



Addressing the need for Indigenous-specific PROMs and PREMs: A focus on methodology

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Abstract

Purpose: Differences in Indigenous worldviews, practices and values highlight the need for Indigenous-specific health quality indicators, such as patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs). The purpose of this paper is to present our methodology, as part of a larger study that sought to develop a framework for creating Indigenous-specific PROMs and PREMs.

Methods: The research design was informed by Indigenous research methodology and a community-based participatory approach. It had three core components: (1) a literature exploration of existing Indigenous-specific PROMs and PREMs; (2) interviews with researchers with expertise in PROMs and PREMs developed for Indigenous populations and community leaders interested in using these Indigenous-informed evaluation tools; and (3) conversations with Indigenous community members about their experiences with health surveys. Interviews were audio-recorded and transcribed verbatim; transcripts were analyzed qualitatively using an inductive and deductive approach. Themes and sub-themes were identified to build a framework that honours Indigenous knowledges and ways of knowing. Results were validated with select research participants and the Project Advisory Committee.

Results: Findings demonstrate how relationship building is the necessary starting point for engagement when developing survey instruments with Indigenous peoples. Engagement requires respectful collaboration through all stages of the project from determining what questions are asked to how the information will be collected, interpreted, and managed. A relational stance requires responsibility to Indigenous communities and peoples that goes beyond research carried out using a western scientific lens. It means ensuring that the project is beneficial to the community and framing questions based on Indigenous knowledge, worldviews, and community involvement.

Conclusions: This study employed a collaborative, participatory qualitative approach to develop a framework for creating PROMs and PREMs with Indigenous peoples.

The methods described offer concrete examples of strategies that can be employed to support relationship-building and collaboration when developing Indigenous-specific survey instruments.

KEYWORDS

access and evaluation, healthcare quality, Indigenous peoples, patient-reported experience measures, patient-reported outcome measures

1 | INTRODUCTION

Indigenous organizations, scholars and communities have called for quantitative information based on culturally relevant metrics and tools.^{1–5} Obtaining accurate nation-specific data is necessary for making policies, planning, and evaluating health services as well as creating indicators that support Indigenous self-determination of health.^{3,6,7} Standard colonial measures frequently produce data that are not relevant or meaningful to Indigenous communities.^{2,8} Hence, there is a pressing need for culturally responsive approaches based on Indigenous methodologies and Indigenous world views.^{1,2,7,8}

Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) are survey instruments developed to evaluate patient outcomes and patient experiences, respectively. PROMs and PREMs are part of quality improvement programmes used by healthcare organizations to measure health system performance and improve services and healthcare delivery.⁹ In addition, patient-reported indicators are increasingly being used by policymakers for decision-making, benchmarking and value-based purchasing.^{10,11}

Yet, despite the health disparities faced by many Indigenous communities, rarely are PROMs and PREMs developed in collaboration with Indigenous Peoples and communities. Further, existing survey tools, coupled with data collection methods, use indicators that reflect limited understanding of Indigenous knowledges, histories and experience. For example, Angell et al.'s¹² systematic review of Indigenous-specific health-related quality-of-life instruments showed that there are limited examples and called for development of Indigenous-specific measures. The urgent need for Indigenous-specific PREMs to make health care services more responsive to the needs of Indigenous patients/users has also been highlighted.^{2,13}

The purpose of our study was to create pathways/a framework to inform the development of PROMs and PREMs with Indigenous peoples. Importantly, the research was guided and underpinned by Indigenous research ethics and methodologies.^{14–16} Specifically, this means putting the needs and interests of Indigenous people at the forefront and ensuring that the research is safe and beneficial.¹⁷ This is the first of two twin articles published in the Journal of Clinical Evaluation on our Pathways project.¹⁸ Here, we describe the core components of the project and describe our

methodological steps in detail. The second paper presents findings, analysis and themes (teachings) that emerged.

2 | OVERVIEW/RESEARCH CONTEXT AND OBJECTIVES

This project aimed to answer the following research question: What best/wise practices can be proposed to support the development or adaptation of PROMs and PREMs with Indigenous Peoples; the intended outcome of our work was to create pathways (a framework) to support the development of these tools. Our study had four core components: (1) a literature exploration on existing Indigenous-specific PROMs and PREMs; (2) interviews with researchers with expertise in PROMs and PREMs developed for Indigenous populations 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 (See Figure 1).

Our project team worked under the guidance of our Project Elder, as well as two Elders-in-training. Elder Sharon embedded ceremony and cultural protocols into all phases of the project and guided the team at every stage with her knowledge and expertise. Members of the project team came from diverse backgrounds in health care (social work, nursing, and medicine), research, evaluation, ethics, psychology, public health, forestry, geography, art and yoga. Seven of the team members self-identified as First Nations, one as Metis, and the remaining five were settlers from Europe or Asia. Our work was further guided by a project Advisory Committee made up of Indigenous and non-Indigenous health care providers, researchers, academics, program planners, policymakers and Indigenous community members.

