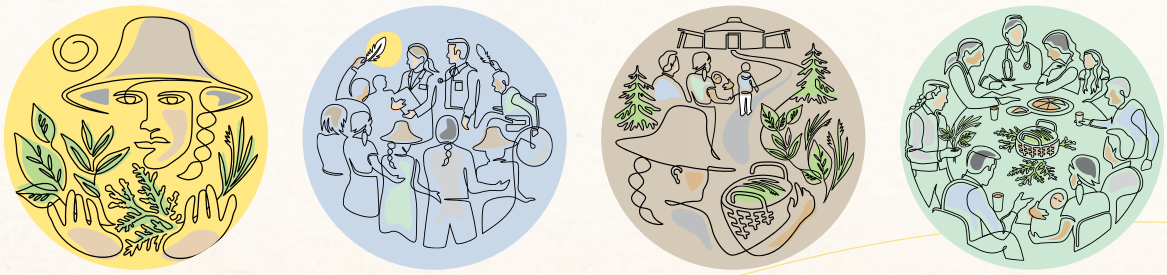
Although this research focused on exploring how to better gather feedback on the experiences of Indigenous patients within the health care system, what emerged from the interviews was much broader. At the heart of the matter lies the experiences of Indigenous people within the health care system, the historical and social context of colonialism, and subsequent power imbalances between Indigenous patients and providers. Themes that emerged in the interviews included: the need for the health care system to honour Indigenous systems of wellness, the ongoing impacts of colonialism, the importance of Indigenous voices being shared and heard by the health care system, and the need for Indigenous self-determination in using patient experiences to shape the health care system. Four wise practices arose from the key findings that everyone in the health care system can apply everywhere:

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

2. **Foster a culture of accountability and work to eliminate conditions that allow and perpetuate Indigenous-specific racism**

3. **Move forward on existing recommendations developed and informed by Indigenous Peoples for hardwiring cultural safety in the health care system**

4. **Redress power imbalances at decision-making levels in health care to support Indigenous health innovation and health sovereignty**



WHAT WE DID

This project combined Western and Indigenous knowledge in alignment with Two-Eyed Seeing (Bartlett, 2012). This approach enabled us to answer our research questions in a decolonial way, while upholding Indigenous self-determination and reaffirming research as a sacred endeavour that illuminates connections between the spiritual and physical world.

Our project included:

- a scoping review of culturally safe, appropriate and relevant approaches of asking Indigenous people about their health care experiences;
- key informant interviews focused on understanding how to gather health care experiences in a culturally safe way; and
- validation gatherings to reflect back what we heard and ensure we were upholding and staying accountable to the messages shared with us by key informants.

Research Process and Oversight

The project was guided by an Advisory Committee consisting of an Indigenous Elder chair, four Indigenous patient partners, and representatives from the FNHA Office of the Chief Medical Officer, FNHA Office of the Chief Nursing Officer, the FNHA Quality team, the Office of the Provincial Health Officer, and a Métis representative. Cultural and wellness workers were available during Advisory Committee meetings.

The project prioritized the hiring of Indigenous project team members, including a senior research coordinator to lead and conduct the key informant interviews and data analysis. The project also prioritized training Indigenous students and involving undergraduate Indigenous students in the thematic coding and writing-up of findings.

Scoping Review

The project team completed a scoping review of peer-reviewed and grey literature to familiarize ourselves with culturally safe approaches to asking Indigenous patients about their health care experiences. The following questions guided the scoping review:

- What culturally safe approaches or protocols are used to gather Indigenous patients' health care experiences in BC, Canada, the United States, Australia and Aotearoa (New Zealand)?

- What Indigenous knowledge-gathering protocols and practices are relevant and important when researching or gathering information about Indigenous Peoples' health care experiences?

The intent was to publish the scoping review separately from this report of key informant feedback; however, staff turnover has resulted in challenges in publishing this component of the project. At a high level, the scoping review identified the following themes from a review of 79 articles and reports:

- Opportunities to demonstrate, describe and learn from a project's culturally safe and appropriate research practices are hindered by limited discussions and descriptions regarding methodology. Word count limits of academic journals contribute to this.

- The inclusion of Indigenous partners within research design and implementation and building relationships with Indigenous key informants and/or communities are vital features of culturally safe and appropriate research.

- The scope and degree of Indigenous inclusion and participation in research varies, and the cultural safety of the Indigenous inclusion and participation is rarely discussed.

- Indigenous cultural safety in PREMs-related research is commonly framed within Western worldviews rather than Indigenous worldviews.

Key Informant Interviews

In 2021, an Indigenous senior research coordinator conducted semi-structured interviews with 11 key informants, including patient partners, health care professionals, Knowledge Keepers and youth. An independent Indigenous researcher reviewed the key informant questionnaires and provided input.

All key informants were Indigenous people living in BC. Interviews were conducted virtually via Zoom. A list of cultural and mental health resources was shared with key informants before their interviews and cultural support workers were available to interviewees upon request. All interviewees were provided with an honorarium to respect their time and willingness to share their perspectives.

Interview audio recordings were transcribed verbatim by a professional transcription service. The Indigenous senior research coordinator thematically analyzed transcripts. The main themes and subthemes were developed by the project team, which included an Indigenous practicum student, and reviewed by the Technical Advisory Committee.

Comprehensive quotes were used with the consent of key informants to honour the words shared. To ensure accountability and to promote co-creation of meaning, each key informant was sent a comprehensive set of quotes from their interview and given the opportunity to edit or add to them. They were also sent the final report, which included their quotes, to review. Key informants were acknowledged at the level of anonymity they preferred, so while some are named or identified by Nation and role, others are only referred to as “key informant.”

In February and March 2022, the team held virtual gatherings with key informants, reflecting back on what we heard to ensure we were upholding their messages and honouring their stories. Themes and wise practices were finalized using informants’ feedback as guidance.

The project team worked with a graphic designer to develop a visual representation of the wise practices emerging from the research.

WHAT WE HEARD

The four key themes and their sub-themes that emerged from the findings are presented on the following pages.

Theme 1 Indigenous Wellness Systems

Theme 2 The Harms of Colonialism and Indigenous-specific Racism

Theme 3 Indigenous Voices for Change

Theme 4 The Way Forward: Nothing About Us Without Us

THEME 1

INDIGENOUS WELLNESS SYSTEMS

Key informants emphasized that Indigenous Peoples have carried teachings to support wholistic, healthy living practices that have sustained Indigenous people from time immemorial. As shared by Duane Jackson, a Gitxsan patient partner:

> *Of course Indigenous Nations have always honoured the acquisition of knowledge, the learning of new things, [and] the searching for a new understanding. We wouldn't have been thriving during first contact. Our nations were thriving when they showed up and they were healthy, that wouldn't have happened if we didn't have research, if we didn't have experimentation, if we didn't understand engineering and science.*

Other key informants highlighted the fundamental importance of connection to culture, oral traditions, Indigenous languages, and the reflection of Indigenous values in health care for sustaining wellness.

