Pathways for Developing Patient-Reported Outcome (PROMs) and Experience Measures (PREMs) for Indigenous Peoples

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Lay Summary

Patients are often asked at hospitals, doctor's offices or in the community to complete surveys or questionnaires about their health and/or health care experience. However, many researchers and survey makers have not taken the time to learn or do not know how to make surveys or ask the types of questions that matter to Indigenous peoples and communities. In our study we created a Pathways document to provide a guide for those who want to create surveys for Indigenous peoples.

How did we create the Pathways?

1. We looked at other research and published work in order to understand how Indigenous surveys have been created and to identify best practices
2. We talked to researchers who have developed surveys for Indigenous communities to learn from them; talked to community leaders who use surveys in decision making in their work (e.g., program managers); and we also talked to Indigenous community members to understand their experiences with surveys, and how they think surveys can be improved.

Once we gathered and analyzed all this information we developed our Pathways document.

Project Findings:

Our Pathways document includes **13 protocols** and under each there are a number of **teachings** listed.

The protocols are:

1. Establish a study team grounded by Indigenous Peoples
2. Build meaningful and reciprocal relationships with Indigenous community partners; recognize the importance of speaking heart to heart
3. Create an "ethical space," meaning that all parties (Indigenous and non-Indigenous) acknowledge their different cultures and worldviews, and work with each other in a respectful and shared space
4. Ensure ceremony and storytelling are a critical part of project from beginning to end
5. Identify Indigenous community-specific priorities; conduct needs assessment, literature review and environmental scan
6. Invite and create content with Indigenous community members leaders and experts
7. Apply Indigenous lens and/or knowledge consistent with Indigenous worldviews to question/content development

   Some examples of teachings:

   a. Define health holistically; capture experiences using a holistic lens
   b. Use a strength-based approach– ask about wellness, resiliency, protective factors
   c. Use a "culture as prevention" lens
   d. Avoid un-safe questions – those that create stereotypes/stigma, feeling of shame or fear
   e. Capture experiences of racism and discrimination in healthcare
8. Ensure Indigenous peoples' knowledge are reflected in the survey tools
9. Validate: Ensure cultural appropriateness, acceptability, relevancy, validity and reliability of survey questions
10. Ensure ethical data ownership, collection and storage
11. Administer the survey using culturally appropriate methods (including in-person or orally over the phone)
12. Analyze data using both Indigenous and western worldviews
13. Accountability: Ensure results are shared and used to inform changes and communicate how those changes were implemented

Introduction

This report was developed as part of a joint research project between the University of British Columbia and the BC Children's and BC Women's Hospital and Health Centres (C&W)'s Indigenous Health Program. It provides a guide for developing patient-reported outcome and experience surveys with and for Indigenous peoples based on Indigenous community strengths and priorities.

Despite growth in the implementation of patient-reported measures globally, there is a scarcity of information about Indigenous-specific measures. The complexity in patient reported experience measurement--together with the inherent anti-Indigenous racism in the healthcare system that has resulted in disparities in health outcomes for many conditions affecting Indigenous peoples compared to non-Indigenous populations--emphasizes the need for accurate, anti-racist, culturally safe and meaningful health assessment and experience measures. Our work starts from the premise that it is best to develop Indigenous-specific instruments, although some aspects of this guide can also be used to adapt general tools for use with Indigenous peoples. In addition, we acknowledge that survey tools/questionnaires do not replace qualitative feedback gathering mechanisms (e.g., talking circles), but complement them.

Reflecting on the insights gained from those who have developed Indigenous-specific patient reported outcome (PROMs) and patient-reported experience measures (PREMs), through literature review and interviews, as well as from Indigenous community members who were interviewed regarding their experiences with surveys, we offer the following pathways. These pathways are intended as a guide for researchers, evaluators, program planners, and managers, health care providers, community leaders, and quality improvement specialists who wish to develop self-reported survey tools for use with Indigenous patients/family members or Indigenous communities. The pathways consist of 13 protocols, and associated teachings, that provide detailed and practical approaches towards PREMs and PROMs development. These pathways can also be used by Indigenous communities to support discussions with potential partners, and to ensure the goals of their community are achieved.

Contextualizing the application of the Medicine Wheel

The project team was fortunate to work under the guidance of Elder Sharon Jinkerson-Brass, as well as Elders-in-training Natasha Anderson and Malina Dawn Rehm. Elder Sharon, a member of Key First Nation in Saskatchewan, guided us on the use of the Medicine Wheel as a holistic framework for the interpretation and presentation of results. The Medicine Wheel is one approach to understanding wellness holistically, that is the balance of emotional, physical, mental, and spiritual well-being. Elder Sharon reminded us that the teaching of holistic wellness (highlighting the four interconnected components of health) is a commonly shared amongst the diversity of Indigenous peoples. It's with much gratitude we acknowledge Elder Sharon for her guidance. We also like to acknowledge that these pathways can potentially be re-framed using different cultural frameworks or symbols. We also view our Pathways as a living document, with more protocols and teachings integrated, as new knowledge is uncovered and old wisdom is incorporated.

“So every person is going to be unique. So there’s two pieces: recognizing that there’s diversity within Aboriginal Peoples and communities, whether they’re Métis or First Nations or Inuit, whether they live on their reserve, whether they live in urban centers or whether they live rurally. Just recognizing we’re not all the same… So there’s that importance about the uniqueness, and recognizing that there’ll never be a checklist of ten on how to work with Indigenous People.” Marigold – Community leader

Why PREMs and PROMs?

Patient-oriented research (POR) refers to a continuum of research that aims to improve healthcare delivery and outcomes through research that is guided by patients (BCSU 2018). POR views patients as experts bringing critical perspectives to the research process based on their knowledge of living with a condition or illness, as well as their experiences with treatments and the health care system. POR has gained attention globally and is seen as integral to improving health outcomes and quality of care. For example, INVOLVE was established by the National Institute for Health Research in the UK to support active public involvement in NHS, public health and social care research. In the US, the Patient-Centred Outcomes Research Institute aims to improve healthcare delivery and outcomes through funding evidence-based research that is guided by patients, caregivers, and the broader healthcare community. Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) are standardized, validated tools that measure respectively patients’ views of their health status and experience while receiving care (Kingsley & Patel, 2018).

There is currently limited understanding of how to develop and/or adapt self-reported measures to reflect Indigenous knowledge and understanding. For example, in regards to health literacy measures (which is an example of a PROM) Smylie et al (2006) argued that Indigenous conceptualization of health literacy need to build on Indigenous worldviews, yet stated that development of relevant measures is a “yet-to-be-charted” area and posed the question of how Indigenous health literacy can be measured? Angell et al’s (2016) systematic review of health-related quality-of-life (HRQoL) instruments used with Indigenous populations showed that there are limited examples of Indigenous-specific instruments and called for development of Indigenous-specific HRQoL measures. Similarly, the urgent need for Indigenous-specific PREMs has also been highlighted (Green et al, 2018; Aboriginal Health Policy Directorate, 2018). Hence, for improving the health status of Indigenous peoples in Canada (and internationally) there is a need for accurate and culturally meaningful health assessment and experience measures (Smylie & Anderson, 2006; Aboriginal Health Policy Directorate, 2018).

Yet if research is to produce knowledge that is truly taken up and used to improve health experiences and outcomes for Indigenous peoples, a foundation for ensuring successful collaboration must first be laid. This study begins to address this gap by creating a framework/pathways document on best practices to guide the development of Indigenous PROMs and PREMS. At the same time, we view these pathways as just a beginning and this report as 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. Changes over time will need to be tracked and measured to know what progress has been made and where more resources and efforts are needed to fully achieve priorities and needs of Indigenous communities. As researchers continue to engage with different communities and different forms of collaboration, more relevant forms of Indigenous PROMS and PREMS can be expected. The value and contribution of these tools to the Indigenous data landscape are vast. In the absence of high-quality, culturally-relevant and community-level data, it would be challenging to inform program and policy initiatives, planning and evaluation (Steffler, 2016; Smylie & Anderson, 2006).