3 | LITERATURE EXPLORATION

A literature exploration, employing an Indigenous lens, was undertaken to explore and synthesize key themes from the scholarly literature related to the development of Indigenous PROMs and PREMs in Canada, the United States, Australia and New Zealand. Selection criteria were used to identify 61 relevant articles, relating to 37 survey tools which were then reviewed and analyzed using

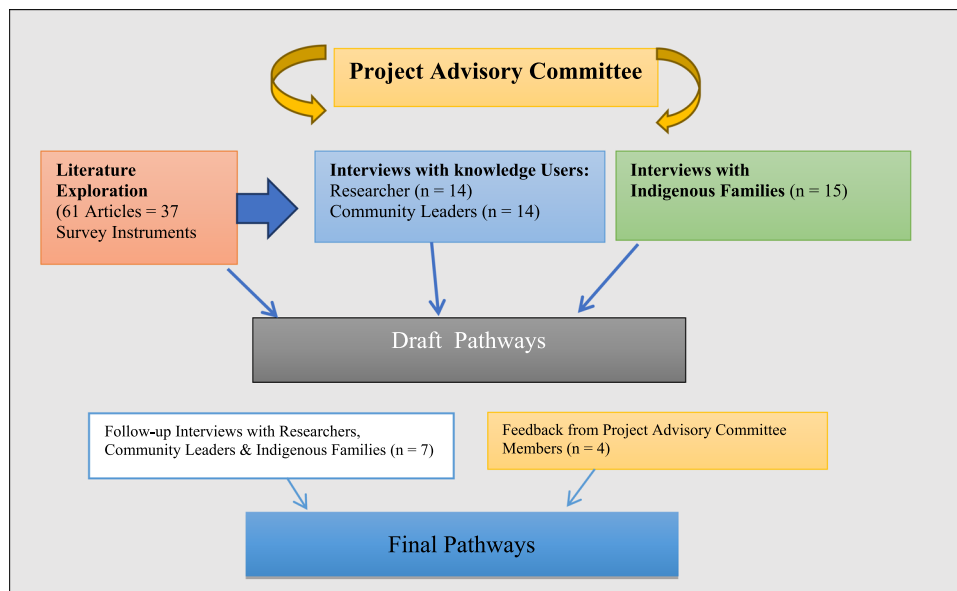


FIGURE 1 Summary of research activities.

collaborative and iterative processes. Detailed descriptions of the methodology and findings are reported elsewhere (see ref. 19).

4 | INTERVIEWS WITH RESEARCHERS, LEADERS AND COMMUNITY MEMBERS

4.1 | Introducing ourselves

The team aimed to bring an Indigenous lens and anticolonial methods to the research. As such, 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.

4.2 | 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 Indigenous-specific PROMs or PREMs. Indigenous community leaders (at the local, regional, provincial, and national community levels) were identified through internal contacts, environmental scans, and referrals from participants (snowball sampling).

Recruitment of Indigenous community members also involved purposeful sampling and was undertaken through the internal contacts of the C&W Indigenous Health Program. We also recruited participants through promotional posters, social media

and information sessions that were led by the team's Indigenous researchers.

4.3 | Data gathering: Researchers and community leaders

Semi-structured interviews were conducted remotely with Indigenous community leaders and Indigenous and non-Indigenous researchers. An interview guide was developed based on our research question, literature review and through a collaborative and iterative process involving all of our team members and Advisory Committee. All interviews were conducted via telephone or Zoom, by a non-Indigenous PhD Trainee with experience in Indigenous community-led research. Each interview lasted between 30 and 60 min and was audio recorded with permission from the participants. Participants were offered a \$100 honorarium as compensation for their time and guidance.

All interviews were transcribed verbatim by a professional transcription service. At the time of the interview, the interviewer asked participants if they preferred to be identified. In the writing phase, the interviewer re-connected with the participants to confirm permission to use their quotes, while ensuring that the quotes used reflected their intent.

4.4 | Listening to stories: Indigenous community members

We also created an Indigenous-informed interview schedule to guide conversations with community members. The interviews were conducted by three Indigenous researchers on our team. Wanting to

ensure that the questions would be meaningful to community participants, the Indigenous PhD student trialled the questions with our project Elder and Elder-in-Training and revised the interview guide accordingly. Upholding protocols common within Indigenous research methodologies, 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 the common Western/colonial approach of asking about demographic questions. The interviewers checked-in with participants throughout the interview to ensure participants' ongoing comfort in answering questions.

All interviews were conducted over telephone or Zoom, each lasting anywhere between 30 and 60 min. The interviews were audio recorded, with permission, and participants received a \$100 honorarium as compensation for their contributions and guidance. All interviews were recorded and transcribed verbatim by a professional transcription service. To ensure the protection of sensitive data, a confidentiality agreement was signed between the research team and 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.