Connection to culture, including Indigenous medicine and practices

Key informants highlighted that health care providers need to learn more about Indigenous cultures. A First Nations/Métis patient safety and quality professional emphasized that:

> *They need to learn something about the land that they're on. They need to learn something about the culture of the people that they're serving. And they need to educate themselves about this and not work in a void. And so, they need to spend the time and then they need to give extra special care, extra special patience, extra special kindness.*

Duane Jackson shared an unsafe experience that exemplified how the narrow biomedical perspectives of some Western-trained health providers were harmful in dismissing his daughter's need for cultural connection for her healing:

> *[The health care system] doesn't honour the patient's journey. It doesn't honour the [...] competency of the person you're dealing with...When I brought my daughter in and they asked me what I thought her real challenge was I said I think she's lost connectedness with her culture. They didn't want to hear it. They had no idea. To them it was strictly just her condition and that's all they were dealing with. So they were dealing with a condition and not a person and so that was a big problem.*

Dr. Barney Williams, a respected Knowledge Keeper and therapist, shared:

> *When I was doing therapy, I used a lot of traditional methodology, because back in the day it wasn't even spoken about. Or when I talked to other therapists they would brush it off and say you know, "It's not in any textbook so why should I use it?" When you're working of course I had cases where therapists tried and had no success and I did.*

These perspectives highlight the importance of cultural humility and integrating Indigenous healers and Indigenous culture and perspectives within health care.

Oral traditions and Indigenous languages

Key informants emphasized the importance of oral traditions and Indigenous languages. As an Ojibwe/Saulteaux Métis and Ukrainian patient partner shared, "W*ithout being able to know our story, you can't understand our experience*." Oral traditions, such as storytelling, are often more accessible and safer methods to share stories and experiences than written feedback, which requires additional time and effort:

> *We need more stuff that's just not five thousand words on a page. The greatest, Indigenous Nations people, the greatest gift we've ever had in our entire existence is storytelling, is this oral tradition and we have to stop seeking ways to replace it because nothing will replace it adequately.*
>
> **Duane Jackson**

Many Indigenous protocols exist around exchanging and managing knowledge and stories that are crucial to learn and respect. Knowledge shared in storytelling is considered a gift, and the receiver has the responsibility to reciprocate by honouring this gift in a meaningful way:

> *No other group of people who have been so discriminated against, are being asked for this information. So it really needs to be viewed as a gift. Same as when we asked about patients' stories. I think it needs to be honoured and viewed as a gift, and treated that way...I think that often...that part gets lost. The asking happens, but recognizing how much of a gift that is that somebody shared with you their experience, told you what it was like for them.*
>
> **Key informant**

Indigenous languages play a key role in expressing many Indigenous concepts of health and well-being that cannot be easily translated. One patient partner shared that her language has words that require entire sentences in English to explain. Duane Jackson noted,

> *"we have some words [...], there'll be a definition for it in English, but to have it go deeper than the actual meaning, that's what our language does."*

The health care system emphasizes and often makes decisions based on quantitative data, and in the process, misses the stories of Indigenous Peoples. It is important to listen to and include the stories of patients and to use these learnings to guide the approach to gathering quantitative data because it allows for a deeper understanding of the issues. Respecting and incorporating oral traditions and Indigenous languages within PREMs is another way that health care organizations can support greater cultural safety of patient experience measurement initiatives.

Work should reflect the distinct values and perspectives of Indigenous people

Key informants emphasized the need for health providers to look beyond narrow biomedical perspectives to acknowledge and integrate Indigenous approaches to healing that are wholistic, relational and client-centred:

> *In mental health we always had to fill out what they called a personal care history...it was dictated by the very Western model type of psychiatry, and the mental health or sociological approaches that had nothing to do with the human people that we were dealing with...How are we supposed to get any good information out of somebody by talking that way? Well, that's the only way I would get information from my Indigenous clients, is to have them speak in their own way. And sometimes if they can speak in their own language first and then describe it to me. Well, nobody had that time. You know, you only had an hour or 45 minutes, and then that's all you had. Well, that's not what it was like for me; for me...If we had to go over, we had to go over.*
>
> **Ojibwe/Saulteaux Métis and Ukrainian patient partner**

Key informants highlighted the need to recognize the distinct perspectives of Indigenous communities:

> *One of the things I've really worked on is Nation-based understanding, right? And not homogenizing everything...Even understanding the topography of the land in which they teach, our river Nation will teach different than a plains Nation. A plains Nation will teach different from a mountain Nation. The language is attached to our connectedness to the land. And our understanding of the universe sending us messages all the time. Right? So, those messages will be different depending on the topography. So when people don't dig into this and try to understand it, they don't honour these people; they don't honour the different peoples that they're dealing with.*
> **Duane Jackson**

Key informants also emphasized the need to embody relational values when gathering patient experiences, recognizing that everyone who has lived a life deserves respect. As Adam Gauthier, a Tla'amin/Cree/Métis child and youth coordinator, shared:

> *"So I think when it comes to relaying it back, it needs to be done in a very direct way of, I would say phone call at the least, but a visit. Something that will say I heard you and I see you."*

Implication for PREMs

Honour and acknowledge the gift of stories and feedback in a more personal way than just a generic 'thank you for participating.'

THEME 2

THE HARMS OF COLONIALISM AND INDIGENOUS-SPECIFIC RACISM

The second theme that emerged from interviews with key informants was the impact of trauma from historic and ongoing colonial policies and practices, as well as Indigenous-specific racism within the health care system. These factors fundamentally shape health-care-seeking behaviours, health system navigation and advocacy, and health outcomes for Indigenous people.