Methods:

Overview

This project aimed to gather knowledge from a number of sources in order to create pathways for development of PROMs and PREMs designed for Indigenous peoples. This included reviewing the literature on existing Indigenous-specific PROMs and PREMs in order to learn how Indigenous lens and knowledge were used in question development. We also engaged with Indigenous and non-Indigenous peoples in a "good way" by building on the experience and insights of Indigenous community members, and the knowledge of community leaders and academic researchers. The project had four core components: (1) literature review on existing PROMs and PREMs that had been developed or adapted for Indigenous peoples; (2) interviews with researchers who are developing Indigenous-specific PROMs and PREMs and community leaders interested in using these Indigenous-informed evaluation tools; (3) conversations with Indigenous community members about their experiences with health and experience surveys; and (4) validation of research findings with select participants and the Project Advisory Committee.

Literature Review

The review process started with a consultation with a librarian with expertise in Indigenous studies, to identify relevant databases, key search terms and websites housing grey literature. The review started in March 2020 (with a few more articles located after this time once the full text review began). The review was conducted using electronic databases of MEDLINE (OVID), CINAHL, Psych INFO, and Google Scholar. In addition, the following websites were manually reviewed: Indigenous HealthInfoNet (Australia), The National Collaborating Centre for Aboriginal Health (Canada), Maori Health (New Zealand) and the American Indicant Health (United States).

Our search criteria included:

- Studies from Canada, Australia, New Zealand and the United States (CANZUS nations).
- Studies that included PROMs or PREMs that were developed for Indigenous peoples or adapted (modified for use with Indigenous peoples). We used the United Nations (UN) definition of Indigenous peoples to guide this review (https://www.un.org/development/desa/indigenouspeoples/about-us.html). However, we included all Indigenous population related terms (e.g., Aboriginal, Native American, etc.) to search for studies on the study population. We also defined the term "health outcome" using a social determinant lens and consistent with how health/wellbeing is conceptualized in Indigenous cultures (Richmond et al., 2009; Smylie et al., 2006; Allen et al.,2019). As such, many studies related to survey tools that at first glance may not have been viewed as PROMs (such as tools that measure identity and cultural engagement) were included in the review.

The search results and their full texts were imported into the citation management software Zotero. All articles were assessed by two reviewers. In the first round, the titles and abstracts were reviewed based on the eligibility criteria outlined above. In the second round, the full texts of the included articles were assessed to ensure relevancy based on criteria. Any inconsistencies in reviewer assessment (in round one or two) were resolved through discussion and reaching consensus. In round three, the articles that met the inclusion criteria were carefully examined by three reviewers and information and key learnings were extracted in an iterative fashion, with multiple rounds of assessment and re-assessment by the reviewers. In total, 53 articles were assessed in-depth, relating to 29 survey tools. Key learnings from these PROMs and PREMs identified through the search were incorporated in the synthesis stage of the study, informing the development of pathways (see Data synthesis: Creation and Validation of Pathways).

Please note that the literature review results are reported elsewhere (an Inventory and a scoping review manuscript are currently under development).

Interviews with Researchers, Leaders & Community Members

Introducing ourselves

Our work began by creating a video, posted on YouTube, to introduce our team and the project to potential participants. We viewed this as a form of reciprocal knowledge sharing. Rather than researchers solely obtaining information from the participants, the research team members introduced themselves in the video in a personal way, with the goal of bringing humanity and humility to the research process. Members of our team came from diverse backgrounds in health care (social work, nursing, and medicine), research, evaluation, ethics, psychology, public health, forestry, geography, art and yoga. Five of the team members self-identified as First Nations, one as Metis, and the remaining five were settlers from Europe or Asia. Over the course of the research project, two members left our study and two new members joined.

Participant selection and recruitment

Recruitment of researchers and community leaders occurred using purposeful sampling. Researchers were identified through the literature review and included both Canadian and international experts in the development of Indigenous-specific PROMs or PREMs. Indigenous community leaders were identified through internal contacts, by conducting environmental scan, and via referrals from participants (snowball sampling). Identified community members included representatives at the local, regional, provincial, and national community levels.

Community engagement was altered due to the Covid-19 pandemic. As we could no longer hold sharing circles as indicated in the original research design, we changed methodology to hold individual telephone/Zoom interviews with Indigenous community members instead. Recruitment of community members involved purposeful sampling and was undertaken through the internal contacts of the BC Women's and Children's Hospital Indigenous Health Program. We also recruited participants through promotional posters, social media and by holding two information sessions that were led by Indigenous team members (Elder, co-investigator and PhD student). At these events, information was shared about the team and purpose of the study as well as how interested persons could contact the research lead.

Data gathering: Researchers & community leaders

Semi-structured interviews were held with the researchers and community Leaders. An interview guide was developed based on the research questions and a comprehensive literature review. Guiding questions were deliberated during planning meetings, allowing each team member to add, edit or suggest questions based on their experiences and expertise. The guide included open-ended questions so that participants could add what they felt were the most important topics related to the research objectives. Interview questions were sent to the participants upon their request prior to the interview. A detailed consent form was also sent to the participants to read and sign before the interviews.

All interviews were conducted via telephone or Zoom, by a non-Indigenous PhD Trainee with experience in Indigenous community-led research. The participant was asked to introduce themselves in a way that was comfortable to them in lieu of asking for demographic information. The interviewer took notes during the interviews and wrote analytical memos afterward (which included field notes, impressions, reflections and learnings). Each interview lasted between 30-60 minutes and was audio recorded after getting permission from the participants. Participants were offered a $100 honorarium as a thank you for their time and guidance.

All interviews were recorded and transcribed verbatim by a professional transcription service. At the time of the interview, the interviewer asked participants if they preferred to be identified or not. Some participants requested that direct quotations were attributed to them. In the writing phase, we went back to the participants to confirm permission to use their quotes, while ensuring that the quotes used reflected their intent.

Listening to stories: Community members

We also created an Indigenous-informed interview schedule to guide conversations with community members. The interviews were conducted by three Indigenous interviewers (PhD student, Medicine Fellow and an Elder-in-training), with majority completed by an Indigenous PhD student. Wanting to ensure that the questions would be meaningful to community participants, the PhD student trialled the questions with our project Elder and Elder-in-Training and made revisions to the interview guide accordingly. Honouring Indigenous ways of knowing, the interviewers aimed to establish a safe space for stories and storytelling. Relationship-building and self-care of participants were prioritized. Each participant was given space to introduce themselves in a way that felt safe to them (as opposed to asking about demographic questions). The interviewers re-checked with participants along the interview to ensure they felt comfortable answering questions and were given space to talk about issues important to them (outside of the research questions).

All interviews were conducted over telephone or Zoom, each lasting any where between 30-60 minutes. The interviews were audio recorded, with permission, and participants were gifted with a $100 honorarium as a thank you for their time and guidance. All interviews were recorded and transcribed verbatim by a professional transcription service; and similar to the researcher/leader interviews participants were asked about their preference to be identified/their quotes be attributed to them or their preferred pseudonym to be used in reporting instead.

Data analysis: Researcher and community leader interviews

Transcripts from the researcher and community leader interviews were imported into the qualitative data software, NVivo 12, for coding and thematic analysis. All interviews were thematically analyzed using inductive technique (Thomas, 2006). Analysis started immediately after each interview by writing memos, summarizing field notes and capturing expressions and learnings. In the next step, two researchers conducted manual coding of the first four transcripts to capture codes and identify and define categories after readings of the raw data. The two sets of categories developed by the two researchers were then merged into a combined set. We selected appropriate quotations that conveyed the core theme or essence of a category and combined some of the categories under a superordinate category when the meanings were similar. We developed a coding scheme supported by the relevant quotations and shared that with the research team for further data analysis. Codes and categories were refined or revised through collaborative and collective thinking. We then used the confirmed coding scheme to continue the coding process in NVivo 12 software for the remaining interview transcripts. The resulting codes were shared with the research team and the codes got merged, re-arranged and/or further refined through an iterative process based on our research questions.

Data analysis: Community member interviews

Analysis of community member interviews involved a slightly different process. The goal of the data analysis process was to obtain a rich description that accurately honoured the stories, thoughts, and experiences of the participants. To make meaning of the transcripts, the Indigenous interviewers/researchers met to discuss participants' responses and identify preliminary themes. The project Elder also informed the coding process, asking the researchers to think through and code participants' responses along dimensions of the Medicine Wheel. Please note that the Medicine Wheel is one approach to understanding holistic wellness, the balance of emotional, physical, mental, and spiritual well-being. Our project Elder reminded us that we can find these holistic models of care in different forms amidst the diversity of Indigenous peoples.

