



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

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## Abstract

**Background:** Members of the Indigenous Health Program, BC Children's and Women's Hospitals and the University of British Columbia embarked on a joint project to describe best practices to support the creation of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) with Indigenous peoples.

**Methods:** The project involved a review of previous research on patient-reported measures (surveys) that had been specifically developed for Indigenous populations. It also involved interviews with key stakeholders—Indigenous and non-Indigenous academic researchers, and Indigenous community leaders and community members. Themes from the interviews and the literature review were combined and synthesized into pathways/a framework for survey development.

**Results:** The pathways document consisted of 13 protocols and associated teachings for guiding processes and framing survey questions. These encompassed building relationships, community engagement and consultation, benefits to community, ceremony and storytelling, two-way learning, participatory content development, governance and accountability. Findings emphasized the criticality of Indigenous leadership in setting priorities for PROMs and PREMs and establishing relationships that honour Indigenous experiences through all phases of a study. Assessment of the framework's validity with select research participants and the Project Advisory Committee was positive.

**Conclusion:** This is the first framework to guide development of PROMs and PREMs with Indigenous peoples and communities. It addresses both process and outcome and includes concrete steps that collaborators can take when establishing a partnership that is respectful and inclusive of Indigenous ways of knowing and being.

## KEYWORDS

health service evaluation, Indigenous peoples, patient-reported experience measures, patient-reported outcome measures

## 1 | INTRODUCTION

In the last decade, quality assessment in healthcare has undergone a major shift towards use of patient-reported indicators. Evaluation tools, such as patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs), aim to improve quality and service delivery by focusing on outcomes and healthcare experiences that matter to patients.<sup>1</sup> While development of PROMs and PREMs should be a collaborative and cocreation process,<sup>2</sup> rarely have Indigenous peoples been included in their design. Given the healthcare disparities between Indigenous and non-Indigenous peoples both in Canada<sup>3</sup> and internationally<sup>4,5</sup> there is a pressing need to fill this gap.

This study sought to develop Pathways (a framework) for creating PROMs and PREMs with Indigenous peoples. The respective pathways comprise 13 protocols and associated teachings for guiding processes and framing questions based upon Indigenous knowledge, worldviews and community involvement. This paper is the second of two consecutive papers reporting on our Pathways project. The first paper (*Addressing the need for Indigenous-specific PROMs and PREMs: A focus on methodology*) described our methodology in detail. Here we present the results, analysis and implications for future studies.

## 2 | METHODS

The guiding question for this study asked, *what best/wise practices can be proposed to support the development or adaptation of PROMs and PREMs with Indigenous Peoples?* The research was guided by an Indigenous Elder, two Indigenous-Elders in training and Advisory Committee (comprised of Indigenous and non-

Indigenous experts from academia and Indigenous community members) who helped ensure the research was conducted in a comprehensive, sensitive and culturally attuned way and adhered to Indigenous research principles and methodologies. A detailed description of methods can be found.<sup>6</sup> It involved a literature exploration<sup>7</sup> and interviews with researchers, community leaders and Indigenous community members.

## 3 | RESULTS

### 3.1 | Demographics

One hundred and fourteen researchers and 70 Indigenous community leaders were invited to partake in research interviews, and 28 participated (14 researchers and 14 Indigenous community leaders). In addition, 15 Indigenous community members were interviewed. Participants were asked to introduce themselves in a way that was comfortable to them in lieu of asking for demographic information. Supporting Information S1: Appendix I presents the information that was shared by the participants.

### 3.2 | Protocols, teachings and stories

Key themes from the interviews with researchers, community leaders and community members, as well as learnings from the literature were synthesized into a Pathways document. The latter comprised 13 protocols as summarized in Table 1. Teachings offer detailed, practical actions that can be taken with respect to each protocol (see Supporting Information S1: Appendix II). Protocols are described below with contributing stories from participants.