The Canadian health care system is a colonial structure that has developed with minimal input from Indigenous Peoples in terms of its scope, structure or approaches. Key informants shared their past and present experiences of racism and their feelings of not belonging within the Western health care system:

> *It feels like stepping into a completely different country and culture, where there's a language barrier, and everyone looks at you like you don't belong. You really get that sense of being an outsider. Mainstream health care comes with all these unspoken expectations – that you know the process, where to go, and what's expected of you. But if you don't know, the response often feels like, "Why don't you?"*
>
> **Judy Maas, Dene health administrator**

One key informant shared how they felt they needed to change how they spoke or presented themselves to be taken seriously:

> *My parents would say, "Put on your White lady voice."*
>
> **Christine Hunt, Kwakiutl/Tlingit patient partner**

Intergenerational impacts of colonialism on seeking health care

Intergenerational colonial traumas, past and present, have a significant impact on the way Indigenous people access health care services. The cumulative trauma experienced by Indigenous Peoples due to the historical and ongoing acts of colonial oppression and genocide by Canada affects their health, ability and willingness to seek health care services from a colonial system that is often triggering and a source of trauma. As one key informant elaborated:

> *The experimental things that have been done, the sterilizations that have been done, the testing of nutrition on our people has always been such – in the back of their mind that they've lost the trust.*

Another key informant shared:

> *Growing up Indigenous, and with residential school survivors, it has been ingrained into our culture to not challenge authority. Health care providers are included in that authority bucket. So, not speaking up or speaking out intergenerationally is how I have and my siblings and generations before me have been raised.*

Adam Gauthier shared a personal experience of mistrust:

> *like my grandmother was in an Indian hospital, and I've just never been that comfortable accessing or walking through hospital doors for that reason.*

Some go without receiving the care they need, and others may struggle with advocating for themselves or their family members and navigating the system. It is vital for health providers to redress the power imbalances that are rooted in oppressive colonial dynamics by being an equal partner and honouring patient autonomy:

> *There's this fear that if you speak up, they might get mad at you or retaliate in some way. It's that punishment-and-reward system you learn – first from the Indian agent, then from the police, followed by residential schools, and later through the Sixties Scoop. It's a constant imbalance of power. In any situation, addressing that power imbalance in the room needs to be the very first step.*
>
> **Judy Maas, Dene health administrator**

Overt experiences of racism in the health care system

As revealed in the *In Plain Sight* report (Addressing Racism Review Team, 2020), pervasive Indigenous-specific racism in the health care system drastically decreases the quality of care and treatment Indigenous people receive, particularly in remote Indigenous communities that experience staffing challenges and where limited services and resources are available locally.

Experiences of racism were consistently highlighted across interviews. One participant shared:

> *I believe that each person I have spoken to who is Indigenous has experienced racism in health care, and so therefore they anticipate not being believed when they go. And so, when they anticipate that, because of their past experiences, there is a lack of trust, because of colonization, because of past atrocities and because of assumptions that the system makes*
>
> **First Nations/Métis patient quality professional**

Experiences of racism lead to future delays in seeking care or anticipation that issues will be minimized or disregarded:

> *The self-determination it takes for an Indigenous person to even…share their health care experiences in a situation like this or for them to even make a phone call to the emergency to 911, right? How much time goes by before they feel like, OK, this is an emergency, or I really do need to get help, because they have, they have been questioned and doubted before…That's just so appalling that the place where help is supposed to have been, be provided, there are barriers to accessing that.*
>
> **First Nations/Métis patient quality professional**

Lack of cultural safety in self-identification

The topic of self-identification was identified as triggering and complex. Key informants expressed that there were instances where a change in the attitude and behaviour of the health care provider was observed after they self-identified as Indigenous:

> *Once people know you're a Status Indian, it brings with it so much bias and deeply ingrained, historical discrimination – often subconscious. You can't create safety without addressing and transforming the system itself. My sister once said, when she was in the hospital, "As soon as they knew I was an Indian, everything changed –I felt it." How do you even begin to put that feeling into words?*
>
> **Judy Maas, Dene health administrator**

There are a variety of reasons some patients may be unwilling to self-identify or feel uncomfortable doing so. Some key informants expressed that self-identifying conflicts with how they define their identity or perceive themselves in relation to their community:

> *And I'm really glad this came up, because I don't self-identify. I am an Indigenous Métis woman, and I don't self-identify, because I'm part of a community, I'm part of my family, I'm part of my matriarchs, I'm part of my Elders, my father, my grandfathers, and I have ancestors. It's not self. …But it's just that I'm not a self, because I'm so much more than that. So when I tell you where I'm from, I want to tell you – I'm telling you who I am and what I identify with and what my teachings have been, and what I've learned from them – from my community and from my family and those kinds of things. I guess that's the heart. And so when you say self, you put me on the spot that I'm here, I stand alone and I'm all by myself.*
>
> **Ojibwe/Saulteaux Métis and Ukrainian patient partner**

Key informants said that learning about the benefits of self-identifying and how their information would be used and protected was essential to creating safety in self-identifying. Adam Gauthier shared how he could have benefited from increased awareness:

> *I didn't self-identify, one, because I've always just known and thought as a First Nations person, I'd never felt the need to talk about it, especially with someone who is a non-Indigenous person. And I ended up walking out of that clinic with antibiotics I had to pay for because I didn't know I was covered.*

Another key informant expressed how dehumanizing and exploitative it feels to be asked to self-identify when it is done from a data collection perspective:

> *Self-identification always really bothered me, because it's always been approached from collecting data. Nobody wants to be counted. And from my own experience, I hate checking the box that says First Nations, because that's not how I actually identify myself. I never say I'm First Nations unless I'm asked, or unless there's a box to check off. ....it's such a narrow way. And it's such a clinical way to identify people.*

Key informants noted that the topic of culturally safe self-identification requires further discussion, particularly the specifics of *how* people should be asked to self-identify. However, the Wise Practices section below includes some initial steps shared by key informants to help increase safety around self-identification.

THEME 3

INDIGENOUS VOICES FOR CHANGE

A third theme raised by key informants was the importance of Indigenous voices to spur systems transformation and hardwire cultural safety into the health care system. While recognizing the progress and good work that has been done to date, informants expressed frustration over the health care system's inaction in addressing the complaints of Indigenous patients and the lack of accountability in implementing the recommendations from existing commission and inquiry reports.