Analysis comprised an iterative inductive process that involved a constant movement back and forth from the written text to the shared thoughts of the Indigenous researchers/coders. The researchers began the process with a line-by-line review of the transcripts. They then met by Zoom to collaboratively compare and discuss initial codes and themes. A second layer of analysis involved thinking through how participants' responses made them "feel" and fit into the emotional, spiritual, mental, physical realm of the Medicine Wheel. Some of the conversations touched on all four quadrants, others just on one. Moving back and forth between the text and shared discussion, the researchers engaged in a deep layer of thinking in which themes were generated and coded alongside the dimensions from the Medicine wheel. Emergent themes were discussed with project's Elder-in-Training for feedback and validation as the entire research process was collaborative with either the Elder or Elder-in-Training present. The collective nature of both process and outcome were considered integral to conducting research respectful of Indigenous relationality/principles and honouring of participants' stories.

Data synthesis: Creation and Validation of Pathways

Key themes from the interviews with researchers, community leaders and community members, as well as learnings from the literature (on PROMs and PREMs developed or adapted for Indigenous peoples) were synthesize and formed the basis of a draft pathways document. Our key research question, "what recommendations and best practices can be proposed to support the development of PROMs and PREMs for Indigenous peoples" informed our data synthesis. Our thematic synthesis occurred in an iterative fashion with cycles of drafting, seeking feedback from team members, and revisions. These feedback gathering and drafting cycles occurred offline and online (via Zoom meetings) where all members of the research team (including our Elder and Elder-in-Training) participated. In developing our draft pathways we framed our recommendations as "protocols", with number of teachings listed under each. We later organized the protocols using the Medicine Wheel, in accordance with teachings from our project Elder and consistent with how the stories (data) from the community members were analyzed.

Validation & member checking

We sought feedback on our draft pathways document from our study participants for member checking and validation of our document. In total, 7 participants (3 researchers, 2 community leaders and 2 community members) reviewed the pathways draft and provided feedback via email, telephone, or Zoom. In addition, our draft pathways document was shared in a Zoom meeting with our Research Advisory Committee members (consisting of health care providers, researchers, academics, program planners and policy makers), where they reviewed the document and provided feedback during the meeting and after via email. The majority of feedback from our study participants and Advisory Members was positive: They viewed the protocols as informative, useful, and in alignment with their work and vision. Community members indicted that they recognized their voice in the document. All the participants and Advisory members appreciated the inclusion of "stories" in the pathways document, as it brought life and voice to the text. Areas of improvement were related to terminology, needing to provide more details/examples for certain teachings, and explanation of the use of Medicine Wheel as framework for the pathways. The pathways document was further revised based on the feedback received. This involved going back to the interview transcripts and literature, as well as consulting with the research team members in an iterative fashion and making final revisions.

Relational and Institutional Ethics

Approval to conduct the study was granted from the Research Ethics Board (REB) at the University of British Columbia, Vancouver, B.C. We also applied an Indigenous lens to the consent process. Consent forms included photographs of the lead investigators, along with text that provided information about their heritage and cultural background. Consistent with the understanding that consent is a two-way process in which both parties (investigators and participants) agree to the tenets of reciprocal relationship (Bull 2010), we thought it important to share information about ourselves in the consent form.

The option of oral consent was also given, as a means of demonstrating respect for the oral tradition of Indigenous peoples. No one opted to give oral consent for this study. As part of the consent process, participants were also asked how they would like to be identified – by name or with a pseudonym. Support exists for the Indigenous protocol of granting participants the choice of being named in the research, as this signals a knowledge-sharing relationship and the participants' custodial ownership of that knowledge (Battiste 2008; Grimwood et al 2012; Wilson 2008). In some cases, participants requested that direct quotations would be attributed to them. If using the participant's real name, we sought and obtained express permission to use their specific quote. The team viewed informed consent, rather than being a one-off process, as a continual process through the collecting, recording, transcribing and sharing of information. Transcription services were governed by a confidentiality agreement. Names were removed from the transcripts by the service provider to protect participant confidentiality.

Findings

Pathways for Developing PROMs and PREMs for Indigenous peoples

Participant Profile

Among the 114 researchers and 70 community leaders who were invited to partake in the study, 28 participated in the interviews (14 researchers and 14 community leaders). In addition, 15 community members were interviewed (who were recruited mainly via word-of-mouth and posters). Demographic information was not captured systematically from participants, as they were asked to introduce themselves in a way that was comfortable to them in lieu of asking for demographic information. Table 1 outlines the information that was shared by the participants.

Table 1: Participant Profile

Participants	Profile
Researchers (n = 14)	• 3 self-identified as Indigenous from New Zealand; 5 not Indigenous; 6 unknown • 7 lived in Canada; 5 in New Zealand; 2 in Australia • 13 were affiliated with universities; 1 worked as a health consultant • All had expertise in the development or adaption of PROMs or PREMs for Indigenous peoples
Community leaders (n = 14)	• 9 self-identified as Indigenous; 2 non-Indigenous; 3 unknown • Indigenous participants were from: ○ Grand Rapids First Nations ○ Ktunaxa Nation ○ Lil'wat nation ○ Nunavut territory (Inuit) ○ Okanagan Nation ○ Titqet Nation ○ Whitefish River Nation • 14 lived in Canada: British Columbia, Nunavut Territory, Ontario • Roles: Elder, Director, Health Lead, Community Planner, Nurse, Operations Lead, Educator, and Research Advisor • All had experience with patient engagement or the use of PROMs and PREMs with Indigenous peoples in their roles
Community members (n = 15)	• 15 self-identified as Indigenous • Communities/peoples/ Nations/regions/bands: ○ Anishinaabe ○ Gitxsan territory ○ Kamloops Indian Band ○ Kahkewistahaw First Nation ○ Lac Seul First Nations ○ Metis/Icelandic ○ Metis Nation ○ Mohawk ○ Nunavut territory (Inuit) ○ Oneida Nation ○ Sto:lo Nation • 15 lived in Canada: British Columbia, Northwest Territories, Alberta, Saskatchewan and Ontario • 9 lived off reserve; 3 lived on reserve; 3 unknown • 7 females; 7 males; 1 transmale • Age range: 22 to 66 • All had experience accessing health care; some had experience completing PROMs and/or PREMs

Overview of the Pathways

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

Emotional

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

Spiritual

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

Mental/Intellectual

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

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)

Physical (Medicine Wheel Dimension)

Protocol 1: Establish a study team grounded by Indigenous Peoples

Indigenous research standards apply to the development of PROMS/PREMS as with any study involving Indigneous peoples. This means survey developers should design the project collaboratively from the start rather than invite community members (or patient groups) to participate in after it has already been begun. Collaboration involves building meaningful partnerships based on an equal balance of power. 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.

Teachings:

- Indigenous leadership is grounding the work
- Include members with expertise in Indigenous health research, Indigenous culture (Elders) along with other relevant areas such as evaluation science, public health, epidemiology, research methodology, data analysis and economy, as appropriate
- Build opportunities for Elders to be hired and trained in paid research roles:
    - Include these roles into project proposals when applying for grant
    - Consider creating positions that are valued within an Indigenous lens for long-term capacity bridging, sustainability, mentorship and knowledge sharing, such as an Elder in Training position
    - Elders should be compensated similar to ‘experts’ in the field
- Build opportunities for Indigenous community members to participate in data collection (e.g., conduct interviews)
- Establish three circles of support: Research team, funders and Advisory Committee
    - Establish Advisory Committee, composed of Indigenous leaders who are subject matter experts, to guide study

Stories

“I think it does and I would prefer the person to be Indigenous just because I feel like when people are working in this field and they’re working in this Indigenous world where their scope or their focus is on our Indigenous peoples, it should be an Indigenous person and if it’s not, that person is kind of taking the space away from somebody who could be doing it who is Indigenous.” –John, Community Member

“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, Researcher

“I mean, ceremony doesn’t cost a lot if you have the people there that can do it, but there’s a lot of ceremony people are getting old and they're passing away and the medicine is not being passed on. That’s the urgency to me, right.” - Sophia – Community Member

Emotional (Medicine Wheel Dimension)

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. Relationship-building takes time and can involve participating in activities outside of and after the project itself. Survey developers should plan for having adequate time and resources to build, sustain and nurture trusting relationships throughout the entire project (Kovach, 2009; Wilson, 2008).