**TABLE 1** Protocols for developing Indigenous PROMs and PREMs.

Protocol 1	Establish a study team grounded by Indigenous peoples
Protocol 2	Build meaningful and reciprocal relationships with Indigenous community partners; recognize the importance of speaking heart to heart
Protocol 3	Create ethical space
Protocol 4	Ensure ceremony and storytelling are a critical part of the project from beginning to end
Protocol 5	Identify Indigenous-specific priorities; conduct needs assessment, literature review and environmental scan
Protocol 6	Invite and create content with Indigenous community members, leaders and experts
Protocol 7	Apply Indigenous lenses and/or knowledges congruent with Indigenous worldviews to questions/content development
Protocol 8	Ensure Indigenous peoples' knowledge are reflected in the survey tools
Protocol 9	Validate: Ensure cultural appropriateness, acceptability, relevancy, validity and reliability of survey questions
Protocol 10	Ensure ethical data ownership, collection and storage
Protocol 11	Administer the survey using culturally appropriate methods (including in-person or orally over the phone)
Protocol 12	Analyse data using both Indigenous and western worldviews
Protocol 13	Accountability—Ensure results are shared and used to inform changes and communicate how those changes were implemented

Abbreviations: PREMs, patient-reported experience measures; PROMs, patient-reported outcome measures.



### 3.2.1 | Protocol 1: Establish a study team grounded by Indigenous peoples

Survey developers should design the project collaboratively from the start rather than inviting community members (or patient groups) to participate in after it has already been begun. Indigenous leadership is central to the project, as is involvement of Elders and an Indigenous advisory group. Survey developers should seek adequate resources to support Elders and community members working on the project and create opportunities for capacity bridging-reciprocal learning and collaboration for sustainability.

'Yeah, so I mean you know there's a huge tradition of research on, not with, Indigenous communities unfortunately, and a lot of bad helicopter in, take what you need and go—you know, leave. And so that's why things like Indigenous methodologies were developed to try and help counteract some of that. And so I think firstly the population or the communities that you're wanting to work with it's really important to include them in the process. Convening a research advisory was a great step for us and really helpful. And also helped to keep us accountable in that way. And I think that accountability piece is really important because sometimes you don't know what you don't know'.

(Basil, Community Leader)

### 3.2.2 | Protocol 2: Build meaningful and reciprocal relationships with Indigenous community partners; recognize the importance of speaking heart to heart

Establishing good relationships is critical, and likely the most important factor in creating PROMs/PREMS with Indigenous peoples. Survey developers should plan for having adequate time and resources to build, sustain and nurture trusting relationships throughout the entire project and beyond.

'Researchers have to commit to a long-term process. The researchers have to commit to the communities and develop that relationship before you even start'.

(Aster, Researcher)

'Well, our people need to be contacted personally and that personal touch—that human touch through voice is so important in—just in every aspect of communication'.

(Peqyexwela, Community Member)

### 3.2.3 | Protocol 3: Create ethical space

An 'ethical space' is formed when Indigenous and Western societies, with their different cultures and worldviews, are poised to engage

each other in a distinct but shared space.<sup>8</sup> Understanding and observing the cultural protocols of an Indigenous community is essential when entering an ethical space with that community.

'We used the Honour Your Strengths framework, which is an Indigenous framework, and everybody abided by that. We put down project values. We were really very strict about doing this using the phrase, it's done for the people by the people. So, we really wanted to incorporate the people to tell us what is native wellness from their perspective, instead of us as the researchers saying, we think from our perspective and our lens on the outside, this is what native wellness is, or this is what values there are etcetera'.

(Rose, Researcher)

### 3.2.4 | Protocol 4: Ensure ceremony and storytelling are a critical part of the project from beginning to end

Storytelling is a form of Indigenous knowledge sharing and connected to traditional Indigenous cultural practices. Spirituality is also integral to Indigenous life with ceremony guiding relationships and interactions in a good way. As such, survey developers should seek guidance from Elders and respected community members on how to include storytelling and ceremony throughout the project in line with traditional practices and protocols of the hosting community.

'The research team would be invited to join the kaumatua (Elders) and to share the project and it was done on a cultural day where there's usually 100 to 150 kaumatua who would come for songs and just socializing. So we had that formal ceremony. Each—you know, typically when we have a meeting there is karakia or a prayer, to start and acknowledge the work that's being done. So those are kind of the ceremonies that would you—you know, that would fit for something like this'.