Importance of sharing information and health care experiences

Key informants shared the importance of gathering and centring Indigenous voices to address issues, provide direction for system change and integrate Indigenous values and approaches into practices, processes and policies in the health care system:

> *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. It really will bring us to equality. So, it's so vital that when something isn't going culturally safe, or they are feeling not secure, or satisfied with their medical visits, or anything in relation to prescriptions or appointments, the time to speak is now and I encourage them to do that.*
>
> **Adam Gauthier, Tla'amin/Cree/Métis child and youth coordinator**

> *I really believe that if Indigenous Peoples share their experiences and if we are able to have people listen for the greater good for future generations, we are able to make a difference.*
>
> **First Nations/Métis patient quality professional**

An Ojibwe/Saulteaux Métis and Ukrainian patient partner described the fruitfulness of her advocacy efforts while also recognizing that the same level of effort is not possible for all Indigenous patients:

> *But it was the effort on my part that I kept at them to change that because there are a lot of people that aren't as articulate as I am or would want to take it that far. They just go home and forget about it and swallow their trauma.*

Key informants expressed fatigue with being overburdened with survey and various project requests, from evaluation to research. Despite this, the desire to improve things for younger generations is what drives them to continue:

> *We still find the energy to keep pushing forward because we don't want to lose hope, and we're motivated by the thought of our children not having to face the same issues.*
>
> **Judy Maas, Dene health administrator**

The need for accountability to influence policy and practice

The health care system needs to be transparent and accountable about how it is using information about patient experiences, for the well-being and safety of patients as well as for advancing systems change:

> *I think accountability is key. But it's – they being the health care system – being accountable to how they treat us because, certainly, if they are, then changes are going to be made slowly. If not, it's going to be the same; we'll have the same narrative again over and over.*
>
> **First Nations/Métis patient quality professional**

Key informants observed that patient feedback about negative and harmful experiences that did not result in severe physical harm has not been taken seriously. Because of this, the health care system may miss a pattern of adverse incidents until an extreme incident occurs. As Adam Gauthier noted, even seemingly innocuous interactions can have severe impacts, reducing a patient's ability and willingness to engage in care:

> *Front desk or intake workers… that can be the biggest difference too. If right away, someone's being very unsettling or unwelcoming, you can guarantee that person just doesn't even want to sit there and wait or fill out a form or even tell them about what's going on. So if you filed a complaint about that, I really doubt someone would do something at least extreme or something that will give a statement that that is not OK and that is not acceptable.*

The sentiment of the health care system being unable or unwilling to hear and address concerns was shared by Judy Maas:

> *But my sense is that they've heard this story a hundred thousand times, and instead of empathy, what they feel is apathy. They don't have the tools – or the will – to fix the problem. So, if I go to a hospital again and have the same experience, that tells me what the truth really is. The gap between truth and reconciliation lies in the fact that you're not reconciling with my truth. Once you reconcile with our truth as First Nations people, that's when real change will happen –when we'll see better access to medical care, improved data, and most importantly, a system where we feel safe.*

> *Imagine being able to speak openly to your doctor, disagree if needed, or even say to a nurse, "No, I'm not comfortable with that," and feel safe doing so. That would be incredible.*

Key informants were also frustrated by the lack of action and progress in implementing the recommendations of the many existing commissions and reports:

> *The Truth and Reconciliation recommendations, how many years need to go past before anybody is actioning the actions? Why is there no action? We don't need more patient stories, we need more action on the report recommendations like TRC and In Plain Sight: Addressing Indigenous-specific Racism in B.C. Health Care.*
>
> **First Nations/Métis patient quality professional**

Because there are many different avenues to provide feedback, patients may have to tell their stories several times before receiving the appropriate response. More information should be shared between providers, researchers and health organizations.

Key informants underlined the importance of making full use of existing information and validating it rather than continuing to ask Indigenous people the same questions:

> *We already have so much information from the environmental scans we've conducted – valuable insights that directly address these issues. All the voices of people who participated and bravely shared their experiences speak to the realities of health care. Why are we still reopening the discussion and asking the same questions again? Why are we letting this knowledge, this evidence, sit somewhere gathering dust?*

> *Quite frankly, we are tired of being treated as research subjects. We've been researched and surveyed endlessly, yet the promises of change and implementation we were given since first contact remain unfulfilled. We don't need more studies or empty gestures – we need action.*

> *It's time to bring this back to the Nation and say, "Here's what we've heard. Does this reflect your truth? What's missing? How can we act on this together?" We don't need more surveys or empty gestures – we need action, grounded in the stories and knowledge we already have.*
>
> **Judy Maas, Dene health administrator**

Story-sharing needs to result in concrete plans and goals for change that are evaluated and reported on. There must be benchmarks tied to decision-making, accountability and changes in processes.

Implication For PREMs

Report results and themes in a timelier way than is currently possible through the Ministry of Health public release process. Report on action plans and progress at First Nations Regional Caucuses.

THEME 4

THE WAY FORWARD: NOTHING ABOUT US WITHOUT US

The last key theme that emerged was about Indigenous people championing health sovereignty and self-determination as the way forward. All PREMs work should be done in relationship and partnership with Indigenous Peoples and respect Indigenous values.

> *We have to go out there and do the work, we're the only ones that know how... And we've got 10,000 years of storytelling behind us, 21,000 years. I'm not going to let them do the work because they don't know how to do it. They're under-resourced, and under-trained. So I'm going to go walk down the road with somebody. And introduce them to hope, and to becoming more, and transformation. And that's why I do this.*
>
> **Duane Jackson, Gitxsan patient partner**

Indigenous people should determine how they are asked about their health care experiences and how their data is governed

Key informants felt strongly that quality initiatives about Indigenous experiences should be Indigenous-led. Indigenous patients often feel more comfortable with Indigenous health providers, researchers and health care staff because there is a sense of mutual understanding:

> *The patients would find out that the person was Indigenous, it would be a visual sigh of relief. And an automatic relaxation and other staff could see it as well... "I don't have to explain why I think this was discriminatory." Or I mean, that kind of thing. There was just this mutual understanding that put people at ease, I think. –*
>
> **Key informant**

Indigenous data governance principles must also be upheld when gathering patient experiences to ensure self-determination and meaningful outcomes. As a minimum requirement, findings should be validated and shared with patients, along with an explanation of how they will be actioned, so that patients can see that their voices have been heard.

Advocacy and support in navigating the system

Many individuals have a hard time articulating their stories. Indigenous people often feel overwhelmed, unsupported or cornered when they are trying to share their experiences, particularly when the health system does not demonstrate understanding or provide helpful responses:

> *They were just kind of blank faces, and nobody really had anything to say, nobody knew how to be supportive about it. So I was expected to go there, tell them some pretty intimate things about what was happening for me, some stuff that was perhaps triggering, and often was. Because we're Indigenous, we're supposed to come and spew this all forward and tell them everything intimate about what we've got to say, and then everybody walks away. It's dropped like a hot potato. It's dropped completely in silence and there's never any feedback.*
>
> **Ojibwe/Saulteaux Métis/Ukrainian patient partner**

Key informants offered suggestions to increase Indigenous people's comfort and awareness of health system processes and spaces, including raising awareness of patient rights, promoting familiarity with health care spaces, and including supports and advocates when sharing patient experiences.

To create a more culturally safe environment, it was also suggested that cultural walkthroughs be hosted for community members at local emergency departments and that security guards wear informal uniforms with "Ambassador" on the name tag.

