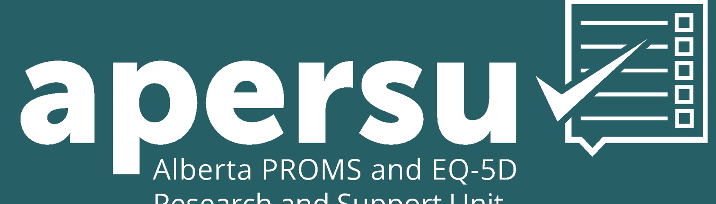
Preference-based Measures of Health-related Quality of Life in Indigenous People: A Systematic Review



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Objective

In many countries, there are calls to address health inequalities experienced by Indigenous people. Preference-based measures (PBMs) provide a measurement of individual's or populations' health and can support resource allocation decisions.

The objective of this review was to identify, summarize, and appraise the literature on the use and performance of PBMs with Indigenous people.

Methods

Search strategy

- The review was supported by an expert librarian.
- 13 major databases were searched with database-specific vocabulary and key words from inception to August 2022.
- Records must include Indigenous people as a target population or sub-group and:
  - Assessed any measurement property of PBMs
  - Directly elicited health preferences
  - Reported the development or translation of PBMs for Indigenous Peoples
  - Measured health-related quality of life (HRQL) using PBMs

Screening

- Records were screened for inclusion by two reviewers (LMR, AN).
- Decisions were made by discussion and consensus; disagreements were reviewed with a senior researcher.

Assessment of Methodological Quality

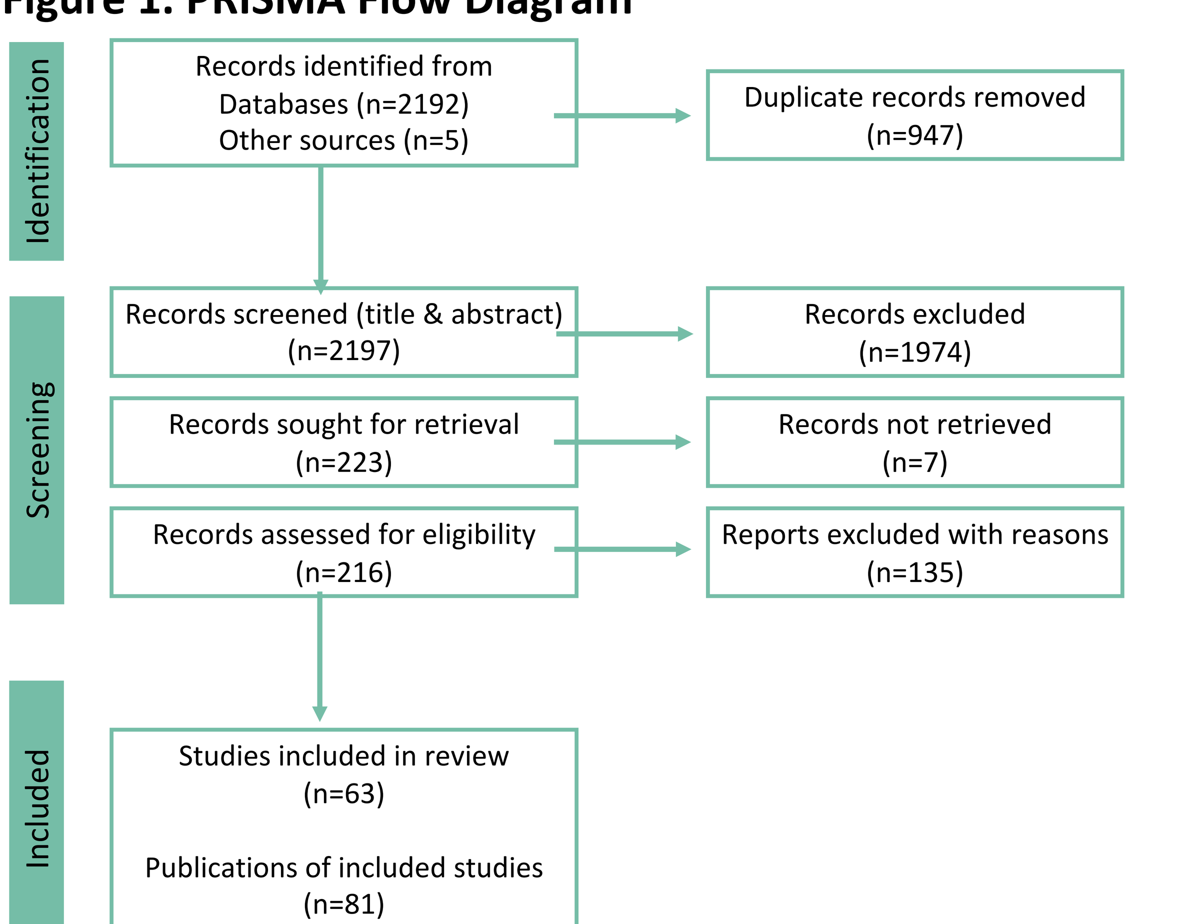
- Ethically engaged research was considered an indicator of quality, and evaluated as:
  - Reporting some form of patient-oriented, community-oriented, Indigenous-centered, or otherwise engaged approach
  - Reporting ethics approval from an Indigenous ethics committee
- Review of quality for all types of publications was not relevant. COSMIN review of performance studies underway as part of an update to the review.