(John Oetzel, Researcher)

### 3.2.5 | Protocol 5: Identify Indigenous-specific priorities; conduct needs assessment, literature review and environmental scan

Before the development of PROMs or PREMS survey developers must work with Indigenous partners and communities to understand needs and priorities and whether the use of PROMs and/or PREMS are the best way to capture health outcomes and experiences.

'I think speaking to the people that are going to be utilizing the tool is really, really important. Just about what's important for whatever your outcome is. So, if

it is wellbeing what's important to you for wellbeing? I think that's a really important first step'.

(Basil, Community Leader)

### 3.2.6 | Protocol 6: Invite and create content with Indigenous community members, leaders and experts

What constitutes wellness and a positive healthcare experience are culturally bound concepts and shaped by distinct worldviews.<sup>9</sup> As such, it is important to create survey content through engagement with community members (patient groups and people with lived experiences), community leaders and experts. Engagement should occur through culturally appropriate methods (e.g., Sharing Circles), respecting preferences of the communities and individuals involved, to inform the development of PROMs and PREMs.

'The question—a question would be what type of communities supports like have and then what kind I would want. Because I was having conversations with my aunty and she was saying we focus on hospitals and all these other spaces, but our health comes from our community and our household before we even go to these services. So what kind of stuff can we be doing in our community to support each other, to live a healthier life and how they can make that happen? What type of preventative care is accessible to us, our community and what else?'

(Jackie, Community Member)

### 3.2.7 | Protocol 7: Apply Indigenous lenses and/or knowledges congruent with Indigenous worldviews to questions/content development

When developing tools that are relevant to Indigenous communities, survey developers should seek to understand and promote Indigenous knowledges and use this to inform new ways of looking at PREMs and PROMS. Survey questions should be devised by applying a wholistic perspective, by focusing on resiliency and applying a strength-based approach, by having a sense of balance (same number of questions on illness and wellness), by ensuring culture, one's relations and experience of racism are areas of enquiry and by ensuring respectful line of questioning—which may translate into asking about protective factors as opposed to sensitive topics such as substance use or suicide. It is also important that survey developers bring a social determinant approach and equity lens to question development and include questions based on what the community views as important to health (e.g., cultural engagement or land based activities). Table 2 provides example of survey questions framed by applying teachings from Protocol 7.

'When it came to the definition of health and the concept of First Nations wellness, a lot of the questions

that were developed, like I said, had that wholistic view of health, or definition of health. So that, when they were reviewing everything, they found that wellness encompassed everything from Indigenous knowledge to language, culture, world view, spirituality, as anything to develop a lot of those indicators of health....And it was developed as a tool and it has all of the different components of what health is. It's a total—I think it's, like health and—yeah, total health of the total person, the total community, the total environment.'

(Jasmine, Community Leader)

'We look at health in a different way than the mainstream society. As Indigenous people, we look at health wholistically. We look at it as in our spirit, in our physical being, and in our mind'.

(Jimmy – Community Member)

### 3.2.8 | Protocol 8: Ensure Indigenous peoples' knowledge are reflected in the survey tools

The feel and the look of the survey tool need to be considered when developing Indigenous-specific PROMs and PREMs, through contextualization (reflecting community members' daily lives and worldviews) and by using relevant cultural symbols, imagery and language. More importantly, the tool must showcase that it was developed by or with, and for use with Indigenous peoples.

'We wanted the tool to be empowering, we didn't want a tool that made people go away going, 'Why am I bothering'. So something that could be part of the empowerment process, help guide people to see where they are and where they could be, and sort of embed it in feeling like—as you're doing it feeling like, 'Yeah, this is mine' rather than, 'This is something some psychologist developed and made me complete', so embedded in the language and image etc'.

(Melissa Haswell, Researcher)

### 3.2.9 | Protocol 9: Validate: Ensure cultural appropriateness, acceptability, relevancy, validity and reliability of survey questions

It is important to exercise rigour when developing PROMs and PREMs. Validation should take place via qualitative and statistical methods, with involvement from patients, persons with lived experience, community members, Elders/knowledge keepers, leaders and validation experts. This should occur through an iterative process of piloting, testing and revising.

**TABLE 2** Teachings from Protocol 7: Apply Indigenous lenses and/or knowledges congruent with Indigenous worldviews to question/content development.