Providing an advocate or support person when patients share their experiences can promote self-determination by reducing the power imbalance, reduce fears around speaking up and promote systems change:

> *We need an advocacy piece here. Because otherwise, this is not going to work. Indigenous people who come and tell us their stories about their experiences, they need to feel like we're on their side. And we need to be on their side, we need to demonstrate we're on their side. Whatever that looks like.*
>
> **Patient partner**

Implication For PREMs

Be able to capture experiences at multiple touchpoints, both formal and informal, rather than just through structured initiatives like the BC Patient-Centred Measurement surveys.

When are standardized questionnaires appropriate and how must they be changed to honour Indigenous worldviews?

It is essential to recognize that while current methods for gathering patient experiences may be quick and effective for the health care system, they may not be culturally safe or trauma-informed for the patients who are sharing their experiences:

> *Because if there's just a letter written, or if there's just a note sent or a quick email, it doesn't feel genuine, it doesn't feel like it's respected even. Because that is not, I think, how conversations should be had, especially when there's this emotional distress or fear involved. So I think when it comes to relaying it back, it needs to be done in a very direct way of, I would say phone call at the least, but a visit. Something that will say I heard you and I see you.*
>
> **Adam Gauthier, Tla'amin/Cree/Métis child and youth coordinator**

As a First Nations/Métis patient quality professional explained, patient-centred measurement needs to serve the interests of patients, and the immediate and long-term needs of patients should be reflected in standard questionnaires:

> *I think that standard questions can be appropriate at a point of care interaction, but I think that the standard questions should not only serve the health system, they should serve the patient. The questionnaires don't ask, "was the staff kind and courteous," the first question. Next question, "did you feel that your safety was in jeopardy at all," they do ask those types of questions, but not about the things that matter to the patient.*

Some key informants expressed that standardized questionnaires are inappropriate when patients are very ill or when gathering sensitive information about stigmatized health concerns such as substance use or sexually transmitted and blood-borne infections. The importance of collecting feedback from Indigenous people living off-reserve and away-from-home was also underlined by key informants.

Key informants also noted that it is important to state that feedback is optional and to provide many options for sharing feedback (surveys, in-person discussion, community engagement sessions), including the option of anonymous feedback. There needs to be clarity and transparency around how the information will be used in adherence to the OCAP® principles. One key informant shared:

> *"Having control over the collection process of the information and how that information is used is crucial." Another shared "If I'm doing a survey, and I don't like the question. I may just end it right there."*

When it comes to conducting patient experience surveys, the same key informant shared their approach to asking questions in a way that allows patients to give as much detail as they want to:

> *Giving them a call later and saying, tell us about your care…or did you feel well cared for…and let them speak…I also was cognizant of wanting to capture stories that people want to tell us versus stories that we were hearing because we had that privilege of being involved in their care…I also wanted to take the approach of posing it as a "yes" or "no" question so that they could say "yes" or "no." And if they wanted to stop there, they could stop there. But if they wanted to expand on why it was a "yes" or "no," it was completely open for them to do it. Because I still say I thought that having the information even if somebody just said "no" that was still really telling.*

Key informants also noted that it can be a great deal of effort to provide written feedback. Adam Gauthier suggested following up with patients via a phone call so they have the opportunity to provide verbal feedback. Phone conversations could be transcribed and then sent to the patient so they can edit their story. Key informants suggested that responses to feedback about negative experiences should include an acknowledgement, an apology, an expression of gratitude for sharing and a summary of the steps being taken to address the issue.

Accessibility was also highlighted by key informants. Some suggested that sending people a link or QR code or providing them with an iPad to fill out questions could allow them to complete a survey while awaiting care. Key informants also emphasized the need to make it easier to access resources, including creating summaries that highlight key findings that are easy to engage with, ensuring presentations for information-sharing with the public are visually stimulating and providing pamphlets or cards on waiting room tables that enable patients to access resources without having to ask.

Implication For PREMs

Be part of a continuum of ways to collect feedback, including health authority Patient Care Quality Offices and the FNHA Quality Care and Safety Office, rather than separate streams that do not share data.

Wise Practices




The following wise practices section draws on our learnings from key informants to help guide health system partners on the way forward alongside Indigenous Peoples.

Wise Practice

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

> *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**

Indigenous people have maintained health and wellness since time immemorial. Health system partners and decision-makers must acknowledge and hold space for Indigenous worldviews and wholistic perspectives of health, which recognize the interrelationship between respect, responsibility, wisdom, land, community, family and Nations and the social, environmental, cultural and economic factors that contribute to health and well-being.

Indigenous peoples should not have to continually attempt to fit into pre-existing structures that do not reflect Indigenous worldviews:

> *Is it inclusive to say, "We've got this; we want you to give us some feedback and information and include you in this process, but… this health care system is already out there and you're going to just have to fit into it, and that's a fact, Jack?"…if you're actually doing research around cultural safety and we're actually setting standards… what we're doing is facilitating change and bringing new knowledge and expanding the body of knowledge around Indigenous health and Indigeneity and the methodologies in research as well as in – and bringing the standards forward.*
>
> **Ojibwe/Saulteaux Métis and Ukrainian patient partner**

Instead, spaces that empower Indigenous people to transcend the boundaries of Western understandings of health and wellness through research, policy and standards development processes are greatly needed. Strategies for gathering data that take from – rather than honour and benefit patients – are not grounded in Indigenous ways of gathering and stewarding knowledge. To be meaningful, PCM should measure the extent to which care is wholistic and inclusive of culture. A higher bar for ongoing and informed consent is required.

Health system partners and decision-makers must recognize the distinct contexts and diversity within Indigenous communities across BC at the local level. Understanding these contexts requires listening to what is being shared by Indigenous people about who they are and their priorities and then tailoring measurement to capture, monitor and enable learning and improvement in these priority areas. The design of PREMs must be inclusive of relationship-building and not be limited to the involvement of Elders. The Indigenous teaching that everyone is inherently worthy of being treated with respect should be reflected in the behaviour of health system partners.

Putting Indigenous PREMs into Practice

Prioritize relationships: Health system actors, including those developing and implementing PREMs, must foster relationships with communities as the basis of their work. Invest in spending time with Indigenous people and communities. Health system actors will understand and appreciate Indigenous perspectives better if they improve their relationships with communities. Enhance relationships with Friendship Centres. A crucial part of research and knowledge exchange with Indigenous communities is setting intentions together by establishing and nurturing relationships through trust, reciprocity and accountability. Consider a variety of relational approaches, such as, but not limited to, healing circles for patients and staff (including health care practitioners) in clinical settings to heal relationships where there's been harm done.

