

Shelby Loft, 2021

ABSTRACT: A Roadmap for Indigenous Patient Reported Outcome and Experience Measures

This project seeks to address a lack of appropriate or adequate measurement tools for understanding Indigenous patient health outcome and experiences with health care services. Understanding patients' self-reported outcomes and experiences are vital for program development and improvement initiatives. In this research study, there are two pathways that are in place to address this gap. First, we will be conducting stakeholder interviews with Indigenous community health experts (leaders) and researchers in the areas of Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs). Second, we will engage with Indigenous patients and families and other community members via in-depth interviews to gather feedback on their experiences with measurement tools and surveys. These two components will work together to inform the development of a pathway to guide survey developers in developing safe, appropriate, and culturally relevant survey tools. In turn, this would improve Indigenous peoples' experiences when completing surveys in future healthcare settings. In this presentation, the co-presenters will share preliminary data from various interviews with stakeholders. In addition, we will share some of the research processes of our study in order to demonstrate how to conduct research using Indigenous methodologies. In particular, we will discuss the development of how we have facilitated creation of Ethical Space in our work, which traces the ethical, accountable, and reciprocal nature of how the team project and the three circles of support have come together as a whole. These three circles, the project team, the advisory committee, and our funders have contributed and shaped the overall work of this research. This work will also feed into the current work at British Columbia's Women and Children's Hospitals.