Teachings	Example questions <sup>a</sup> or approaches
Use wholistic conceptualizations of wellness and lenses in developing PROMs and PREMs; address the emotional core of interaction with healthcare providers	<p>Q. Able to move without pain/strong in my cultural identity/my relationships with whanau [family] and others are healthy/able to manage unwelcome thoughts and feelings [agreement scale] (Hua Oranga survey)</p> <p>Q. I need to pay attention to my spirit because it is important to my physical well-being [agreement scale] (Native Wellness Assessment)</p> <p>Q. Did the healthcare provider ask about your [emotional/mental/physical/spiritual] health?</p> <p>Q. Were support and resources provided for your [emotional/physical/mental/spiritual] wellness?</p> <p>Q. How did the [visit/your appointment today] make you feel?</p>
Recognize the importance of land-based activities and ceremonies in individual and community wellness	<p>Q. I take initiative to be physically active through land based activities [agreement scale] (Native Wellness Assessment)</p> <p>Q. How often do you engage in your communities' traditional ceremonies?</p>
Ensure balance	<ul style="list-style-type: none"> <li>• Have the same number of questions that focus on illness and wellness</li> <li>• Have balance between questions that focus on the different dimensions of health (e.g., emotional, physical, etc.)</li> </ul>
Use 'culture-as-prevention' lens; ask about cultural engagement and sense of community and identity	<p>Q. I feel comforted when I participate in cultural activities and ceremonies; The more I learn about my culture, the more confident I feel about my life [agreement scale] (Native Wellness Assessment)</p>
Frame questions using a strength-based/resiliency approach; wellness focused as opposed to deficit focused	<p>Q. I understand what contributes to my concerns and how to address these [agreement scale] (Hua Oranga survey)</p> <p>Q. Feel safe and secure, can face whatever is ahead [agreement scale] (Growth &amp; Empowerment Measure)</p>
Focus on protective factors, especially when asking about sensitive topics such as addiction and suicide; consider the concept of 'respect' when developing questions	<p>Q. I understand how the creator helps me/I treat my body as sacred [agreement scale] (Native Wellness Assessment)</p> <ul style="list-style-type: none"> <li>• It may not always be seen as respectful to ask directly about sensitive issues—focus on protective factors</li> </ul> <p>Q. What resources are available in your community to support people with [mental health issues/addiction/suicide risk]?</p> <p>Q. I have a strong sense of belonging to my [aboriginal/FNMI] community or Nation [agreement scale] (Cultural Connectedness Scale)</p> <p>Q. I want to make changes in my life that contribute to my well-being [agreement scale] (Hua Oranga survey)</p>
Use a social determinants of health approach in developing questions	<ul style="list-style-type: none"> <li>• Ask about racism, discrimination, poverty, availability of resources, disability and accessibility and so forth</li> </ul> <p>Q. How often did the healthcare provider ask about resources that affect your health, such as food, clothing or shelter? (Equity Oriented Health Care Scale)</p>
Pose questions that address the impact of racism on health and healthcare experiences	<p>Q. How often have you felt unfairly treated at this hospital because of your race or cultural background? (Cultural Safety Survey)</p> <p>Q. I am treated with the same courtesy and respect as other people; Health staff act as if they think I am drunk or I am asked about substance use [frequency scale] (Indigenous People's Survey)</p>
Apply an inclusivity lens	<ul style="list-style-type: none"> <li>• Use inclusive language in surveys (e.g., not all maternity patients are women); ensure demographic questions are inclusive</li> </ul>
Apply an equity lens—ask about accessibility of services and gaps in services	<p>Q. How often did your healthcare providers help you to work on any barriers you have accessing healthcare (e.g., costs of medication or services, problems with transportation or childcare, problem getting a referral)? (Equity Oriented Health Care Scale)</p>

(Continues)

TABLE 2 (Continued)