Teachings:

- Connect and partner with regional affiliates representing Indigenous communities or associations
    - Find out who the host nation is and ways to engage
    - Build relationships without an agenda—is there opportunity, capacity, interest to collaborate outside of the study
    - Plan for long term relationship as opposed to project based
- Don’t send anonymous asks—these feel empty in terms of engagement, ‘faceless’
- Build, maintain and foster meaningful relationships with the community or patient groups
    - Ensure time and space to create meaningful relationships
    - Meet face-to-face whenever possible
    - Ensure respectful ways of data gathering that honour Indigenous-specific research principles and ethical aspects of data ownership
- Ensure that people know that their participation is going to build better outcomes for the community (not just lip service or academic outcomes)

Stories

“Yeah, well I mean we have to approach the community to get the permission to work with the elders, so we will usually – I mean we’ve got some nice friendships and our research centre has been going for a long time, since 1992, and so there are some deeply-established relationships and some deep-established relationships of trust and that is real currently. And the thing is you can never take those relationships for granted and you have to front up. So you actually have to show face in the community, you cannot sit from your desk and type them emails and just keep typing emails and expect them to jump every time you want something. So turning up regularly and being really committed to their kaupapa, I mean when I say kaupapa, to what they want, you know.” -Grape, Researcher

Stories

"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." – PQ, Community Member

"You have to be consistent, and you have to you know work with people and stay with them, and develop them, and bring back the results. And show that there's some good things coming out of the research for it to be worthwhile. And that's you know long-term journey, not a short-term thing. So in the preparation, the 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

Stories

“We're trying to fit this research into a Western paradigm a lot of the times, so even in this case this is coming out of – it's at a hospital right, that is provincially funded and under kind of a Western leadership and despite having Indigenous health programs and people working towards those kinds of things, you also kind of dance this line as a researcher wanting your research to be accepted in the wider scientific community….. So I guess maybe like a two Two-eyed seeing approach where you're taking the best of the Indigenous methods available, taking the best of the Western methods available, and combining those two so you are ultimately creating a tool that is helpful to the people you want it to be helpful to, but also not going to be disregarded by the institutions that you're implementing the measure in.“
-Basil, Researcher

“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

Spiritual (Medicine Wheel Dimension)

Protocol 3: Create Ethical Space

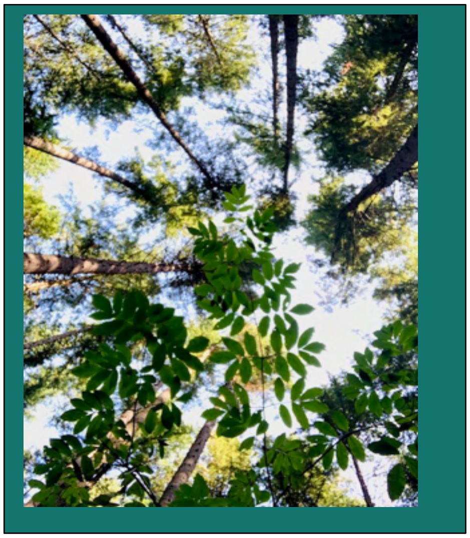
An “ethical space” is formed when Indigenous and Western societies, with their different cultures and worldviews, are poised to engage each other in a distinct but shared space.

As a concept, ethical space refers to a meeting place where representatives from both First Nations and Western systems can come together as equals to work for the benefit of all. It is a space of “possibility” based on respect for each other’s histories, knowledges and traditions (Ermine, 2007). Understanding and observing the cultural protocols of an Indigenous community is essential when entering an ethical space with that community.

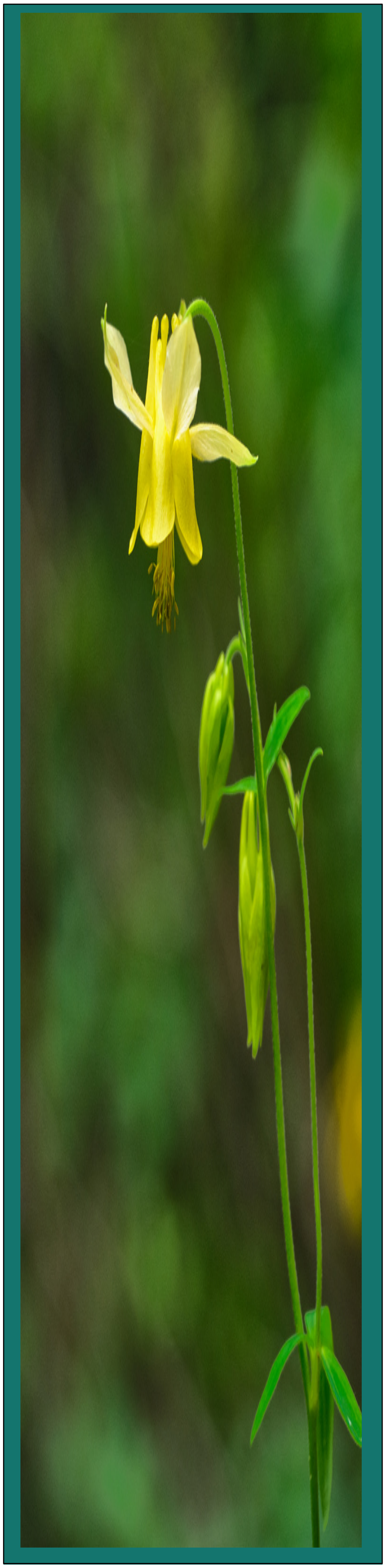
> *“What might work for here, might not be the same for another Indigenous community somewhere else. So it's important that whether you're – no matter what race you are as a physician - that you have to understand the protocol of where you're working.”* –PQ, Community Member

Teachings:

- ► Connecting and balancing Indigenous and Western worldviews to guide the process
- ► Understand Indigenous Peoples who are participating are putting their reputation on the line
- ► Identify and work with those who are trusted speakers for the Indigenous communities
- ► Address priority topics identified by the communities
    - ○ Priorities (ideally) should be explored with community members prior to proposal development
    - ○ Ensure communities can decline to participate if study priorities do not align with community priorities
    - ○ Create space for study elements to shift and grow and adapt—how could projects adapt as group learning happens; remain flexible



- Ensure members most impacted are engaged/participate: "it's done for the people by the people"; honour the strength of the person receiving care
- Ensure participant engagement and recruitment follow community-specific protocols
- Recognize that each community is distinct and has its own specific protocol to guide interactions
- Ensure appropriate reciprocity for each participant and that they are honoured (compensated) for their time
- Ensure the process is done in a way that values Indigenous knowledge systems
    - Develop a systematic method to get feedback from community members
    - Bring results back to the community/participants
- Ensure funds to allow enough time to be flexible and adaptive to meet the changing needs of Indigenous community participants



Spiritual (Medicine Wheel Dimension)

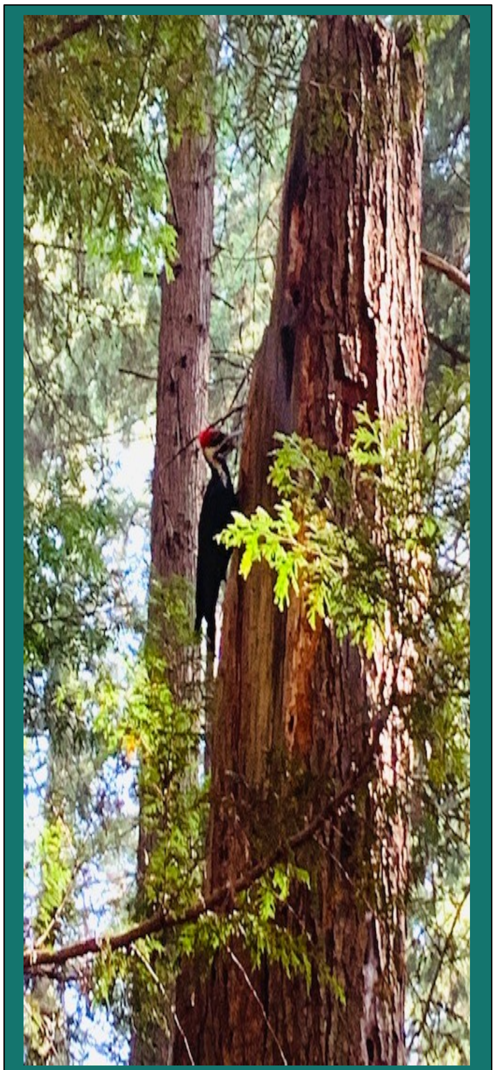
Protocol 4: Ensure ceremony and storytelling are a critical part of the project from beginning to end

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.