Be thoughtful with your communication style and accommodate appropriately: Culturally inappropriate communication can negatively impact health care experiences and outcomes. Listen with your heart and not just your ears. Be conscious of tone and non-verbal communication cues (e.g., body language) and stigmatizing language. Actively listen, show empathy, be attentive and avoid interrupting or speaking over people. Provide feedback mechanisms that are easily accessible and straightforward to use. Avoid using acronyms and technical jargon. Co-design what to monitor and how to reach the right people with lived experience in ways that feel safe to them with people who understand Indigenous ways of communicating and navigating the health care system.

Maintain open-mindedness and flexibility: Surveys are often positioned with an agenda in mind. This can dictate their structure with questions worded in a manner that elicits the desired responses from respondents. Evaluators and researchers must be mindful of their own assumptions and biases. Tools that treat respondents as "consumers" may do harm by ignoring the power imbalance and only focusing on individualistic and episodic elements of experience. Most tools will not fit "out of the box". Be prepared to rebuild tools from the ground up if they are identified as inappropriate, ineffective or unsafe. A range of modalities to hear from community members' lived experiences should contribute to the overall PREMs picture. Stories that are shared must be deeply honoured and treated as gifts. When done thoughtfully, survey processes positioned within storytelling approaches can be therapeutic. Ensure that there are clear benefits to Indigenous people and communities.

Wise Practice

2 Foster a culture of accountability and work to eliminate conditions that allow and perpetuate Indigenous-specific racism

> *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**

Colonial health care systems and Western approaches to research result in immense harm to Indigenous Peoples. While recognizing and acknowledging the impact colonialism had and continues to have on Indigenous Peoples is crucial, it is equally important to acknowledge Indigenous strength and resilience: amid the broader context of systemic and structural inequities, Indigenous people have maintained traditional health and wellness practices. The health care system must be decolonized in its entirety, and it can be difficult to simply add culturally safe approaches and ideals into PREMs within an existing system that is unsafe for Indigenous people. Yet, it is a starting point.

Health care system partners and decision-makers must respond with humility when Indigenous people share health care experiences and work quickly and collaboratively to address concerns. From an Indigenous understanding of justice, demonstrating a commitment to decolonization, reparation and reconciliation means taking action to remedy harms with the utmost transparency and accountability. This shift requires a commitment from all Canadians, not just health care workers and researchers.

Putting Indigenous PREMs into Practice

Promote lifelong learning: Challenge thought patterns and behaviours by educating yourself and encouraging others to do the same. You can become more familiar with Indigenous ways of being and knowing through interaction with Indigenous people and community involvement. All individuals working in PCM initiatives should receive training focused on dismantling Indigenous-specific racism and fostering cultural safety for Indigenous Peoples. Participate in Indigenous PREMs-related learning opportunities, (e.g., OCAP® training, knowledge translation for diverse audiences, including Indigenous people with lived experience), to bolster Indigenous approaches to leadership and scholarship.

Challenge colonialism: Be conscious of the contexts that have informed your own identity and privileges. Work to rebalance power dynamics and strive to disrupt knowledge hierarchies. Avoid pan-Indigenous approaches and instead incorporate those that are community-specific or cross-cultural. Do not dilute Indigenous perspectives in overall rollups like score cards. Consider how PREMs will be applied to confront culturally unsafe experiences in health care settings and push for accountability from health system partners to enact change. It is also vital that organizations develop, enact and enforce cultural safety and humility policies and that progress is measured to improve Indigenous people's health care experiences. Develop ways of integrating learnings across different ways of receiving feedback. Health decision-makers who have operational accountability for leading quality improvement initiatives and championing change among their clinical teams should be responsive to results and engage with communities to co-design solutions. Data should be shared throughout the health care system with different organizations and regulatory bodies so there can be a system-wide understanding that different approaches need to be used.

Move forward with humility: Acknowledge your own role in working to reconcile the past and ongoing harms on Indigenous Peoples. It is okay not to know something as long as you encounter learning with openness, respect, honesty and humility. Be willing to seek guidance if you need clarification on protocols or the local expectations of guests in traditional territories and Indigenous communities.

Wise Practice

3 Move forward on existing recommendations developed and informed by Indigenous Peoples for hardwiring cultural safety into the health care system

> *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**

Indigenous people have described the systemic barriers that perpetuate inequality at great lengths (see Key Recommendation Reports section). Much work has been done to seek feedback from Indigenous people around improving cultural safety and humility in the health care system. It is time for us to take action on supporting the journey of Indigenous people and Indigenous communities toward self-determination and health sovereignty. Countless provincial, national and international declarations, inquiries, recommendations, frameworks, principles and strategies have already been put forth. These provide a roadmap that encompasses an array of prospective methods to measure quality and safety, understand Indigenous patient experiences, and address reports of racism and unsafe experiences.

As PREMs become more familiar, accessible and culturally safe for Indigenous people, the number of people speaking up about their experiences with health authorities will likely increase and patient-reported scores may decrease. However, this will also allow for a more fulsome depiction of the realities within the health care system and the service improvements that are needed. Quality improvement processes add value because they keep important discussions on the table and help ensure that perspectives are respected and followed up on. The inclusion of storytelling, an environment of safety and trust, and a relational approach are all key to making it safer and more accessible for people to share their stories within PREMs. An increase in reporting that encompasses these aspects may, in fact, be a marker that cultural safety in PREMs is improving.

Putting Indigenous PREMs into Practice

Push for change: It is crucial that the health care system uphold Indigenous Peoples as rights-holders and not merely stakeholders. More recruitment and retention of Indigenous employees is needed across all health care settings. It is important to have culturally relevant resources and supports (e.g., Elder-in-residence programs, cultural support workers, advocates, pamphlets, etc.) ready at the moment when Indigenous patients are sharing their stories to safely effect change for them and future patients and support healing. Sharing circles where advocates can share their stories are a valuable way for hospital administrators and staff to hear first-hand. As well, family, community and cultural support systems are crucial to health and wellness. Informing and equipping family members to support their loved ones is important for improving system navigation and health outcomes and helping patients share their stories.

Use what has already been shared: Do not collect data for data's sake. Consideration should be given to balancing the need for information with the potential for re-traumatizing people and the justifiable need for accountability and dedication to tangible changes to policy and practice. Start by cross-referencing the themes from engagement that has already been conducted, alongside other measures of population health needs and strengths, and giving health system partners tools to learn from. Use this wealth of information before setting out to collect more data.