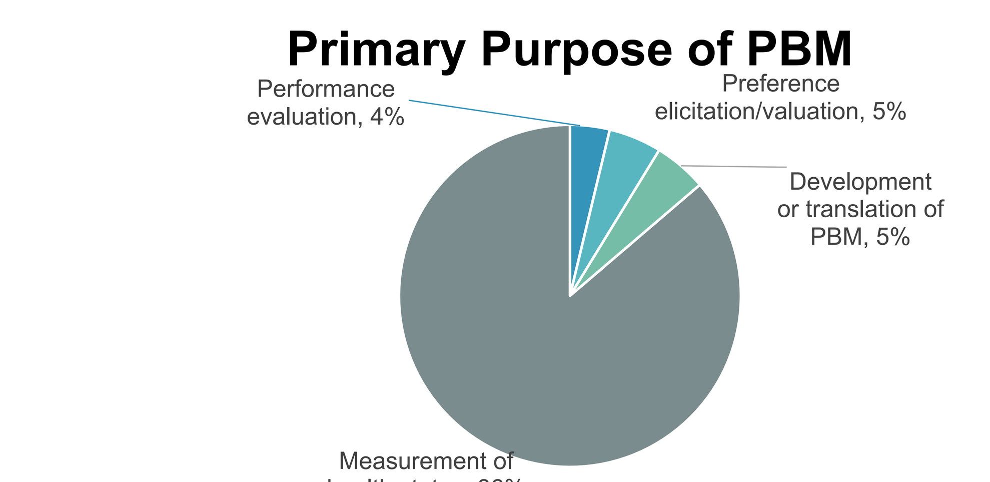
Equity, Diversity and Inclusion

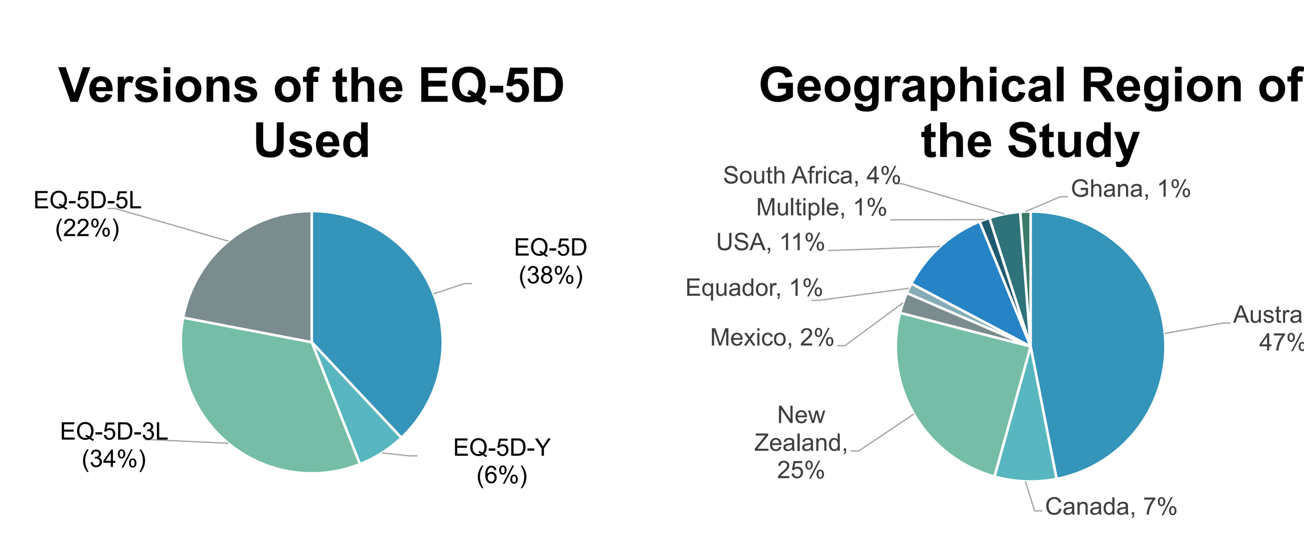
This work prioritizes the value of Indigenous perspective and acknowledges the need for culturally relevant PBMs. Indigenous representation on the research team was a priority and strengthens the interpretation of the findings and discussion. Sex, gender, power, and social factors are considered broadly as known influences on health and patient-reported outcomes. It is our hope that this review can facilitate meaningful conversations and work towards accurate and appropriate measurement of health-related