Teachings	Example questions <sup>a</sup> or approaches
Frame questions using a trauma-informed approach: ensure questions are not triggering; consider the 'safety' of questions	<ul style="list-style-type: none"> <li>• Be cognisant of what questions are unsafe to ask—those that perpetuate stigma/ stereotypes, feeling of shame or fear</li> <li>• Due to colonial child removal practices questions about parenting and living conditions may be viewed as unsafe (e.g., How confident are you in taking care of your infant? How many people live in your household?)</li> </ul>
Use a relational lens in developing questions; recognize the interrelationships between individual and family, community and land health	<ul style="list-style-type: none"> <li>• Ask questions about the impact of patient's health and experience on family/community's experience and vice versa               <ul style="list-style-type: none"> <li>Q. When I am hurting, my family hurts with me; My [community's/family's] happiness is part of my happiness [agreement scale] (Awareness of Connectedness Scale)</li> <li>Q. Did your family feel comfortable visiting you in the hospital? (Cultural Safety Survey)</li> <li>Q. Does your family have the support they need to care for you?</li> </ul> </li> <li>• Consider the importance of social/community support as opposed to focusing on individual agency alone               <ul style="list-style-type: none"> <li>Q. Can you do [tasks] on your own?; Can you do [tasks] with support from family members?</li> <li>Q. Working together with [family/friends] I can solve many of my problems; I can do what I set my mind to do because I have the support of my family [agreement scale] (Multicultural Mastery Scale)</li> </ul> </li> <li>• Focus on relationships with care providers (e.g., is there trust? Are they advocates?)               <ul style="list-style-type: none"> <li>Q. Do you trust the hospital staff with your medical care?; Do you feel the hospital staff really care about your health?; During your time in this hospital, were you ever asked if you would like to talk to the Aboriginal Hospital Liaison Officer? (Cultural Safety Survey)</li> <li>Q. How often did the healthcare provider encourage you to come and see them or call when you need to? (Equity Oriented Health Care Scale)</li> </ul> </li> </ul>
Apply a cultural humility lens	<ul style="list-style-type: none"> <li>• Ask whether care was non-hierarchical; was there acknowledgement of different perspectives?               <ul style="list-style-type: none"> <li>Q. Did your healthcare provider acknowledge [non-western] ways of healing/medicines?</li> <li>Q. Did the healthcare provider ensure that you are involved as much as you wanted in decisions about your care or treatment?</li> </ul> </li> </ul>

<sup>a</sup>Note: Some of the example questions are from the survey tools identified in our scoping review:

Awareness of connectedness scale.<sup>10</sup>

Cultural connectedness scale.<sup>11</sup>

Cultural safety survey.<sup>12</sup>

Equity oriented healthcare scale.<sup>13</sup>

Growth & empowerment measure.<sup>14</sup>

Hua oranga.<sup>15</sup>

Indigenous peoples' survey.<sup>16</sup>

Multicultural mastery scale.<sup>17</sup>

Native wellness assessment.<sup>18</sup>

Abbreviations: PREMs, patient-reported experience measures; PROM, patient-reported outcome measures.

'We want to make sure it's safe and appropriate for our kaumatua (Elders), not simply what's been done in science before. So we're giving up some type of—so when there's a standard measure to compare it with we're giving that up, said forget it. We don't care. We're going to do what works. And ultimately that works for us because we then post comparisons of change. So, so long as we're consistent doesn't matter. That's all we're trying to say. And you know, that idea is comparing Maori to Western models where it doesn't really fit'.

(John Oetzel, Researcher)

### 3.2.10 | Protocol 10: Ensure ethical data ownership, collection and storage

Data governance is about what stories will be told; who will be telling the stories and how; and for what purposes the stories will be used. Hence, it is paramount that in the administration of PROMs and PREMs the Ownership, Control, Access and Possession (OCAP) principles<sup>19</sup> are followed. Clear communication about the survey developers and administrators, purpose of survey (including why information on self-identification is being asked) and use of results can help with establishing trust,



assuring participants that the survey findings will be used in a 'good way'.

'We're trying to move towards nation-based data sovereignty and intellectual property ownership, which is about identity ownership, which is about language and everything that relates to us Indigenous Peoples, as unique Indigenous Peoples, that as we're moving incrementally these projects we have to take every opportunity to change how we do things, the methodology, or the sampling frame or something, to move us incrementally toward what it is we want over the long haul'.