Create opportunities for collaboration: We must recognize the enormous opportunity to improve health experiences and outcomes for Indigenous Peoples and all Canadians by leveraging Indigenous knowledges, perspectives and practices. To do this, partnerships are crucial for fostering resource-sharing, bridging gaps and identifying solutions. While we have been provided with a roadmap towards a better health system, this also necessitates the willingness of decision-makers to listen, contribute and action the wise practices shared by Indigenous people. Collaboration is needed to break down siloes between different areas that receive feedback from Indigenous patients/families, including Patient Care Quality Offices and Indigenous health teams in health authorities, FNHA Quality Care and Safety Office, BC Patient-Centred Measurement and other decision support/evaluation teams that collect data on health system performance.

Measure meaningfully: For standardized questionnaires, ensure that the following factors have been considered:

- *Self-identification:* More work is needed on culturally safe approaches to self-identification as this is a sensitive and complex issue. Recognize that Indigenous people bear a risk of discrimination by self-identifying. Reflect on whether self-identification meets Indigenous patient needs and explore options for how to improve this tool so that it addresses their needs, and not just those of the health system. Increase the safety of self-identifying by centring it on the cultural, care coordination and navigation needs of individuals and communities, instead of the data collection needs of the health system. Increase access to Indigenous health care providers, support workers and local language interpreters. Stay up to date as recommendations and tools are released.

- *Informed consent:* The benefits of self-identifying and sharing experiences should be laid out clearly before patients are asked to do so (e.g., informing patients about their rights to access services and coverage, how their information will be used in writing and verbally, and developing resources and signage on the benefits of self-identification and how the system is making it safe). Increase transparency on what will be done with self-identification and patient experience data. Provide enough time for individuals to consider their participation and honour requests to stop. Include local languages in consent processes.

- *Cultural safety and humility:* Continuously engage with cultural safety and humility teachings and approaches. Practice these.

- OCAP® *and Indigenous data governance principles:* Implement the principles of Ownership, Control, Access, and Possession as well as the CARE Principles of Indigenous Data Governance in accordance with the preferences of Indigenous people and communities so they have control over how their information is reported and shared. Data, especially that which involves self-identification, should only be collected when tied to concrete actions that will directly benefit Indigenous people and communities. This data should be evaluated and aggregate non- identifiable results should be reported within the health care system, to the public and Indigenous governments in as close to real time as possible. This requires updating processes for releasing results from provincially coordinated PCM initiatives so that the government restrictions on public release are lifted. This could be done through expanding access to the BC Patient-Centred Measurement Steering Committee's Dynamic Analysis and Reporting Tool to include a portal for Indigenous governance, and a modified release process that either makes the results publicly available as soon as they are received (similar to the process that the Office of the Seniors Advocate uses) or specifically includes Indigenous governments among the internal audiences with whom health authorities are allowed to share embargoed results.

Wise Practice

4 Redress power imbalances at decision-making levels in health care to support Indigenous health innovation and health sovereignty

> *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 technical advisory committee member**

Indigenous people are experts in their own health and must, therefore, hold prominent roles within the health care system as decision-makers. Context is critical when asking questions about health care experiences; Indigenous people must guide PCM initiatives so that data is appropriately gathered and knowledge is meaningfully translated.

Indigenous people are not only underrepresented in decision-making spaces in health care but are systematically excluded from these spaces through colonial processes. Recognize that many Indigenous people may feel safer accessing services and giving feedback in their own communities and consider this when designing services. PREMs are the system reaching out to patients to gather information the health system finds valuable. Consider co-designing opportunities with local Nations for community members to reach out and contribute their experiences in the areas they find important. This establishes a two-way relationship and increases self-determination. Having patient experience initiatives run by organizations independent from those providing care could also combat the power imbalance between patients and providers.

Putting Indigenous PREMs into Practice

Nothing about us without us: Indigenous people should be leading PREM work. Instead of trying to fit community priorities into existing tools, the system must work meaningfully with Indigenous partners to employ Indigenous PCM, measuring what matters most to the communities with methods deemed acceptable by communities (e.g., oral tradition and storytelling). To incorporate Indigenous practices and views into existing PREM structures, consider whose story you are telling and from whose point of view you are telling it. Ensure that self-determination is respected when sharing patients' words. As Duane Jackson, a Gitxsan patient partner, said, "*quot[e] as much of [patients'] words as possible*," and if you need to paraphrase, "*request permission to do that*." It is also important to include stories that do not fit squarely into the research narrative and gather stories from Indigenous health care providers. PREMs must be made safe for Indigenous patients and staff who want to share their experiences.

Provide the appropriate resources and capacity: Fund research and capacity for Indigenous innovation around PCMs. Resources may be required to create an independent structure for gathering Indigenous health care experiences. Having accessible and transparent information about patient rights and the steps involved in sharing experiences helps patients feel safe and more willing to trust the health care system. A communications campaign would help let patients know their rights, who they can go to, and how those people can help. This could be shared in newsletters, at friendship centres, in mental health resources, on social media and in posters in health facilities (e.g., waiting rooms, exam rooms). Patient activation is a tool that, for example, could help patients navigate the system by thinking about why they are attending the appointment and marking down questions they have.

Celebrate good work: The path to cultural safety requires ensuring that new work builds on the excellent work already being done. Learning from and sharing positive experiences with communities and the health system is fundamental to safety, healing and working together for change. Share case studies where things have been done well or where there was a fulsome response and commitment to change, to inform discussions and push for more systems change within the health care system. (See *Additional Resources* below for examples.)

Make space: People working within the system may lack the expertise to address issues themselves. It is therefore essential to include the people who have been adversely affected and to ensure that there is a diverse representation of Indigenous people who play an active role at decision-making tables. Since context is important in conducting PREM research, Indigenous people need to be involved in the process so that Indigenous patients and families are asked appropriate and meaningful questions. To ensure maximum benefit to communities and effectiveness of PCMs, community members, including Elders, Knowledge Keepers and youth, should have decision-making power in the development of PCM tools.

CONCLUSION

> *I think about hope, and becoming more. Not better because we're all good. You're all fantastic. I absolutely celebrate all of you. But just becoming more. And then staying in the process. And adhering to the process, and trusting the process. And if we feel alone in that sometimes, remember this meeting. And remember that we're not. Remember that our gang is huge. We've got people…it's hard because we have to go out there and do the work, we're the only ones that know how.*
>
> **Duane Jackson, Gitxsan patient partner**

Foundational work is still needed to ensure the health care system is culturally safe with a workforce that consistently practices cultural humility. For Indigenous people to feel safe and comfortable sharing their experiences as patients, those working within the health care system must first recognize the importance of providing basic cultural safety and humility and take the necessary actions to ensure this. Cultural safety and humility must remain at the forefront throughout the design and implementation of patient-centred measurement initiatives.