quality of life, particularly given the need to address health inequalities experienced by Indigenous people.

Results

Figure 1. PRISMA Flow Diagram

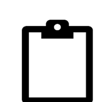


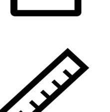




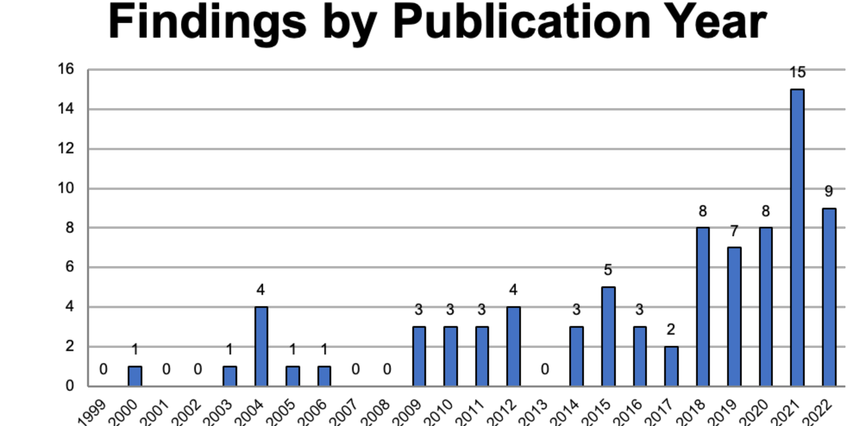
General Findings

38% records reported ethically engaged Indigenous research


Nearly all the records used indirect, multi-attribute PBMs (90%), the most common of which was the EQ-5D (62%)


VAS infrequently reported alongside EQ-5D dimensions (34%)

5% records reported using a direct PBM with Indigenous people (standard gamble or VAS)



