

Pathways for the development of patient-reported outcome (PROMs) and experience measures (PREMs) for Indigenous peoples

Lori d'Agincourt-Canning (PhD), Clinical Associate Professor, University of British Columbia
 Jenny Morgan (EdD), Assistant Teaching Professor, University of Victoria
 Shabnam Ziabakhsh (PhD), Evaluation Specialist, BC Women's Hospital & Health Centre
 Dr./Elder Sharon Jinkerson-Brass, Project Elder



Background

There is a need for culturally meaningful patient-reported health outcome and experience measures for Indigenous peoples; yet there is limited understanding of how to develop and/or adapt self-reported measures to reflect Indigenous knowledges and worldviews.

Research objective

- Create pathways (a framework) for developing culturally relevant PROMs and PREMs for Indigenous peoples.

Methods

- Established an advisory group, including patient partners and Elder
- Created ethical space to carry out work
- Conducted scoping review: Focused on studies from Canada, US, Australia and New Zealand.
- Interviewed researchers (n = 14) & leaders (n = 14): Those with experience with PROMs or PREMs for Indigenous peoples
- Interviewed Indigenous community members (n =15): Focused on their experiences with surveys and/or health care
- Analyzed and synthesized data using a collaborative and iterative process resulting in a pathways document, consisting of 13 protocols

Acknowledgements

Our work was carried out on the traditional and unceded lands of the xʷməθkʷəyəm (Musqueam), Skwxwú7mesh (Squamish), and səliilwətaʔ (Tsleil-Waututh) First Nations, in Vancouver, BC. We would also like to gratefully acknowledge our funder, the BC Office of Patient-Centred Measurement's Methods Cluster that provided CIHR SPOR funding through the BC Support Unit. In addition, we would like to thank the many Indigenous and non-Indigenous community members, researchers and leaders who informed and contributed to this work.

13 PROTOCOLS and examples of teachings



- 1 Establish a study team grounded by Indigenous Peoples**
 - Build opportunities for Elders to be hired and trained in paid roles
 - Build opportunities for Indigenous community members to participate in data collection (e.g., conduct interviews)
- 2 Build meaningful and reciprocal relationships with Indigenous community partners; Recognize the importance of speaking heart to heart**
 - Build relationships without an agenda
 - Plan for long term relationship as opposed to project based

- 3 Ensure an ethical space is created**
 - Balancing Indigenous and Western worldviews
 - Ensure appropriate reciprocity for each participant
- 4 Ensure ceremony and storytelling are a critical part of the project from beginning to end**
 - Welcoming and closing ceremonies for meetings; Elders leading talking circles; Creating medicine bundles, etc.
- 5 Identify Indigenous-specific priorities; conduct needs assessment, literature review and environmental scan**
 - Needs assessment in partnership with community/patient groups
 - Develop a good understanding of existing PROMs/PREMs
- 6 Invite and create content with Indigenous community members, leaders and experts**
- 7 Apply Indigenous lens and/or knowledge congruent with Indigenous worldviews to question/content development**
 - Define health in holistic terms; use a relational lens
 - Frame questions using a strength-based/resiliency approach
- 8 Ensure Indigenous people's knowledge are reflected in the survey tools**
 - Use culturally appropriate art and representations
 - Embed questions within cultural frameworks
- 9 Validate: Ensure cultural appropriateness, acceptability, relevancy, validity and reliability of survey questions**
 - Invite Indigenous leaders, Elders, and community members to be part of the validation, while respecting honorariums
 - Provide meaningful translations of tool (as needed)
- 10 Ensure ethical data ownership, collection and storage**
 - Indigenous communities must be owners of their own health data
 - Ensure the purpose of the survey is clearly stated
- 11 Administer the survey using culturally-appropriate methods (including in-person or orally over the phone)**
 - Build relationships with survey participants prior to data gathering
 - Provide a "gift" for survey completion
- 12 Analyze data using both Indigenous and western worldviews**
 - Ensure disaggregation in data reporting
 - Present quantitative data alongside comments/stories
- 13 Accountability: Ensure results are shared and used to inform changes and communicate how those changes were implemented**
 - Ensure accountability to the community
 - Share results and changes/improvements with community