4.5 | Data analysis: Researcher and community leader interviews

Transcripts from the researcher and Indigenous community leader interviews were thematically analyzed using a combination of inductive and deductive techniques.^{20,21} Analysis started immediately after each interview with the interviewer writing reflections in field notes. Initially, two researchers conducted manual coding of the first four transcripts to devise a preliminary coding scheme. We shared the coding scheme, supported by relevant quotations, with the larger research team for collaborative discussion and further refinement. We then used the confirmed coding scheme to continue the coding process in qualitative data management software, NVivo 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 question.

4.6 | Data analysis: Indigenous community member interviews

Analysis of interviews with Indigenous community members 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 on our team 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 using Medicine Wheel teachings (which highlights the four interconnected dimensions of health—emotional, spiritual, mental and physical).

The analysis comprised an iterative inductive and deductive process that involved 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 and physical realm of the Medicine Wheel. The key themes were further refined based on our research question and feedback gathered from all team members. The collective nature of the coding was considered integral to conducting research respectful of Indigenous relationality/principles and honouring participants' stories.¹⁵

4.7 | Data synthesis: Creation and validation of pathways

Key themes from the interviews with researchers, Indigenous community leaders and Indigenous community members, as well as learnings from the literature¹⁹ were synthesized and formed the basis of a draft pathways document. Our key research question, 'what best/wise practices can be proposed to support the development of PROMs and PREMs with Indigenous Peoples' informed our data analysis. Our thematic synthesis occurred in an iterative fashion with cycles of drafting, seeking feedback from team members, and revisions. 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.

4.8 | Validation and member checking

We sought feedback on our draft pathways document for member checking and validation. Seven study participants (three researchers, two Indigenous community leaders and two Indigenous community members) plus our Advisory members reviewed the pathways draft and provided feedback via email, telephone, or Zoom. Most feedback was positive: They viewed the protocols as informative, useful, and in alignment with their work and vision. Indigenous community members indicated that they recognized their voices 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.

5 | RELATIONAL AND INSTITUTIONAL ETHICS

Approval to conduct the study was granted by the Research Ethics Board (REB) at the University of British Columbia. We 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. The consent form was reviewed and signed by each participant before the interview. The option of oral consent was also given, as a means of demonstrating respect for the oral tradition of Indigenous Peoples in Canada. No one opted to give oral consent for this study.

6 | DISCUSSION

The approach to research used in the *Pathways* project has important implications regarding the development of Indigenous PROMs and PREMs. Patient-reported measures are seen globally as integral to assessing and monitoring health outcomes and quality of care.¹⁰ While several strategies have been employed to develop measures that reflect what matters to service users, tools for measuring PROMs and PREMs have been created for the most part, by those who are not experienced with the unique knowledge of Indigenous peoples. Hence, the involvement of Indigenous peoples in shaping PROM and PREM development, with attention to and integration of Indigenous ways of knowing, is crucial.

Currently, in the field of Indigenous health research, the application of Indigenous ways of knowing and Indigenous research methodologies has an increasingly strong grounding.²² Within the quality improvement field, however, there is less clarity on how specific methods might be used to realize these principles. The *Pathways* project is one of the first to apply Indigenous research methods to the context of quality improvement and measurement with PROMs and PREMs. This study uses a relational and community-based approach to explore the lived experiences of Indigenous and non-Indigenous experts, Indigenous community leaders and Indigenous community members across a variety of settings. The approach discussed in this paper offers a concrete example of strategies that bring Indigenous research principles to the area of PROM and PREM development. It aligns with guidelines for program evaluation put forth by the National Collaborating Centre for Aboriginal Health.²³ The NCCAH guidelines endorse a fully participatory approach, including relevant stakeholders in all processes, from needs assessment to knowledge mobilization. Our research approach also aligns with the recommendations outlined by Harfield et al.,¹⁶ as part of their Quality Appraisal Tool of health research involving Aboriginal and Torres Strait Islanders.

7 | LIMITATIONS

Several forms of qualitative enquiry were originally planned for this study. Our initial research design was to meet with community participants face to face and hold sharing circles within the community. These activities had to be altered due to the Covid-19 pandemic and public health mandates; we conducted individual telephone/Zoom interviews with Indigenous community members instead. This meant that the in-person ceremonial practices recommended by our project Elder could not occur. We posit that it is quite possible that sharing circles would have resulted in additional or deeper understanding of dimensions important to creating PROMs and PREMs.

8 | CONCLUSION

The *Pathways* project seeks to explore and describe culturally resonant ways to support the development of PROMs and PREMs with Indigenous peoples. This article shows how Indigenous knowledge and research methodology can be applied to this work. The accompanying paper, 'Pathways: A guide for developing culturally safe and appropriate patient-reported outcome (PROMs) and experience measures (PREMs) with Indigenous Peoples' presents the findings, analysis and as implications for future research on Indigenous-grounded PREMs and PROMs.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Data available upon request.

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