While this research focused on PREMs, Indigenous people's experiences within the health care system is the heart of the issue. The historical and social context of colonialism and the subsequent power imbalances between Indigenous patients and the health care system are prominent factors in shaping Indigenous people's experiences in health care settings. Sub-themes that emerged in this area included the lack of Indigenous customs and traditional values in the health care system as well as the prevalence of Indigenous-specific racism and discrimination. The essential need for Indigenous people to share their health care experiences was a prevalent finding. Recommendations on how to embed cultural safety into PREMs included:

- Nothing about us without us: All PCM-related activities should be embedded in, and co-designed with, Indigenous communities, reflecting traditional values. This is crucial in promoting health literacy and empowers Indigenous people to understand and advocate for their rights as patients. PCM initiatives must embrace the involvement, perspectives and leadership of Indigenous people.

- Oral traditions and storytelling are protective, and these Indigenous ways of knowing and being could fundamentally impact the health care system in a positive way.

- Work in this area should be consistent with Indigenous data governance principles, particularly with respect to the use of Indigenous self-identification data in data collection, quality improvement and research. Share timely, meaningful information back with Indigenous communities about their feedback and how it is being actioned.

- Individuals wishing to share their experiences should be supported. Patients are often responsible for providing evidence to corroborate their experiences, but many of the issues raised are systemic. The burden of reflection and sharing should be refocused on the system rather than on individuals.

- Literacy around processes and system navigation, empowerment through advocacy, and raising awareness of patient rights are critical to the well-being of Indigenous people.

For millennia, storytelling and other oral traditions have been paramount in protecting, sustaining and restoring Indigenous ways of life. By bearing witness to this, PCM initiatives should be more inclusive of Indigenous voices, methodologies and ways of knowing to positively impact the health care system. A recurring lack of action around the recommendations shared by Indigenous people has resulted in a profound mistrust towards the health care system. To demonstrate accountability and due diligence, a sincere commitment to redressing past and ongoing harms must be accompanied by policy, programming and practice changes. Key informants also expressed that unnecessary duplication of data and information is undesirable and that health practitioners and researchers should make better use of what has already been shared.

Further work and close collaboration with Indigenous people are needed to better understand specific elements of PREMs. For example, while issues around self-identification, specifically, appeared to be a core aspect of the project, strong “push and pull” factors are associated with this. Key informants noted that identifying as being of Indigenous ancestry could assist with measuring progress around cultural safety but that this also has the potential to be unsafe and triggering for some. Cultural safety and humility must be honoured when individuals are asked to self-identify. Further, exploring this topic should be consistent with OCAP® and Indigenous data governance principles, particularly regarding control over the collection and use of self-identification information.

RESOURCES

- ☐ BC Human Rights Clinic "We have the Right to Discrimination-free Health Care" Poster: https://bchrc.net/wp-content/uploads/2021/07/IHRC_Poster_11x17_V3-3-revised.pdf

Key Recommendation Reports

- ☐ Report of the Royal Commission on Aboriginal Peoples: https://www.bac-lac.gc.ca/eng/discover/aboriginal-heritage/royal-commission-aboriginal-peoples/Pages/final-report.aspx
- ☐ Truth and Reconciliation Commission of Canada Reports: https://nctr.ca/records/reports/
- ☐ Jordan's Principle Information Sheet: https://www.fncaringsociety.com/sites/default/files/2024-07/Jordan%27s%20Principle%20Information%20Sheet%202024%20EN%20%281%29.pdf
- ☐ In Plain Sight: Addressing Indigenous-specific Racism and Discrimination in B.C. Health Care: https://engage.gov.bc.ca/app/uploads/sites/613/2021/02/In-Plain-Sight-Data-Report_Dec2020.pdf1_.pdf
- ☐ HSO BC Cultural Safety and Humility Standard (health professionals can request a free copy) https://healthstandards.org/standard/cultural-safety-and-humility-standard/
- ☐ Joyce's Principle: https://principedejoyce.com/sn_uploads/principe/Joyce_s_Principle_brief___Eng.pdf
- ☐ Reclaiming Power and Place: National Inquiry into Missing and Murdered Indigenous Women and Girls Final Report: https://www.mmiwg-ffada.ca/final-report/

Examples of Good Work:

- ☐ **ASK Wellness Society (formerly AIDS Society of Kamloops)**: The organization provides low-barrier services to people struggling with substance use and homelessness. They serve a large Indigenous community and include regular cultural activities like smudging and medicine bundles in their services. They also prioritize culturally relevant programs rather than merely providing typical services like harm reduction supply distribution.

- ☐ **Culturally Safe Engagement for Patient Partners Companion Guide and Pamphlet**: Patient Voices BC hosted an event where they heard from Indigenous patient partners about what makes them feel comfortable and safe during engagements. From this event, a guide to creating culturally safe engagements, as well as a pamphlet, was created.

- ☐ **Thunderbird Partnership Foundation Native Wellness Assessments (NWA):** The NWA™ tool is the first of its kind to measure how cultural interventions impact a person's wellness from a whole person and strengths-based lens.

Indigenous Self-identification Resources and Initiatives:

- ☐ Video: This is Why: Indigenous Self-Identification supports culturally safe care www.youtube.com/watch?v=KLUtc1zIaZM

- ☐ Report: Measuring Cultural Safety in Health Systems: Lessons Learned From Providence Health Care in British Columbia www.cihi.ca/sites/default/files/document/measuring-cultural-safety-in-health-systems-lessons-learned-en.pdf

INFORMATION PAGES

- ☐ Vancouver Coastal Health Indigenous self-identification process: www.vch.ca/en/indigenous-self-identification-process

- ☐ Fraser Health self-identification initiative: www.fraserhealth.ca/health-topics-a-to-z/indigenous-health/indigenous-self-identification-initiative

- ☐ New Indigenous self-identification process at BC Children's and Women's hospitals: www.bcchildrens.ca/About-Site/Documents/Patient%20Information%20-%20Indigenous%20Self%20Identification%20Process.pdf

- ☐ BC Cancer Indigenous self-identification: www.bccancer.bc.ca/our-services/patient-guide/cst-for-patients/indigenous-self-identification

PRINT MATERIALS

- ☐ BC Cancer Indigenous self-identification poster: www.bccancer.bc.ca/Documents/Indigenous_Self_Identification_Poster_Jn2023Update_Web.pdf

- ☐ Fraser Health Indigenous health liaison postcard: www.fraserhealth.ca/-/media/Project/FraserHealth/FraserHealth/Health-Topics/Aboriginal-Health/Indigenous-Health-Liaison-Postcard.pdf

First Nations Health Authority
Health through wellness

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