Teachings:

- ► Embed ceremony and storytelling within the entire cycle from relationship building to survey development to analysis, validation and knowledge translation, along with community guidance
    - ○ Examples are welcoming ceremony for the start of the project/meetings and closing ceremony for the end; Elders leading a talking circle; tobacco ceremony; smudging or cedar brushing at meetings; accepting invitation to sweat lodge/medicine lodge; Elders developing medicine bundle; feasting (sharing meals)

"So the new researchers here's – you sit on one side if from the organization you're with them. If you're a visitor you're on the other side and there's a formal back and forth of acknowledging each other and welcoming. And 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



Mental (Medicine Wheel Dimension)

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

Prior to the development of PROMs or PREMs survey developers must work with Indigneous 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. In addition, one must gain a firm understanding of existing landscape of available and appropriate PROMs and PREMs that can potentally be used with Indigenous peoples.

Teachings:

- ► Collaborate on needs assessment in partnership with specific Indigenous community to understand priorities of each Indigenous community and use these to drive the research/study
- ► Identify health and experience indicators that have already been developed with and by Indigenous peoples
- ► Develop a good understanding of existing survey tools (PROMs/PREMs)
- ► Determine whether the development of PROMs/PREMs is warranted; whether there already exist validated tools that can be used for the population/community

“Obviously being driven by Indigenous people, you know, it's, obviously needs to work in the health systems and there needs to be one eye on that somewhere. But there's no point measuring stuff if it's not useful information and if it's not important to Indigenous people then I don’t think it's useful information and there's no, sort of,

"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

Mental (Medicine Wheel Dimension)

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

What constitutes wellness and a positive health care experience are culturally bound concepts and shaped by distinct worldviews (Richmond et al, 2007; Smylie et al., 2006; Angell et al., 2016; Green et al., 2018). As such, it is important to create survey content through engagement with community members (patient groups), community leaders and experts. Engagement should occur through culturally appropriate and qualitative methods, respecting preferences of the communities and individuals involved, in order to inform the development of PROMs and PREMs.

Teachings:

- Gather feedback from Indigenous community members about their experiences and what is important to measure in terms of health outcomes and experiences, via storytelling, healing/sharing/talking circles, interviews, focus groups and/or open-ended questions:
    - Connect with people through face-to-face interaction
    - Respect peoples' right to be in control of what they share
    - Provide options to gather feedback alongside family members or community members if preferred
    - Use creative and hands-on methods/approaches for content creation, such as art-based activities, photo-voice and concept mapping
    - Facilitate activities that are meaningful for Indigenous peoples and connected to their lived experiences and the land
- Gather feedback from content experts and other stakeholders (e.g., health care providers, Elders, health administrators, community leaders, etc.) via methods such as interviews, focus groups, Delphi survey process (surveying in rounds to reach consensus), etc.
- Share qualitative findings with participants and get feedback
- Provide support and have follow up mechanisms when asking sensitive information (e.g., Elder support, link to community resources)

Stories

"You're already vulnerable when you're there. The doctor or doctor or physician or healthcare providers don't always know that you've had a bad experience. So it would definitely work to be asked more frequently like just basic, how was it?, is there anything else we could improve on?, was there anything that like, you felt weird about?" -Unique, Community Member

"I think it was really that focus group where there was face to face interaction and people were, a lot of talking amongst themselves, not just to the researcher, that's where a lot of the rich input came from. And people talking about their experiences, but sort of, it sort of…. it crystallizes things "- Cherry, Researcher

"Yeah, so lots of workshops and – first of all, analyzing interviews with people where they were simply asked, "What changes did doing the [name] program make in your life, what were you able to do" and those stories. And of course, it went – there were hundreds of different things that people said and trying to condense into some pathways, yeah, and then get some questions in the right format to measure that and then validation and … yeah [laughs], a long journey."- Dr. Melissa Haswell, on creating the Growth and Empowerment Measure

"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

"..they're not from the community, so why ask them? Why ask a social worker that came from Toronto, what does the community need? Ask the community what they need, right. Every community is different, and you need to find out what you think their needs are, right, and ask the people. And sometimes it's helpful to ask the people that are dealing with the problem, but also ask some of the people that have healed. Because it's, how did you get there?" – Sophia, Community Member

Spiritual (Medicine Wheel Dimension)

Protocol 7: Apply Indigenous lens and/or knowledge congruent with Indigenous worldviews to questions/content development

Stories

"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 holistic 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, Researcher

"And then when you think about myself and my medical training has been challenged by thinking about the Maori world view of these things. So even in our medical training we have the understanding that the concept of health is much broader for Maori and incorporates four pillars not just two. And one of them is the land and the connection to the land.... Well, so you have to allow yourself to take on the idea that actually challenging those original assumptions is a good thing and that you'll learn together." – Apple, Researcher

"I do bring back to the emotional pieces. So they ask you your symptoms; where does it hurt, what's going on, blah, blah, blah, blah, how long has this been happening? I do think we need to incorporate more of an emotional part into the surveys." Star Woman, Community Member

When developing tools that are relevant to Indigenous communities, survey developers should seek to understand and promote Indigenous knowledge and use this to inform new ways of looking at PREMs and PROMS. This means recognising and valuing knowledge approaches other than the scientific or Western ones.

Teachings:

- Use Indigenous conceptualizations/ definitions of wellness in developing questions:
    - Define health in holistic terms; acknowledge different dimensions of health in question development (e.g., physical, spiritual, emotional, mental)
- Use a holistic lens in capturing experiences/framing questions:
    - Were emotional and/or physical symptoms dismissed by providers?
    - Were support and resources provided for each dimension of health/wellness?
    - Not just ask about what services were provided, but address the emotional core of interaction – "how did it make you feel?")
- Honour the relationship between land-based health and healing; for example, recognize the importance of land-based activities (e.g., hunting, fishing) and ceremonies in individual and community wellness
- Ensure balance: Balance between questions that focus on illness and wellness; balance between questions that focus on the different dimensions of health (e.g., spiritual, physical, etc.)

- Use “culture-as-prevention” lens; focus on cultural engagement and identity as these are closely tied to health
- Frame questions using a strength-based/resiliency approach; wellness focused as opposed to deficit focused
    - Focus on protective factors, especially when asking about sensitive topics such as addiction and suicide
- Use a social determinants approach in developing questions - racism, discrimination, poverty, lack of resources, disability and accessibility, etc. are determinants of health
- Consider the concept of “respect” when developing questions – for example, it may not always be seen as respectful to ask directly about sensitive issues, but acceptable to ask about protective factors (e.g., what resources are available, does the person have strong connection to the community and culture?)
- Pose questions that address the impact of racism on health and healthcare experiences
    - Experience of implicit bias and racism should be captured in all PROMs and PREMs
    - Mistrust and dismissal of Indigenous patients’ symptoms and/or experiences by health care providers need to be captured in surveys
- Apply an inclusivity lens: Use inclusive language in surveys (e.g., not all maternity patients are women; ensure demographic questions are inclusive)
- Apply an equity lens – ask about accessibility of services and gaps in services
- Frame questions using a trauma-informed approach: Ensure questions are not triggering; define trauma; consider intergenerational trauma/trauma as a result of colonialization and historical contexts when developing questions to assess wellness and experience
- Consider the “safety” of questions: Be cognizant of what questions are unsafe to ask – those that perpetuate stigma/stereotypes, feeling of shame or fear (especially when there is a history of children being removed from families)
- Use a relational lens in developing questions:
    - Recognize the interrelationships between individual and family, community and land health
    - Recognize the connections between the health of the family and health of the community– leads to a sense of balance
    - Consider asking questions about the impact of patient’s health and experience on family’s wellbeing
    - Consider importance of social/community support as opposed to focusing on individual agency alone
    - Consider family support when asking about wellness (e.g., can they do tasks on their own versus can they do it with support from family)
    - Focus on relationships with care providers (e.g., is there trust, are they advocates)
- Apply a cultural humility lens– for example, did providers acknowledge different perspectives; did they acknowledge non-western ways of healing; was care non-hierarchical - was there shared-decision making