Element of Interest	Specific Findings
Generic vs. Condition-specific PBMs	Generic: EQ-5D (3L, 5L, Y) AQoL, CHU-9D, HUI3, QWB, SF-6D v2, QoML Questionnaire Condition-specific: NEI-VFQ-25, FACT-GP, EORTC-QLQ-C30, oral-specific health utility scale
Indigenous Groups	Native American, American Indian, Native Hawaiian, Alaskan Native, Pacific Islander, First Nations (of Canada), Inuit, Metis people (of Canada), Māori (or New Zealand Māori), Indigenous Australians, Aboriginal and Torres Strait Islander, Indigenous Fijians, Tongans, Saraguara People of Ecuador, and Xhosa
Value Sets Used	Australia (n=3), Canada (n=1), New Zealand (n=5), UK (n=3), USA (n=2)
Translations (n=8)	Formal (n=2): Xhosa and Afrikaans (EORTC-QLQ-C30); Xhosa (EQ-5D) Informal (n=6): Ghanaian (EQ-5D), Xhosa (EQ-5D), Creole (AQoL), Australian Northern Territory Indigenous languages (EQ-5D-5L, n=2), Maori (EQ-5D-3L)
Validity & Reliability (n=3)	EQ-5D, Xhosa people: Reliable and valid EQ-5D-3L, Maori: Content validity but perhaps not construct validity, test-retest reliability EQ-5D-5L, Indigenous Australians: Good concurrent, discriminant and convergent validity, adequate internal consistency NEI-VFQ-25, American Indian/Alaskan Natives: Acceptable internal consistency

*AQoL: Assessment of Quality of LIfe; CHU-9D: Child Health Utility 9-D; HUI3: Health Utility Index Mark 3; QWB: Quality of Well-Being; SF-6D: Short-Form Six-Dimensions; QoML Quesitonnaire: Quality of My Life Questionnaire; NEI-VFG-25: National Eye Institute Visual Function Questionnaire; FACT-GP: Functional Assessment of Cancer Therapy – General Population; EORTC-QLQ-C30: European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire

Engagement

This work was supported by an Indigenous Elder (EJA) and an Indigenous research assistant (KS) who joined the research team later in the project (July 2022 & March 2023, respectively), supporting the interpretations and conclusions of the review. The Elder and Indigenous research assistant also advised on relevancy, strength-based language (writing in a good way), and future directions for research in this area. EJA and KS will be working with the team on projects arising from this review.

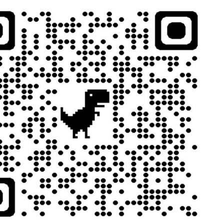
Conclusions

- This review provides an understanding of when, where, and for which purpose PMBs have been used in Indigenous people around the world.
- There is a rather large number of recent publications from diverse areas of research reporting the use of PBMs in Indigenous people.
- A wide variety of PBMs have been used to report health status, despite relatively little evidence on their performance in various Indigenous populations.
- This review suggests that further work is required to evaluate the performance of PBMs in Indigenous people, including not only validity of health status descriptive systems, but also the concept of valuation and preference elicitation. Theoretical assumptions of the health economic paradigm itself should also be considered in terms of their euro-western roots, and the relation to Indigenous ways of knowing and approaches to decision-making and priority-setting.
- Understanding the performance of PBMs in Indigenous populations is essential to better understand how they might (or might not) be used in decisions that affect Indigenous populations.
- We hope that this review can facilitate meaningful conversations and work towards accurate and appropriate measurement of HRQL for Indigenous populations.

Author Position

LMR is a non-Indigenous RN and PhD candidate of mixed Scottish, English, and French settler ancestry who lives between Una'maki and Treaty 6 Territory. Her PhD research is motivated by the need for population-appropriate approaches to measuring HRQL. AN is an experienced federal public servant and resource professional (CPA, CPHR) who has undertaken a course of PhD studies as a personal response to the Truth and Reconciliation Calls to Action in Health. KS is from One Arrow First Nation, has experience working as a RN in Indigenous communities, and is a Master of Education student. EJA is on their Elder journey and advising on the work. SMC is a non-Indigenous librarian experienced in systematic reviews. SC, FAS, and JAJ are all non-Indigenous senior researchers. SC has experience in health systems and Indigenous health research in northern and remote communities. FAS has experience in health outcomes, patient-reported outcomes and measurement of health-related quality of life. JAJ has extensive experience in epidemiology, pharmacoepidemiology, economic evaluation, and measurement of health-related quality of life. FAS and JAJ are experienced partners with clinical, provincial, and national government and non-government agencies.

Bibliography



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