(Gwen Phillips, Community Leader)

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

In administration of PROMs and PREMs one should take into account patient and community preferences and cultural ways of connecting and communicating. Some of the teachings under this protocol include engaging in meaningful introductions with survey participants, providing 'gifts' for survey completion (as form of respect and reciprocity), and having Indigenous interviewers if the survey is being verbally administered. In addition, one must consider when it might be appropriate for family members or trusted healthcare providers to provide feedback as proxy or to administer the survey in a group (social) format. Providing support mechanisms to survey participants when sensitive questions are asked should also be considered.

'When working with Indigenous people, the most important thing, I think, is to establish relationship first. They always want to know, who's your mama, who are you, before they talk to you. And if you can't say who you are, I mean even if you say, 'I'm the lady that walks by with the big dog, and I come from Newfoundland', people would still kind of connect'.

(Sophia – Community Member)

### 3.2.12 | Protocol 12: Analyse data using both Indigenous and western worldviews

At the data analysis stage there is a need to present disaggregated data to contextualize and demonstrate needs, inequities and systematic barriers by community. In addition, the analysis of PROMs and PREMs would benefit from ensuring that stories and patient voices are captured (via open-ended questions) alongside quantitative data.

'If everything I present in an academic paper is normed then they can't do the work themselves, whereas if I publish everything based on raw data, it's transparent and we give them a spreadsheet and say don't give data into here, the filters are all set up, you can pick boys, girls, older, younger, whatever you want and it will redo all your graphs'.

(Elderberry, Researcher)

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

Measures to ensure accountability should be cocreated with Indigenous partners in discussions before starting the study. After the study is completed, survey developers should make findings available to communities so that communities can implement changes to existing services or respond to new opportunities based on the findings. Asking participants to self-identify as Indigenous on surveys requires a commitment on the part of the health system to recognize the impact of colonial oppression on Indigenous peoples and to be prepared to respond through reconciliatory strategies.

'The other thing is to always consider the entire loop. The closing of the loop. So if you're engaging somebody to give you some information on—what should something look like? You actually give them the finished product and show them how it's being used at the end of it all and not just knowing that we've contributed to something that might happen. And even if it doesn't get used somewhere, what's happened with what I've given you? Right? Always ensure that we're closing that research loop'.

(Gwen Phillips, Community Leader)

## 4 | DISCUSSION

PROMs and PREMs are seen as critical tools in evaluating patient experience and patient outcomes, respectively. Although we are mindful that each Nation and community is distinct, the purpose of this project was to develop a framework/pathways to help guide future efforts in developing PROMs and PREMs with Indigenous peoples. Findings emphasize the criticality of Indigenous leadership in setting priorities for PROMs and PREMs and establishing collaborations that honour Indigenous voices, experiences and lives. Stories emphasize the need to create measurement tools relevant to the peoples and communities they are designed to serve.

Like Indigenous research methodologies more broadly,<sup>20–22</sup> the pathways speak to both process and outcome. They include concrete steps that collaborators can take when establishing a partnership that is respectful and relationally accountable. They align with the First Nation

principles of OCAP (Ownership, Control, Access and Possession).<sup>4</sup> They also echo the principles of a community-based participatory research, an approach that has been shown to be particularly effective in honouring the research needs of Indigenous communities.<sup>23</sup>

Based on teachings of our project Elder, the 13 protocols that comprise the pathway are organized using the Medicine Wheel. The Medicine Wheel's teachings represent one perspective of how to approach PROMs and PREMs or any other form of knowledge process in a good way. We invite other communities to reframe these protocols based on their own cultural frameworks or symbols as appropriate. While we recognize each community will have distinct needs, we believe that these protocols create space for a 'collaborative experience' at each stage of the development process.<sup>20</sup> Further, using an Indigenous framework—such as the Medicine Wheel—aims in recognizing that engagement is not a linear process but is interactive and wholistic.

#### 4.1 | Emotional (speaking from the heart)

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

'Indigenous ways of being hold that we are not to only operate from our heads—meaning with just thought—but must also make the journey to our hearts—meaning we incorporate our emotional responses and inner experiences to develop understandings'.<sup>24</sup> Foundational to the development of PROMs and PREMs then is building meaningful relationships with Indigenous partners based on respect, trust and reciprocity. Creating safe spaces for potential partners to connect and 'speak from the heart' is core to all interactions.