Stories

"And then when you think about myself and my medical training has been challenged by thinking about the Maori world view of these things. So even in our medical training we have the understanding that the concept of health is much broader for Maori and incorporates four pillars not just two. And one of them is the land and the connection to the land.... Well, so you have to allow yourself to take on the idea that actually challenging those original assumptions is a good thing and that you'll learn together." - Agrimony, Researcher

"We look at health in a different way than the mainstream society. As Indigenous people, we look at health holistically. We look at it as in our spirit, in our physical being, and in our mind." (Jimmy – Community Member)

"Probably questions about drinking and drug use and domestic violence. This isn't a medical example, but for my - in my band we had to fill out these questionnaires to get band funding for school. And there was questions on there about domestic violence and drinking and drug use and I'm like who's - why would you willingly give out that information? What are they doing with that. Yeah just questions like that, I'm just kind of like what are you doing with this? And just doesn't make you feel good, even if you're not a drug user and you're not a drinker." -Jackie, Community Member

You know, like, even, "How many people live in your house," or "Who do you live with," or whatever. Why do you want to know, right? Because they want – because they've had their kids taken away from them, and if there's ten people living in your house and it's a two-bedroom house, it's overcrowding, so maybe your kids will be taken away. So people won't sometimes answer. They're like, "What are you going to do with this information?" Sometimes they just say, "No, I don't want a survey." –Sophia, Community Member

"I like to add a fifth quadrant to the medicine wheel, 'cause I think family's absolutely one of those pieces, kinship relations. There's got to be a fifth quadrant whether you put it right in the heart as a second circle or anything. All four spheres speak to family and relation and the teachings that are received from, you know, our elders and valued members of our community always remind us that, you know, we're always connected not only to the earth and to the natural world, but we're connected to our families in the same way. So balanced health equals strong family health." -Max, Community Member

Mental (Medicine Wheel Dimension)

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.

Teachings:

- Use culturally appropriate art, symbols and representations
- Embed survey questions within cultural frameworks or symbols important in the community (e.g., questions can be embedded within an image of button blanket, Medicine Wheel, or a tree of life)
- Use creative forms of answers and scoring
- Make it visual: more pictures, less text
- Provide space for comments and have questions that allow open-ended answers
- Make sure the tool is simple, brief, and plain language is used
- Contextualize questions to reflect community members' everyday lives and activities (e.g., if measuring functionality ask about their ability to get on a boat, go fishing, etc.)
- Ensure the survey truly reflects Indigenous knowledges; not just adding images to a tool which is solely based in Western knowledge

Stories

"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 etcetera."
- Dr. Melissa Haswell, Researcher

"Yes and that's where the research kind of gets difficult, because well, they have to quanify it and qualitative and quantitavie research, whatever, it's still hard to capture it all with a yes or a no" –
Bob, Community Member

Mental (Medicine Wheel Dimension)

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 (Basch et al., 2015; Van der Wees et al., 2019; Male et al, 2017), and there is a need for such validated and relevant measurement tools for Indigenous peoples. Validation should take place via qualitative and statistical methods, and through an iterative process of piloting, testing, and revising. Validated tools allow communities to have access to evidence-based reliable data in order to make decisions, make improvements, allocate resources and improve health care delivery for Indigenous peoples.

Teachings:

- Invite Indigenous leaders, Elders, and community members to be part of the validation process, respecting honorarium protocols and reciprocal relationships
- Use an iterative process in survey development: Draft questions, gather feedback, revise, re-assess via further feedback, and repeat steps as necessary
- Establish face and content validity via qualitative methods (e.g., cognitive interviewing) – to ensure we are measuring what we intend to measure
    - Assess questions for relevancy, appropriateness and cultural safety
    - Assess scoring and answer choices
    - Ensure wording is understandable, clear and concise; ensure appropriate literacy level
    - Ensure there are not too many questions
    - Explore how sensitive topics such as suicide and substance use should be addressed in surveys
    - Provide feedback back to participants/member check
    - Show openness and willingness to change approach as needed
- Provide meaningful translations of tool from/to Indigenous languages (as needed)
    - Ensure equivalency of meaning through the translation and back-translation process by conducting focus groups with bilingual experts and community members
    - Ensure equivalency in content, semantics and concept and reach consensus between expert reviewers and revise as necessary
- Conduct Psychometric testing (as appropriate)- some examples:
    - Assess the structure of the survey through Factor Analysis – to understand what components/ dimension are being measured
    - Establish convergent validity: Compare the survey tool with other established measures/surveys
    - Establish reliability: Ensure question items that are measuring the same thing correlate with each other

“So it’s very much a grounded up process even though we’re taking existing measures. We’re not afraid to adapt them which some people find problematic. Those who usually are constrained by a traditional science model and we are not. We are about fitting. 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

Physical (Medicine Wheel Dimension)

Protocol 10: Ensure ethical data ownership, collection and storage

Data governance is essentially about what stories will be told? Who will be telling the stories and how? And for what purposes the stories will be used? Indigenous approaches to data governance, mainly through principles of Ownership, Control, Access and Possession (OCAP) (FNRHS, 2011), highlight that data can and have been used for all kinds of purposes, including to categorize and oppress through colonial relationships (Bruhn, 2013). Hence, it is paramount that in the administration of PROMs and PREMs the OCAP principles are followed. Clear communication about the survey developers and administrators, purpose, and use of results can help with establishing trust, assuring participants that the survey findings will be used in a 'good way'.

Teachings:

- Indigenous communities and organizations must be owners of their own health data
- Ensure patient confidentiality in collecting data
- Ensure the highest standards for protecting individual and collective confidentiality and privacy; provide the option to do the survey anonymously
- Ensure the purpose of the survey is clearly stated in the introduction: Who is doing the survey? Are the survey developers/administrators Indigenous? What is the purpose? Information about privacy and confidentiality; how will the results be used?
- Ensure safety – that there would not be any repercussions or "less care" if one speaks out against the service/providers
- When asking sensitive questions provide reasoning as to how this information will be used
- Clearly state why information on Indigenous self-identification is being collected in the survey – how will the results be used? Be cognizant that it may not always be "safe" to self-identify – due to fear of discrimination or feeling shame when one does not know one's heritage due to past colonial actions of child removal
- Implement procedures to ensure data is held securely
- Ensure that data is stored in a way it can be used by Indigenous communities in the future

Stories

“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 towards what it is we want over the long haul.” – Gwen Phillips, Community Leader

“You know, yes. You know, tell them what the – put, you know, like I mean for the first part, your introduction of your survey, and of who you are, explain to them who it’s for, and what it’s for. Because, you know, like I mean again, it’s – if you don’t include that, most people would think it’s going to be a non-indigenous survey, right? And as I said, white man’s words to some indigenous people don’t mean nothing, right? They’ll just, you know, hit the old delete button, or just spam, or trash, or whatever they call it. Where if you, you know, and if you put the word ‘indigenous’ on that, you know, you might get more people looking at it.” - Victor, Community Member

“Some people don’t know their background. They know they're indigenous, but they don’t know where they’ve come from, they're part of the Sixties Scoop. They know, I’ve been in the system, I don’t really know where I am. There’s some kind of embarrassment or shame to it. Other ones feel like they're going to be discriminated against.” -Sophia – Community Member

Physical (Medicine Wheel Dimension)

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. Indigenous communities are accustomed to using oral traditions of storytelling in sharing knowledge (Stevens, 2008), and adhere to a worldview that knowledge is inherently relational (Wilson, 2008). In other words, not only knowledge is gained through sharing of information (stories) through oral means, but it is built upon relationships. Hence, administration of PROMs and PREMs need to honour traditional ways of connecting, by attending to relationship building, establishing trust, and by providing mechanisms for oral exchange of feedback whenever possible.

Teachings:

- Build relationships with survey participants prior to data gathering (e.g., by engaging in meaningful introductions)
- Provide a “gift” for survey completion – as a way to honour people’s time and voices
- Provide the survey in Indigenous languages, as appropriate
- Administer the survey face-to-face or orally as much as possible
- Use Indigenous interviewers if survey is administered orally; use interviewers who speak the same language
- Hand the survey to people instead of mailing/emailing if possible; going door-to-door might be appropriate in some Indigenous communities
- Give participants the option to complete the survey by themselves or by having an interviewer read the questions to them (especially with Elders)
- Make sure the interviewer is objective and is not interpreting patients’ responses for them
- Consider when it might be appropriate for someone to complete the survey on someone’s behalf (e.g. a family member, advocates or councillor in the case of addictions or mental health needs)
- Provide opportunities for care providers to provide patient feedback with the patient’s permission – many times patients voice concerns to trusted care providers
- Consider including opportunities for people to fill the survey in a group format and in communication with others if appropriate
- Consider offering electronic options when appropriate
    - Use a tablet app to capture direct data
    - Have a paper and pencil version as option, when needed
- Offer the option for answers to be made confidentially and anonymously which might be especially important in small communities/health care centers
- If surveys are going to be mailed/emailed, let the patients/community members know prior; provide stamped envelope for mail-back surveys
- Be flexible and change survey administration methods as needed
- Provide support and have follow up mechanisms when asking sensitive information (e.g., Elder support, link to community resources) to mitigate harm
- Create processes for the continuous patient/community member feedback (PREMs); ensure feedback mechanisms are easily accessed /available to patients/community members across the patient/care journey
- Consider using surveys as part of other care processes (e.g., at pre-assessment - as a way for care providers to get to know the patients and their concerns, or at follow-ups/check-ins)

- Timing of PREMs: Capture experiences after patient's care journey is complete (not in the middle); ensure enough time has passed for reflection; ensure the survey is not sent too long after the care appointment
- Provide option for a follow-up if the patient /community member desires to provide further feedback (e.g., provide telephone number, ask for contact information); ensure timely follow-up and response.
- Ensure patients/community members know where to go/what number to call or email if they want to make a formal complaint

- In tandem with the survey, whenever possible, provide opportunities for facilitated individual or group feedback/circle discussions to allow for deeper sharing and story telling

Stories

"I think a better way of doing it would be to have chat groups, you know, to have a facilitator facilitating and making it more social, more of an engagement, more of a ... and more visual, and the opportunity for them to stand and tell stories even if it's like competition, games or something like that, that would be a more fun experience for them. Even to sing, like we go away with kaumātua and they will sometimes surprise me, they'll sing these stories and not everybody, only some, but it actually makes it a more group thing." -Grape, Researcher

"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

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

"I feel like doing a formal complaint is really extreme. We'd only do it in an extreme case like that, but then there does need to be some type of intermediary thing to give feedback to medical services. Yeah and for this to be readily available, instead of having to go through all this searching it out. Because obviously people don't want to be critiqued or have these serious complaints, but then with indigenous people that happens more often than not that we're having bad experiences." -Jackie, Community Member

"Well, the ones [surveys] that don't work are the ones where you have to actually write something out. I think for a lot of our people, the younger generation is maybe a little further along with the ability to write, but for the most part I think the survey we're doing now is a great example of doing it right, because we're having a conversation. Because of – you know our people are people of stories and oral history and just not writing, we're not into filling out things too much." -PQ, Community Member

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

Protocol 12: Analyze data using both Indiegnous and western worldviews

At the data anlaysis stage there is a need to present disaggregated data in order to contextualzie and demonstrate needs, inequalities and systematic barriers by community (BCOHRC, 2020). The current lack of disaggregated data on Indigenous populations creates significant challenges in terms of resource allocation, health program planning and improvement and accountability (Steffler, 2016). In addition, the analysis of PROMs and PREMs would benefit from ensuring that stories and patient voices are captured (via open-tex quesitons) along side quantitative data.

Teachings:

- Ensure disaggregation in data reporting: Present data by community or population, rather than just aggregated data
- Present quantitative data alongside comments/stories from participants to contextualize findings and honour their voices
- Qualitative data in surveys should be analyzed using participant voice as guide to accurately reflect their contribution and viewpoints
- Study team should engage in reflexivity – be aware of social and historical contexts; be aware of study team members' particular lens and worldviews and how they have impacted analysis and reporting

> *"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

Emotional (Medicine Wheel Dimension)

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 co-created with Indigenous partners in discussions prior to 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.

Teachings:

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

Stories

"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

"But I'm trying to think of any time that I had a really bad experience I definitely did not get any survey or questionnaires. But the places I already had positive experiences are the places that offer the questionnaires and surveys, because I think those go hand in hand. But the places that are continually asking for help and feedback are the places that are continually improving. And the places that are not asking for any feedback or questionnaires are not improving." -Paul, Community Member

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

Glossary of Terms

Terms	Definitions
Accountability	Accepting responsibility and showing ownership for its activities.
Culturally appropriate	Following the values, behaviours and beliefs that are preferred by a person, community or Nation, including meeting peoples' social, cultural, emotional, spiritual and linguistic needs, acting with the knowledge and awareness of Indigenous ways of being, in a way that makes a person feel safe, comfortable and welcome.
Cultural humility	Cultural humility is a perspective that involves practicing lifelong learning, exercising self-reflection, recognizing the dynamic of power and privilege and being comfortable with not knowing.
Culture-as-prevention	The belief that a strong cultural identity leads to health protective behaviour and in turn to improved health.
Disaggregated data	Disaggregated data is data that has been broken down by sub-categories, for example by ethnic or cultural groups, gender, region or level of education. Disaggregated data can reveal needs and inequalities that may not be fully reflected in aggregated data.
Elder	Someone who has gained a high degree of understanding of Indigenous history, teachings, ceremonies, worldviews and healing practices. Elders pass this knowledge on to others and give guidance on personal issues, as well as on issues impacting their peoples. This is a socially defined title that is not based on age and is different for each community or Nation. Elder-in-training is someone who is being mentored by an Elder.
Equity lens	Focuses on equality and the equitableness of actions, decisions and resource allocation.
Environmental scan	Searching and examining grey literature/unpublished documents through internal and external sources on a desired subject matter.
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.
Good way	A way that is respectful, culturally safe and appropriate, and upholds the inherent power and autonomy of Indigenous peoples and our relations and responsibilities to ancestors, future generations, non-humans, the air, land and water.
Holistic	Based on Indigenous worldviews, the whole person (physical, emotional, spiritual, and intellectual) are interconnected to land and in relationship to others (family, communities, nations). This is called a holistic view.
Inclusivity lens	Focuses on being inclusive – ensuring diversity and that no one group is left behind.
Indigenous	WHO definition: Identify themselves and are recognized and accepted by their community as Indigenous. Demonstrate historical continuity with pre colonial and/or pre-settler societies. Have strong links to territories and surrounding natural resources. Have distinct social, economic or political systems. Maintain distinct languages, cultures and beliefs. Form non-dominant groups of society. Resolve to maintain and reproduce their ancestral environments and systems as distinctive peoples and communities.
Indigenous self-identification	Indigenous self-identification is the voluntary declaration of ancestry among Indigenous peoples.
Medicine Wheel	A circle, with four quadrants, representing different dimensions of wellness (physical, mental, emotional, spiritual) and the importance of balance between these dimensions for wellness. The Medicine Wheel can take many forms and interpreted differently depending on the particular culture/community.