Building relations begins with learning as much as possible about the host Nation/community. Survey developers should approach communities without an agenda, ensuring there is enough time, resources and flexibility to build long-term relationships as opposed to ones that are just project based. Respecting local, cultural protocols is central to an understanding of relationship building.<sup>25</sup> Once engagement has occurred, the processes for initiating and nurturing relationships take place throughout the entire project from forming an Indigenous-led study team to engaging in collaborative fieldwork to analysis and dissemination of findings.

Attending to relationships calls for accountability in all phases of the project; as such, each choice and action must be done with this in mind. Ideally, measures to ensure accountability should be cocreated with Indigenous partners in discussions before starting the study and encompass its different phases. Knowledge dissemination, for instance, requires presenting and sharing findings with the

community first. Study outcomes should be crafted to be presented in a way that is accessible, informative, culturally appropriate to the community context and protective of participant confidentiality. Accountability also means that survey developers have a responsibility to consider whether the specific PROM or PREM could have negative effects on the community, such as perpetuating and reinforcing stereotypes.

#### 4.2 | Mental & intellectual

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

In accordance with Indigenous research ethics, protocols and teachings emphasize the responsibility of investigators to ensure that their project fits with and addresses the needs of the community. This requires that survey developers collaborate on a needs assessment in partnership with specific Indigenous communities to understand what priorities to address. It begins by asking whether the development of PROMs/PREMs is even warranted or whether there already exist validated tools that can be used for the population/community/patient groups. It is important to ensure participation in the project will lead to better outcomes for the community; for example, developing measurement tools that are geared toward informing community practice and/or enhancing quality of healthcare delivery.

What constitutes wellness and a positive healthcare experience must be viewed in the context of a specific place, time, community and history.<sup>26</sup> As such, creating opportunities for Indigenous leaders, experts and community members to share perspectives and inform survey content is core to the development of PROMs and PREMs. The look, the feel and the content of the survey should also reflect and honour Indigenous knowledges and worldviews.

Community-based participatory research is not static, but involves rounds of production, review and revision until all involved are satisfied with the final outcome.<sup>27</sup> Related recommendations for PROMs and PREMs focus on establishing an iterative process for survey development. Once questions are drafted, survey developers should gather feedback, revise, reassess via further feedback, and repeat steps as necessary. This approach requires inviting Indigenous leaders, Elders and community to be part of the validation process, respecting honorarium protocols as needed. Questions should be assessed by members of the specific community for relevancy, appropriateness and cultural safety and modified as necessary. At times, consensus may be required to make important decisions.<sup>28</sup>

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### 4.3 | Physical

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

Collaboration with community involves building meaningful partnerships based on mutual respect and sharing of power. Survey developers should seek adequate resources for Elders to be hired and paid as experts, and to include these roles into project proposals when applying for funding. Further, just as it is expected that the researchers who hold grant funding hire and train students, grant holders should consider funding learning positions that promote Indigenous knowledge sharing, such as Elders-in-training opportunities.

Likewise, hiring and training Indigenous community member to participate in the project (e.g., data collection and analysis) supports collaboration, mutual exchange of knowledge and capacity bridging.<sup>29</sup> In addition to helping ensure that local protocols are respected/maintained, employing community members helps to reduce the power differential between community and survey developers. This, in turn, may lead to gathering more accurate data for the community. Indeed, several community participants expressed unwillingness to participate in interviews with someone who lacked understanding of their history or context. Dawson et al.<sup>30</sup> made similar observations, adding that having community members conduct research may increase participant comfort and enhance cultural safety.

Cultural safety further requires that survey developers reflect upon cultural, historical and structural differences and power relationships in how the project is conducted.<sup>31</sup> It also requires that the survey is administered using culturally appropriate methods (including in-person or orally over the phone).

Indigenous ownership of data is a key feature of any research conducted with Indigenous Nations and communities.<sup>32</sup> Recognizing Indigenous peoples as rights holders means survey developers have a responsibility to the community to ensure Indigenous governance over not only content development, but administration and analysis of survey findings. Taking direction from Indigenous communities further includes control of the flow of information from the research to the public, and accordingly their desired involvement in publications.<sup>20,33</sup>

### 4.4 | Spiritual

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

As a concept, ethical space refers to a meeting place where Indigenous and non-Indigenous views come together to create a more holistic understanding of the world and health-related issues.<sup>34</sup> It is a

space of 'possibility' based on respect for both First Nations and Non-Aboriginal histories, knowledges and traditions.<sup>8</sup> Procedurally, it means creating opportunities for representatives from both Indigenous and Western systems to work together for the benefit of all. Relationally, it encourages 'balanced opportunities for listening and voicing, seeing and showing, feeling and practising ideas and ways to challenge self and others to understand, to think and to do better'.<sup>35</sup>

Recognizing that each Indigenous Nation has its own specific protocols to guide interactions, teachings highlight the importance of embedding ceremony and storytelling within the project from beginning to end. This might include Elders conducting welcoming and wrap up ceremonies throughout the project (introduction, survey development, analysis and validation, knowledge translation), as well as a closing ceremony when the project comes to an end. Ceremony helps create and foster stronger relationships based on respect for Indigenous ways of knowing and traditions.<sup>36</sup>

Content development for PROMs and PREMs must centre on Indigenous knowledges and worldviews. For example, a common thread running through many Indigenous cultures is a holistic perspective on health, reflecting the interconnectedness of the mental, physical, emotional and spiritual aspects of life.<sup>37-39</sup> All four dimensions need to be addressed when framing questions capturing experience and outcome. For example, survey developers should consider asking not just about what services were provided, but the emotional core of the interaction as well ('how did it make you feel?'). Similarly, for some Indigenous communities, connection to traditional lands and land-based activities (e.g., hunting, fishing) are viewed as intimately tied to health. These should be included as health indicators in connection with the community's culture and traditions.

Similar to other Indigenous-led surveys,<sup>32,40</sup> teachings also support framing questions using a strength-based/resiliency approach. Although trauma (historical and current) has resulted in poor health outcomes for Indigenous peoples both in Canada and globally, participants emphasized the need to recognize the strength and resilience that Indigenous peoples and their culture hold. A strengths-based approach does not ignore problems but attempts to identify what resources an individual or community hold to positively address problems.<sup>38,41</sup> For example, rather than posing questions directly about sensitive issues (e.g., substance use, suicide), a strength-based approach urges survey developers to focus on protective factors (e.g., what resources are available, does the person have a strong connection to the community and culture?). At the same time, however, participants emphasized the need for PROMs and PREMs to examine the impact of racism on health. Mistrust and dismissal of Indigenous patients' symptoms, and other instances of racism by healthcare providers, negatively affect wellness and should be incorporated as areas of enquiry in PROMs and PREMs.

Another foundational element of many Indigenous cultures is the connection between individual and family well-being.<sup>31</sup> As one community participant stated, 'balanced health equals strong family health'. This means survey developers should consider family and relational dimensions in framing questions for PROM and PREMs. For example, in considering physical health, it would be important to ask

about not just the individual but also the impact of patient's health and experience on family wellness and the family's well-being on the patient.

## 4.5 | Limitations

Although the proposed framework is meant to be used by Indigenous communities broadly, we recognize that some of its elements will need to be adapted to reflect specific cultural practices and worldviews. For example, the Medicine Wheel is just one approach to understanding wholistic wellness. At the same time, there are some common principles amidst knowledge systems and our project Elder reminded us that we can find wholistic models of care in different forms amidst the diversity of Indigenous peoples. Instead of the Medicine Wheel, other cultural paradigms can be utilized to frame the proposed protocols.

Appropriate structures and resources are also needed to support the implementation of these proposed pathways. Accordingly, the value and utility of our pathways in practice should be further investigated.

## 5 | CONCLUSIONS

This study describes pathways and wise practices to guide the development of Indigenous centred PROMs and PREMS. Committing to partnership and supporting Indigenous self-determination in survey development contributes to decolonization by creating tools meaningful and useful for the Nation and/or community.

At the same time, we view these pathways as just a beginning and a living document. We wish to highlight the importance of continuously building a comprehensive evidence base that describes PROMs and PREMS work in different Indigenous communities, with different groups of people with specific needs, and in particular contexts.

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## CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

## DATA AVAILABILITY STATEMENT

Data is available upon request.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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