Needs assessment	A systematic process for determining and addressing needs and barriers/gaps between current conditions and desired conditions. Needs assessment can be conducted using qualitative and/or quantitative methods.
Patient-reported experience measure (PREM)	Survey instruments (tools) measuring patients' perceptions of their experience whilst receiving care. Patient satisfaction surveys are examples of PREMs.
Patient-reported outcome measure (PROM)	Survey instruments (tools) used to assess a patient's self-reported health status at a particular point in time. PROMs can be completed either during an illness or while treating a health condition. PROMs can also be used to assess health at the population level. From a social determinant approach to health, any components that impact health and wellbeing can be considered a health indicator and can be measured by PROMs.
Protective factors	Characteristics and conditions (e.g., family, community, culture, available resources, lack of systematic barriers and discrimination) that are associated with a lower likelihood of problem outcomes or that reduces the negative impact of risk factors.
Protocols	Rules to follow; cultural understanding of customs and respectful way of doing things within a particular community.
Psychometric testing	Psychometrics is a field of study concerned with the theory and technique of psychological measurement (of attitudes, behaviour and opinions). Psychometric testing of survey tools refers to the process and tests that survey developers apply to assess the tool's validity and reliability.
Qualitative data/methods	Qualitative data describes qualities or characteristics and captures in-depth stories. It is often collected in narrative form via interviews, focus groups, talking circles or observations. Qualitative data can also be captured in surveys when asking open-ended questions.
Quantitative data/methods	*Quantitative data* are presented in the form of counts, numbers and/or percentages; each data-set has an unique numerical value associated with it. Quantitative methods emphasize objective measurements and the statistical, mathematical, or numerical analysis of data collected through polls, questionnaires, and surveys, or by manipulating pre-existing statistical data using computational techniques.
Reciprocal/reciprocity	Respect, recognizing a two-way balanced relationship, give and take / fairness/ traditional way of survival and growth respecting relationship, acknowledging one another's gifts and strengths.
Reliability	Ability of a scale to give consistent results. A measure of reliability reflects the extent to which items within an instrument measure various aspects of the same characteristic or construct. It measures whether several items that propose to measure the same general construct produce similar scores. Internal consistency is usually measured with Cronbach's alpha, a statistic calculated from the pairwise correlations between items.
Resiliency	Resiliency is the ability to persist despite difficult life events and conditions. Being resilient does not mean that people don't experience stress, emotional upheaval, and suffering. Resilient people tap into their strengths and support systems to overcome challenges and work through problems. For Indigenous peoples the idea of resiliency is grounded in cultural values that have persisted despite historical adversity and colonial practices.
Social-determinants of health	Social determinants of health refer to a specific group of social and economic factors within the broader determinants of health. These relate to individuals' place in society, such as income, education or employment and systematic barriers to resources individuals may experience. For example, experiences of discrimination, racism and historical trauma are important social determinants of health for Indigenous Peoples.
Strength-based	This approach focuses on individuals' strengths, resiliency, wellness, as well as wider social, cultural and community networks that support individuals.

Trauma-informed & intergenerational trauma	Trauma-informed is an approach in the human service field that assumes that an individual is more likely than not to have a history of trauma. Trauma-informed care recognizes the presence of trauma symptoms and acknowledges the impact of trauma on an individual's life and wellbeing. The impact of residential schools and other colonial practices continue to be felt by subsequent generations among Indigenous peoples in Canada. This is called intergenerational trauma. Historical trauma occurs when trauma caused by historical oppression is passed down through generations.
Two-eyed-seeing	Introduced by Mi'kmaq Elders, Albert, and Murdena Marshall, from Unama'ki (Cape Breton), Nova Scotia, Canada, in 2004, stresses the importance of viewing the world through both Western (what is considered to be mainstream) and Indigenous worldviews. Based on this approach, there are diverse understandings of the world, and only by recognizing and respecting different perspectives can we build an understanding of health and health issues facing Indigenous peoples and communities.
Validity	Validity refers to whether the concept under study is accurately measured. There are different types of validity. Some common forms: Face validity = Extent to which a measure/tool appears, "on its face", to measure the construct of interest. Content validity = A survey has content validity if, in the view of experts and stakeholders, the survey contains questions which cover all aspects of the construct being measured. Face and content validity are subjective opinions of experts and stakeholders. Construct validity = Extent to which the survey measures the theoretical construct it is intended to measure. In some cases, confirmatory factor analysis (CFA) is used to assess construct validity Convergent validity = The degree to which two measures of constructs that theoretically should be related are in fact related - refers to the observation of strong correlations *between* two tests that are assumed to measure the same construct. Discriminant validity = Demonstrated by evidence that measures of constructs that theoretically should not be highly related to each other are in fact not found to be highly correlated to each other.

References

Allen, J., Rasmus, S. M., Fok, C. C. T., Charles, B., Trimble, J., & Lee, K. (2019). Strengths-Based Assessment for Suicide Prevention: Reasons for Life as a Protective Factor From Yup'ik Alaska Native Youth Suicide. *Assessment*, 1073191119875789. https://doi.org/10.1177/1073191119875789

Angell, B., Muhunthan, J., Eades, A.M., Cunningham, J., Garvey, G., Cass, A., Howard, K., Ratcliffe, J., Eades, S., & Jan, S. (2016). The health-related quality of life of Indigenous populations: A global systematic review. *Qual Life Res*, 25(9), 2161-78.

Basch, E., Spertus, J., Dudley, A., Wu, A. Chughan, C., Cohen, P., Smith, M.L., Black, N., Crawford, A., Christensen, K., Blake, K. & Goertz, C. (2015). Methods for developing patient-reported outcome-based performance measures. *Value in Health*, 18(4), 493-504.

Battiste, M. (2008). Research ethics for protecting Indigenous knowledge and heritage: Institutional and researcher responsibilities. In *Handbook of critical and Indigenous methodologies*, ed. N. K. Denzin, Y. S. Lincoln, and L. T. Smith. Thousand Oaks, CA: Sage Publications, 497–509.

British Columbia's Office of the Human Rights Commissioner (BCOHRC) (2020). Disaggregated demographic data collection in British Columbia: The grandmother perspective. https://bchumanrights.ca/wp-content/uploads/BCOHRC_Sept2020_Disaggregated-Data-Report_FINAL.pdf

Bull, J. (2010). Research with Aboriginal Peoples: Authentic relationships as a precursor to ethical research. *Journal of Empirical Research on Human Research Ethics* 2010 Dec;5(4):13-22.

Ermine, W. (2007). The ethical space of engagement. *Indigenous Law Journal*, 6, 193-203.

First Nations Regional Health Survey (FNRHS). April 2011. Best Practice Tools for OCAP™ Compliant Research. Ottawa.

Green, M., Anderson, K., Griffiths, K., Garvey, G., Cunningham, J. (2018). Understanding Indigenous Australians' experiences of cancer care: Stakeholders' views on what to measure and how to measure it. *BMC Health Services*, 18:982.

Grimwood, B., Doubleday, N., Ljubcic, G., Donaldson, S., Blangy, S. (2012). Engaged acclimatization: Towards responsible community-based participatory research in Nunavut. *The Canadian Geographer / Le G´eographe canadien* 2012, 00(0): 1–20

Kovach, M. (2009). Indigenous methodologies: Characteristics, conversations, and contexts. Toronto: University Press Inc.

Le Grande, M., Ski, C. F., Thompson, D. R., Scuffham, P., Kularatna, S., Jackson, A. C., & Brown, A. (2017). Social and emotional wellbeing assessment instruments for use with Indigenous Australians: A critical review. *Social Science & Medicine, 187*, 164-173. https://doi.org/10.1016/j.socscimed.2017.06.046

Male, L., Noble, A., Atkinson, J., & Marson, T. (2017). Measuring patient experience: A systematic review to evaluate psychometric properties of patient reported experience measures (PREMs) for emergency care service provision. *International Journal for Quality in Health Care*, 29(3), 314-326.

Richmond, C.A.M., Ross, N.A., & Bernier, J. (2007). Exploring Indigenous concepts of health: The dimension of Metis and Inuit health. *Aboriginal Policy Research Consortium International*, 4, 3-16.

Richmond, C.A.M., & Ross, N.A. (2009). The determinants of First Nation and Inuit health: A critical population health approach. *Health & Place*, 15(2), 403-411. ISSN 1353-8292, https://doi.org/10.1016/j.healthplace.2008.07.004

Smylie, J., Williams, L. & Cooper, N. (2006). Culture-based Literacy and Aboriginal Health. *Can J Public Health* **97,** S22–S27. https://doi.org/10.1007/BF03405369

Steffler, J. (2016). The Indigenous data landscape in Canada: An overview. *Aboriginal Policy Studies*, 5(2), 149-164.

Thomas, R.D. (2006). A general inductive approach for analyzing qualitative evaluation data. American Journal of Evaluation, June. https://doi.org/10.1177/1098214005283748

Van der Wees, P.J., Verkek, E.W., Marjolein, E.A., Zuidgeest, M., Baker, C., Braspenning, J., de Boer, D., Terwee, C.B., Vajda, I., Beurskens, A., & van Dulmen, S.A. (2019). Journal of Patient-Reported Outcomes, 3(75): https://doi.org/10.1186/s41687-019-0171-9

Wilson, S. (2008). *Research is ceremony: Indigenous research methods*. Halifax, NS: Fernwood Publishing.